DOLENTIUM HOMINUM

No. 70 – Year XXIV – No. 1, 2009

JOURNAL OF THE PONTIFICAL COUNCIL
FOR HEALTH CARE WORKERS
(FOR HEALTH PASTORAL CARE)

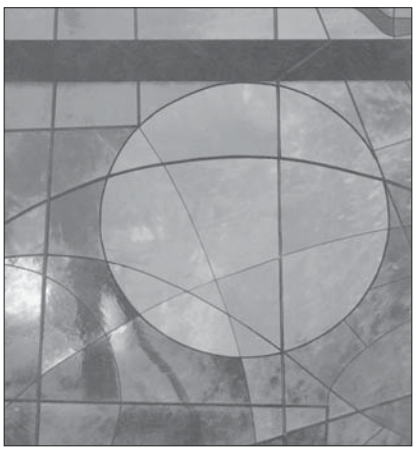
Proceedings of the XXIII International Conference

Organised by
the Pontifical Council
for Health Care Workers

Pastoral Care in the Treatment of Sick Children

November 13-14-15, 2008

New Synod Hall
Vatican City



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Published three times a year. Subscription rate: 32 € postage included

Printed by Editrice VELAR, Gorle (BG)

Cover: Glass window Rev. Costantino Ruggeri

Poste Italiane s.p.a. Spedizione in Abbonamento Postale - D.L. 353/2003 (conv. In L. 27/02/2004 n° 46) art. 1, comma 2, DCB Roma

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friday 14 november

saturday 15 november

The illustrations in this edition are taken from the book:
In continua ricerca
by Carlo Tarantini
Editrice Velar, 2008

Dilecto ac Venerabili Fratri

SIGISMUNDO ZIMOWSKI

Episcopo Radomensi

Ad bonum Ecclesiae Universae providendum et Sedis Apostolicae servitium efficacius reddendum, cum rem in Domino mature perpendi, decrevi Te Praesidem Pontificii Consilii pro Valetudinis Administris (pro Pastorali Valetudinis Cura) ad quinquennium nominare et constituere, simulque archiepiscopali dignitate honestare.

Proinde Tibi omnia et singula huic officio adiuncta iura et honores concedo et onera tribuo.

Vota faciens ut Deus Tibi propitius adsit in huiusmodi munere ad gloriam suam et Christifidelium utilitatem implendo, Benedictionem Apostolicam, fraterni amoris testem, Tibi libenter impertio.

Ex Aedibus Vaticanis, die XVIII mensis Aprilis anno MMIX.

RESIGNATION OF THE PRESIDENT OF THE PONTIFICAL COUNCIL FOR HEALTH CARE WORKERS (FOR HEALTH PASTORAL CARE) AND APPOINTMENT OF HIS SUCCESSOR

The Holy Father Benedict XVI has accepted the resignation of His Eminence Javier Cardinal Lozano Barragán as President of the Pontifical Council for Health Care Workers (for Health Pastoral Care) due to age limit, and has appointed Bishop Zygmunt Zimowski of Radom, Poland, to succeed him, elevating him at the same time to the dignity of Archbishop.

His Excellency Msgr. Zygmunt Zimowski

PRESIDENT OF THE PONTIFICAL COUNCIL
FOR HEALTH CARE WORKERS (for Health Pastoral Care)

was born in Kupienin (the diocese of Tarnów, Poland), on 7 April 1949; ordained a priest on 27 May 1973 and incardinated in the diocese of Tarnów; obtained a Licence in Dogmatic Theology from the Catholic University of Lublin; and obtained a Doctorate in Dogmatic Theology from the Theological Faculty of the Leopold-Franzens University, Innsbruck.

On 1 February 1983 he began service at the Congregation for the Doctrine of the Faith.

He was appointed Chaplain of the Holy Father on 14 April 1988 and Prelate of Honour on 10 July 1999.

He was the Postulator of the beatification and canonisation processes of Karolina Kózka, Rev. Roman Sitko and Sr. Maria Julittae Ritz.

He taught ecclesiology at the Catholic University of Lublin and the Stefan Wyszyński University of Warsaw.

He is the author of 120 publications, including a number of books and articles, as well as 40 pastoral letters.

He was involved in the preparation of the *Catechism of the Catholic Church,* and in particular its Polish edition.

He worked with the Polish section of the Vatican Radio.

Appointed by Pope John Paul II as the Bishop of Radom on 28 March 2002, he was ordained on 25 May 2002 by the then Prefect of the Congregation for the Doctrine of Faith, Cardinal Joseph Ratzinger, in the cathedral of Radom, Poland.

He has held the following positions in the Polish Episcopal Conference: President of the Episcopal Commission for the Doctrine of Faith, Member of the Permanent Council, Delegate for the Pastoral Care of Polish Immigrants, Member of the Ecumenical Commission and the Group for Contacts with the Ecumenical Council of Poland, Member of the Group of Bishops for Pastoral Care for Radio Maria, and Member of the Polish Society of Mariology.

Besides Polish, he also speaks Italian, German, English, French and Russian.

ADDRESS OF HOMAGE TO THE HOLY FATHER

Most Blessed Father,

All those who have taken part in this twenty-third international conference on pastoral care for children, and I would like to observe that these participants come from sixty-seven countries, greet Your Holiness with devotion and deeply thank you for your paternal goodness in receiving us at the end of our deliberations. You, Your Holiness, are the clear guide who will direct the whole of the Church in this important field of pastoral care in health.

Holy Father, after the subject was introduced in a general way we studied it in three stages, namely *reality, thought and pastoral practice* in care for sick children. In the first part – *reality* – we examined the history of this form of care in the Church, the current situation of infant mortality, and today's diseases and illnesses and their impact in the globalised environment. Then we reflected on the origins of these diseases and illnesses both at a personal level and a technological, scientific, political and ecological level. During the second part of this international conference – *thought* – we presented the facts of Revelation in Holy Scripture and the Fathers of the Church. Then we listened to testimony on a number of saints who consecrated their lives to care for sick children. Lastly, we reflected on these facts in the light of the theological virtues and the responsibilities of Christians in this field. We then began an inter-religious dialogue on care for children with representatives of Judaism, Islam, Hinduism, Buddhism and Post-modernity. During the third part, that on *pastoral practice*, we analysed the following subjects: from the religious point of view – sick children and the catechesis, sacramental pastoral care, dioceses and parishes, religious Orders and Congregations, voluntary work, spiritual support for sick children, and the pastoral aspects connected with psychology; from a biomedical point of view – sick children and research, forms of treatment, and accompanying and institutions; from a social-political point of view – sick children and the social means of communication, national and international health-care systems, legislation in this field, migrations, economic, scientific and technological resources, and food and social hygiene policies; and from a family point of view – the family of a sick child, health-care personnel and visits to sick children.

Forty-one speakers from fourteen nations – Italy, Spain, Poland, Slovakia, Switzerland, the United States of America, Mexico, Colombia, Egypt, India, Taiwan, France, Argentina and Burkina Faso – helped us to understand this form of pastoral care in all its breadth and taken as a whole. Now, Most Blessed Father, we ask you to guide us with your words and your apostolic blessing as the light that is to guide us in the Church with regard to the subject of pastoral care for sick children.

H.Em. Cardinal JAVIER LOZANO BARRAGÁN
President of the Pontifical Council for Health Care Workers, the Holy See

ADDRESS OF HIS HOLINESS BENEDICT XVI

Your Eminence,
Venerable Brothers in the Episcopate
and in the Priesthood,
Distinguished Professors,
Dear Brothers and Sisters,

I am glad to meet you on the occasion of the 23rd annual International Congress organized by the Pontifical Council for Health Pastoral Care. I cordially greet Cardinal Javier Lozano Barragán, President of the Dicastery, and thank him for his courteous words on your behalf. I extend my gratitude to the Secretary, to the collaborators of this Pontifical Council, to the speakers, to the academic authorities, to the important figures, to those in charge of health-care institutions, to health-care workers and to those who have offered their collaboration by taking part in various ways in the organization of the Congress whose theme this year is: *"Pastoral care in the treatment of sick children"*. I am sure that these days of reflection and discussion on such a topical subject will contribute to sensitizing public opinion on the duty to give children all the attention they need for their harmonious physical and spiritual development. If this applies to all children, it is even more important for those who are sick and in need of special medical treatment.

Thanks to the contribution of experts of world renown and people directly in touch with children in difficulty, the theme of your Congress, which ends today, has enabled you to highlight the difficult situation in immense regions of the earth in which a rather large number of children are still living and to propose necessary, indeed, urgent interventions to come to their help. Medicine has certainly made considerable progress in the past 50 years: this has led to a substantial reduction of infant mortality, although much still remains to be done with this in view. It suffices to remember, as you pointed out, that each year four million newborn babies die within 26 days of birth.

In this context, the treatment of the sick child is a topic that cannot fail to raise the attentive interest of all those who are dedicated to health pastoral care. A detailed analysis of the current state of affairs is indispensable in order to undertake, or continue, a decisive action aimed at preventing illnesses as far as possible and, when they are present, at curing the small patients by means of the most modern discoveries of medical science as well as by promoting better standards of hygiene and sanitation, especially in the less fortunate countries. The challenge today is to ward off the onset of many pathologies once characteristic of childhood and, overall, to encourage the growth, development and maintenance of good health for all children.

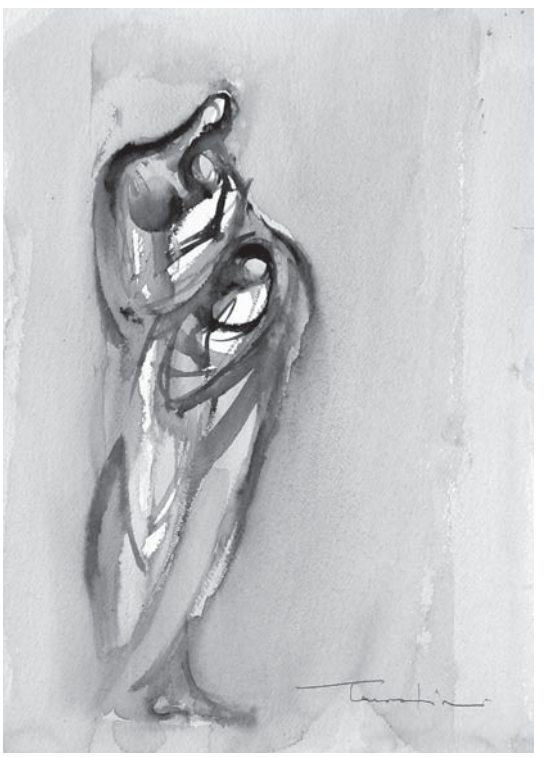
All are involved in this vast action: families, doctors and social and health-care workers. Medical research is sometimes confronted by difficult decisions when it is a question, for example, of reaching a proper balance between the continuation or abandonment of therapy to ensure adequate treatment for the real needs of the small patients without succumbing to the temptation of experimentation. It is not superfluous to remember that the focus of every medical intervention must always be to achieve the true good of the child, considered in his dignity as a human being with full rights. Thus it is always necessary to care for him lovingly, to help him to face suffering and sickness, even before birth, as his situation requires. Then taking into account the emotional impact of the illness and treatment to which the child is subjected which are quite often particularly invasive, it is important to ensure constant communication with his relatives. If health-care workers, doctors and nurses feel the burden of the suffering of the little patients they are assisting, one can easily imagine how much more acutely their parents must feel it!

The medical and human aspects must never be separated and it is the duty of every nursing and health-care structure, especially if it is motivated by a genuine Christian spirit, to offer the best of both expertise and humanity. The sick person, especially the child, understands in particular the language of tenderness and love, expressed through caring, patient and generous service which in believers is inspired by the desire to express the same special love that Jesus reserved for children. *"Maxima debetur puero reverentia"* (Juvenal, *Satire xiv,* v. 479): the ancients already acknowledged the importance of respecting the child who is a gift and a precious good for society and whose human dignity, which he fully possesses even unborn in his mother's womb, must be recognized. Every human being has a value in himself because he is created in the image of God in whose eyes he is all the more precious the weaker he appears to the human gaze. Thus, with what great love should we also welcome a unborn child who is already affected with medical pathologies! *"Sinite parvulos venire ad me",* Jesus says in the Gospel (cf. Mk 10: 14), showing us the attitude of respect and acceptance with which we must look after every child, especially when he is weak and in difficulty, suffering and defenceless. I am thinking above all of little orphans or children abandoned because of the poverty and the disintegration of their family; I am thinking of children who are the innocent victims of AIDS or of war and of the many armed conflicts that are being fought in various parts of the world; I am thinking of children who died because of poverty, drought and hunger. The Church does not forget her smallest children and if, on the one hand, she applauds the initiatives of the richer nations to improve the conditions of their development, on the other, she is strongly aware of the need to invite them to pay greater attention to these brothers and sisters of ours, so that thanks to our unanimous solidarity they are able to look at life with trust and hope.

Dear brothers and sisters, while I express the wish that the many conditions of imbalance that still exist may be set right as soon as possible with decisive interventions on behalf of these small brothers and sisters, I also express my deep appreciation of those who dedicate their energy and material resources to serving them. I am thinking with special gratitude of our *Bambino Gesù* Hospital and of the numerous Catholic social and health-care associations and institutions which, following the example of Jesus Christ the Good Samaritan, and inspired by his charity, offer human, moral and spiritual support and relief to so many suffering children, loved by God with special predilection. May the Blessed Virgin, Mother of every human being, watch over sick children and protect all those who do their utmost to nurse them with humane consideration and a Gospel spirit. With these sentiments, as I express my sincere appreciation of the work of sensitization achieved at this International Congress, I assure you of my constant remembrance in prayer and impart the Apostolic Blessing to all.

BENEDICT XVI

Pastoral Care in the Treatment of Sick Children



PROLUSION

thursday
13
november

JAVIER LOZANO BARRAGÁN

Pastoral Care in the Treatment of Sick Children

Following precedent, during the course of our international conference we will advance by three stages: reality, reflection and action. On the basis of these perspectives we will try to carry out the task assigned to us by the Holy Father of directing, promoting and coordinating the pastoral care that should be exercised in the very urgent field of sick children.

Allow me to introduce our study by making a few brief references to two of these three points. These references could be a primary approach to our subject, which will be dealt with broadly by our very competent speakers, while awaiting the directions that the Holy Father Benedict XVI will give us.

I. REALTY

A brief overall vision of the current state of children's illnesses in the world could be presented in the following way:

1. Illnesses

Almost 40% of the deaths of children under the age of five take place during the neonatal period, that is to say during the first month of life. However, the mortality percentages have declined almost the whole world over.

– About 26% of these neonatal deaths (which constitute 10% of all deaths of children under the age of five) are caused by grave infections.

– A significant percentage of these infections are caused by pneumonia and sepsis (a grave bacterial infection transmitted by blood but which can be treated with antibiotics)

– About 2 million children under the age of five die each year of pneumonia (approximately one in every five deaths at a world level) and up to another million die because of grave infections, including pneumonia, during the neonatal period.

– Despite the advances that have been achieved since 1980, diarrhoeal illnesses cause 17% of the deaths of children under the age of five.

– Malaria, measles and AIDS are responsible overall for 15% of infant deaths. Over 4,300,000 children have died in recent years from AIDS, every day 7,000 new children are infected by it, and over 10 million children have become orphans because of AIDS.

Other illnesses that are common during childhood are malaria, lymphatic filiariasis, schistosomiasis (worms in the blood) and dengue's disease, Amongst the chemical substances that cause injury to children there are pesticides, detergents, oil, solvents, badly kept pharmaceuticals that are left within reach of children (who are explorers by nature), and lead in paint and the air (this can reduce their intelligence levels). In 2001 685,000 children under the age of fifteen died because of preventable accidents, for example road accidents or suffocation.[1]

In addition to the repercussions at an individual level, many illnesses and health problems interact, thereby increasing mortality rates. Malnutrition is a factor in up to 50% of infant deaths. 149 million children are malnourished. Unhealthy water, a lack of hygiene and inadequate health-care conditions not only explain the high level of diarrhoeal illnesses but also contribute in an important way to the death of children under the age of five because of pneumonia, neonatal complications and malnutrition. Most of these cases of death are avoidable. It is calculated that eleven hundred million people do not have access to drinking water and that twenty-four hundred million people do not have access to adequate health-care services.

Today there are between 50,000 and 100,000 synthetic substances. Many of these have a bad effect on the health of children .

2. Causes

Poverty remains the principal cause of children's illnesses. Twelve hundred million people live on less than a dollar a day. In the richest countries as well one in every children lives below the poverty line. The gap between rich and poor is growing ever greater. Most poor people live in miserable

areas on the outskirts of cities – slums, shantytowns etc. The water that reaches than from the pipes is not clean; their housing is not adequate; and they have neither services nor sewerage systems. In these cities environmental pollution is at a very high level and the population density is also very high.

The places where children live in particular are three in number – homes, schools and communities. At times one is dealing with a home without running water, with earth floors, without adequate ventilation, but at times, also, one is dealing with a single room where the cooking is also done and where people sleep. Often the smoke created by cooking causes major damage to children, as do the insects which breed in the earth, the mosquitoes which transmit malaria, flies, mice etc. and a number of domestic animals. As regards schools, many of these do not have latrines and suitable amenities, at the level of both lighting and ventilation. The community is the place where a child lives his or her life outside the home, for example the neighbourhood streets, parks, sports fields, rivers or lakes, garbage heaps and workplaces. All of these places are a risk for the health itself of children. In addition to external environmental pollution there is also internal pollution. It is calculated that two million children under the age of five die because of respiratory illnesses caused by a contamination of the air outside and inside their homes brought about by concentrations of sulphur and carbon dioxide.

3. The Environment

The influence of the environment on children's illnesses is calculated as being the following: diarrhoea, 90%; malaria, 90%; respiratory illnesses, 60%; chronic respiratory illnesses, 50%; accidents, 30%; cancer, 25%; cardiovascular diseases, 10%. The risks are physical, biological and chemical in character. The environment is made of the parents, kitchens, rooms, courtyards and the streets, neighbours, schools, fields, the communities, workplaces and the ecosystem. Over 250 million people are directly affected by desertification and a million people in over a hundred countries are threatened by it. In addition, in 1990 over 110 million hectares of woods disappeared.[2]

The environmental elements that affect children in a special way are water and air, food and the soil, objects, other people, and animals, including insects that transmit diseases. The contexts in which they are hit are: eating, drinking, playing, sleeping, learning, working and travelling. The vulnerability of children exists at the level of their respiratory systems, size and body weight, and their functions at the level of physical and mental development and their ability to learn.

There are six principal aspects of environmental deterioration that affect children: water security in their homes, lack of hygiene and low levels of care, air pollution, catching children's diseases, infections caused by chemical products, and accidents. Because of a lack of drinking water the commonest malady, namely diarrhoea, causes each year 1,300,000 infant deaths. This is the illness that causes most deaths amongst children. Other infections are hepatitis A and E, dysentery, cholera and typhus. Associated with these are eye infections and skin infections, trachoma, and schistosomiasis. As regards chemical substances, an excess of fluoride in water causes a paralysing fluorisis of the skeleton and arsenic provokes arsenicosis.[3]

4. Children and Armed Conflicts

Over the last decade over two million children have been murdered in armed conflicts, six million have been made invalids, tens of thousands have been mutilated by anti-personnel mines, and in 2002 alone 300,000 children were recruited by various armies to fight.

5. The Sex Trade

The phenomenon of the sex trade and paedophilia has spread. The number of children subject to the abuse of the sex trade is 2.5 million, 29.9% of cases of sexual abuse of minors is the work of their parents. The paedo-pornography industry is worth eight thousand million euros a year. This is a very large network generated in particular by globalisation and the existence of internet.

6. Child Labour

Another cause of infant illnesses is child labour: in developing countries 250 million children un-

der the age of 15 work and between 50 and 60 million of them work in dangerous conditions. According to the International Labour Organisation, 120 million children between the ages of 5 and 14 work full time, many of them for six days a week and others for an entire week, forced to do so, often shut up in inappropriate places, and even with armed guards to make sure that they do not escape.

7. Instruction

A very important cause of children's illnesses, especially from a mental point of view, is the inadequate instruction that they now receive. Parents, in fact, are absent from the field of upbringing and this is also true of teachers. Everywhere we can find stereos and compact disk readers, computers, play stations, and digital and cell cameras. There is no control over the television programmes watched by children. In the first world in particular many of them have a television in their rooms and watch it until going to bed, without there being any control on the part of their parents. The same may be said of internet where they surf without any moral guidance. Violence has spread in schools, crime has increased, there is the phenomenon of gangs, etc.

Many families have abandoned their role at the level of upbringing. They do not give their children love and personal care, they do not engage in a constant conversation with them, they do not trouble to form their moral consciences by teaching them the difference between right and wrong. The situation is even worse when families are divided and the children, too, are divided. Most children and teenagers are abandoned to themselves and their instincts. Their teachers are internet and TV. According to the statistics of ISTAT,[4] during their period of schooling children watch 15,000 hours of television and 'witness' 18,000 murders.[5]

Faced with this by no means flattering scenario, supplemented by the data that we will listen to during the first part of our international conference, we will ask: what should be the pastoral role of the Church in helping to remedy this situation?

The answer will be given during the third part of our conference, but not without first having engaged in a reflection beginning with the illumination that is provided to us by the Word of God.

II. ILLUMINATION BEGINNING WITH THE WORD OF GOD

Here please allow me to set out certain reflections on the approach of Christ towards children. In the synoptic gospels, which show us this approach, I would draw attention to three points: the welcoming of children (Mt 19:13, Mk 10:15 and Lk 18:17); not doing scandal to them (Mt 18:6); and the company of their angels (Mt 18:10).

1. Welcome

'Let the children come to me because to them belongs the kingdom of heaven' (Mt 19:14).

In pastoral care for sick children first of all we must ensure that children draw near to our Lord. This is not only a psychological resource on which to base ourselves in order to draw near to sick children. The point is not that they draw near to the pastoral worker but, rather, that they draw near to God our Lord. This does not mean that we should refuse those resources that come from the psychological sciences. They should certainly be accepted in a suitable way but only as mere instruments that can help us in understanding something that is deeper than mere comprehension of the developmental stage of the person during the first steps of his or her existence.

In order to draw near to children the first thing is the love of God. This love is the Holy Spirit, the infinite love of God. The principal resource is prayer to the Holy Spirit so that he may bring children near to Jesus Christ. A pastoral worker must implore the Spirit to infuse his love into him or her and once he or she is full of that love to have all the delicacy and tenderness that is needed to become a transparency of the love of Christ for children and thus ensure that they draw near to the source of life, identifying with our Lord. At times one might think that at a psychological level a child does not have the ability to do this because of his or her age. However, even when one does not work with a behavioural psychology, the psycho-

logical canons are amply superseded by the grace of God, by the divinisation that He grants to His little children and which gives them a connatural status with God the Father which is achieved in a mysterious and inexplicable way through psychological exercises. We should not forget that the only door that allows us to encounter Christ to the full is suffering, and that beginning with suffering one attains happiness. This is the Redemption that is applied to the full to sick children. Thus, in conformity with ecclesial practice, an instrument of primary importance in assuring that a child draws near to God our Lord is the sacraments, baptism and those others suited to the age of the child in question. A pastoral worker can explain some things to children but we should not forget that the most important teacher is the Holy Spirit who leads us to the whole of the truth and who also prays for sick children through cries that are inexpressible and which we can neither narrate nor understand.

2. Scandal

'Whoever causes one of these little ones who believe in me to sin, it would be better for him to have a great millstone fastened round his neck and to be drowned in the depth of the sea' (Mt 18:5-6).

The second observation concerns the need not to cause scandal to children. Scandal, as we well know, is every action that leads another person to sin. As an action, seen objectively, scandal goes from the undue genetic manipulation of embryos and foetuses to all those Mathusian approaches designed directly or indirectly to kill children that have already been born. We may reflect on the scandal of making children work unsuitably rather than giving them the best education possible. A fundamental scandal is that poverty which forces children to work to survive at an absolutely inappropriate age. It is a scandal when the right drugs and medicines for the survival of so many sick children are absent. The fact that so many children cannot develop because of a lack of health care in all forms is a social scandal that leads to death or at least to severe physical or mental consequences. It is very often the case that these shortages are not the fault of the family as such because it, too, finds itself in those limit situations but are a matter of national and international social justice because the economy has been established as the principal objective of a country or set of countries and thus of relations between nations. In addition, it is a scandal when at various levels the above mentioned Malthusian policy supports population control at the cost of the lives of the poorest and weakest and which in reality more than being population control is the suppression of a population. A fundamental scandal also exists and this is the destruction of the natural environment in which a child grows up, namely the family. A divided family is the most profound scandal there is and it deprives a child of the right prospect of love. This is the greatest injury that one can do to a child. Another instance of scandal is when parents, guided by an economistic approach, in order to maintain a high economic standard of life dedicate themselves so much to work outside the home that they do not have time for an affectionate relationship with their children and abandon being their real educators. Naturally, an example of a terrible scandal is sexual abuse committed against children and even more when they are prostituted for the sake of sexual tourism. An even greater scandal is when children are abused of at a military level with their transformation into boy soldiers. Another instance of scandal is when parents do not control their children and these become corrupted in particular by the mass media. Indeed, I have already observed that from surveys carried out in various countries children during their school age watch 15,000 hours of television and 'witness' 18,000 murders. It is also scandalous to allow children, without any guidance, to assimilate everything that is presented on TV as criteria for guidance in human interaction, criteria which are based upon violence and the sexual revolution.

3. Angels

'See that you do not despise one of these little ones; for I tell you that in heaven their angels always behold the face of my Father who is in heaven' (Mt 18:10-11).

The mission of the angels is to transmit the vision of the heavenly Father which, in the ultimate analysis, is the purpose of every life. The vision of the face of the heavenly Father is what I have defined as the 'blessed vision', the fullness of life, eternal life. This is the meaning of the guardian angels, this is the mission that they have received: to transmit to us the Face of God our Father.

In referring to the meaning of the face of God we can say that it is infinite love in Omnipotence and Truth. One thus reaches the face of God the Almighty Father through the Truth-Word, the Son of God, Christ our Lord, led by the Love of the Holy Spirit. This Omnipotence, Truth and Love are achieved in totality in the death and resurrection of Christ. The angels guard us because we draw near to Christ and through him to God our Father, full of an inexpressible love, the Holy Spirit, but who through dwelling in the Trinity makes us aware of a divine proximity which is the only thing that can make us feel safe in our lives.

For this reason, Christ, when he tells his disciples that they should not stop the children from coming to him because the angels of children always behold the face of the Father, tells them not to create obstacles but rather to cooperate with the angels in making children aware in their little hearts of the presence of the one and triune God.

As a consequence, in the pastoral care of sick children we cannot forget that the great protagonists are the guardian angels, and pastoral mission in care for sick children must have as a priority the recognition, trusting to, and cooperation with these mysterious figures. An angel communicates the power of God, His Truth and His Love. An angel is an envoy of the Trinity. He looks over the lives of each one of us and in the case of sick children he takes responsibility for the strength, truth and love

of each one of them. A guardian angel is a great co-worker of the Lord in ensuring that each human person performs the mission that has been entrusted to him or her by God, and which always passes by way of the death and resurrection of Christ. To commend a sick child to his or her guardian angel means to pray to him, asking him to draw the child ever nearer to Christ, and in his childlike personal mystery to receive the gift of earthly health or to come fully to conform himself or herself to Christ in the total health of his death and resurrection.

Devotion to the angels is a very important part of pastoral care for sick children. Not to take advantage of these allies who are so important in pastoral care in health, encapsulated in a Bultmanian mythical positivistic vision, will mean that we will see as myths of a superseded age what is very essential for pastoral life, namely the effective company of angelic creatures. Furthermore, it will mean not taking advantage of beings whom, in His infinite goodness, the Lord God has placed at our service so that we can draw nearer to Him. To implore the help of angels in pastoral care in health, and especially in this sphere of sick children, is of decisive importance, in particular because the angels rise very much above what the psychological sciences can offer us when they help us to understand children in relation to their age of development. However, when these sciences are manipulated they prevent children drawing near to Christ.

These summarising reflections seek to begin our international conference on care for sick children. During its proceedings we will dwell greatly upon the current problems of the reality of children's illnesses, there will be other lights beginning with the Word of God by which to help sick children, and many practical guidelines will be offered so that we can engage in pastoral care in an effective way.

H.Em. Cardinal JAVIER
LOZANO BARRAGÁN
President of the Pontifical Council for Health Care Workers, the Holy See

Notes

[1] UN, The Johannesburg Summit on Sustainable Development. Political Declaration World Health Organization, *Shaping the Future*, Geneva, 7 April 2003, pp. 1-20.

[2] DE ROSA GIUSEPPE, 'Infanzia e adolescenza oggi in Italia', *La Civiltà cattolica*, 2001, (I), 179-188.

[3] UNEP, UNICEF, WHO, *Children in the New Millennium*, 2002.

[4] Translator's note: the Italian office of national statistics.

[5] WHO, Strategy for child and adolescent health and development. Report by the Secretariat. Fifty-sixth World Health Assembly. A56/15. 27 March 2003

First Session

Reality

ARCADI DE ARQUER

1. The History of the Treatment of Sick Children in the World

I would like to thank the organisers of this important conference for inviting me to give a paper on the history of the treatment of sick children. This greatly honours me. As a paediatrician who reflects upon the past, my intention is to understand why things today are as they are with reference to the facts that have configured them and thus to move towards a more human future.

Premise

Paediatrics was born in Europe at the beginning of the nineteenth century and sprang from a branch of the trunk of medical science, thus separating itself from the clinical practice of obstetricians who, because of their care and proximity at the moment of childbirth had acquired responsibility for the health of neonates and breastfed children (indeed it is very probable that some of you, even though you are not very old, studied chapters of paediatrics within the framework of the discipline of 'the illnesses of women and children').

Paediatrics and *puericultura* ('child-welfare') are terms that have ancient roots which are very similar and they were both coined in recent centuries. Paediatrics, which comes from ancient Greek, combines the word *paidos* ('child') with *iatros* ('physician') and means the study and the treatment of children's illnesses. The term appeared for the first time in 1772 in the treaty *Paedojatreja pratica* by the Swiss medical doctor and professor of anatomy and medical theory at the University of Basle, Theodor Zwinger.

Puericultura, which comes from Latin, adds the suffix *cultura* – cultivation, attention – to the prefix *pueris*, a child, and refers to a set of rules and forms of treatment to achieve the best physical and moral development of children. It was proposed by a professor at the University of Paris, Alfred Pierre Caron, in 1865, to refer to a new discipline which dealt with the treatment of children to obtain the best possible physical and moral development of both healthy and sick children.

Puericultura today may be seen as an area that complements paediatrics, but with some very special characteristics given that it transcends the purely medical field and has been enriched by the contributions of various socio-humanistic disciplines which have transformed it into an area for multidisciplinary study. Everybody can take an interest in *puericultura* because interest in, and contact with, children is, praise be to God, within everyone's reach.

My much admired mentor, Prof. Manuel Cruz Hernández, who held the chair of paediatrics and is at the present time Professor Emeritus at the University of Barcelona, says: 'paediatrics grew stronger during the nineteenth century at the time of great social transformations and very diverse episodes such as industrialisation and romanticism. It is interesting to recall that its scientific flowering at the same time as that artistic, literary and philosophical current, with its return to nature, the exaltation of love and concern for the weakest, can still be the motto for contemporary paediatricians' (here many of us are paediatricians). 'These came to be the romantics of modern medical science because they worked towards the same principal goal – that of having healthy and happy children, agreeing to be both doctors and the educators and defenders of children, faced with a form of medical science that tends to dehumanise because of technical advances and faced with a society that does everything possible to ensure that there are less children but which, at the same time and in a paradoxical way, seems to look after them less'. 'Nor should we be very surprised', he goes on, perhaps with a certain cynicism, 'by the fact that in most historical periods children have been neglected and at times abandoned, ill-treated and turned into slaves'.

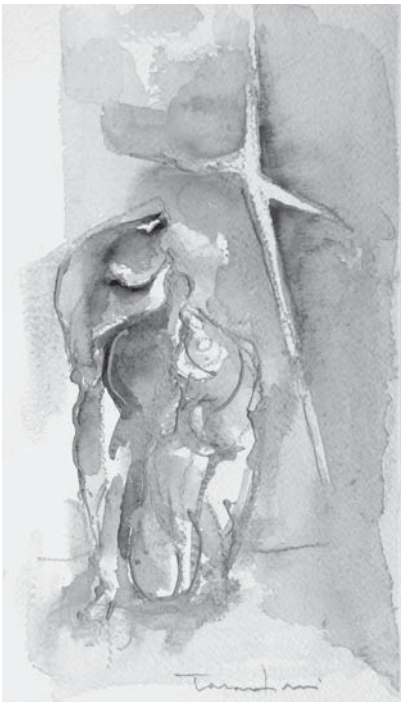
Antiquity

We find the first historical refer-

ences to the world of children in the Veda Sanskrit writings, with their chapters on hygiene and looking after children. The most ancient writings that we have on children's illnesses, where there dominates a marked magical-religious element, can be dated to 2100 BC. They were found during excavations in Nippur, in Mesopotamia, and correspond to a number of clay tablets with a cuneiform writing. It has been demonstrated that they formed a part of a book on care for children. Later, the Codex of Hammurabi (1692 BC) called for the protection of orphans by the Babylonians. This is the first known legislation on children.

In Egyptian society it appears that children enjoyed good treatment in general, something that some scholars attribute to the dominant patriarchal culture of that civilisation. Knowledge about children's health in ancient Egypt remained imprinted in papyri, three of which, written between 15600 and 1450 BC refer to children. I am referring here to the famous papyri of Ebers, Wester and Brugsch. The papyrus of Ebers, for example, has a section on births and another on children's illnesses. The papyrus of Wester deals with subjects such as playing, food and clothing, and also contains a number of rules on social behaviour. The papyrus of Brugsch (Berlin) deals with the health of mothers and children and contains magic spells for the protection of children. In ancient Egypt people did not exist who were exclusively concerned with providing care to sick children. This role was performed by midwives.

We have descriptions of certain clinical conditions in children of the age of Hippocrates, although in ancient Greece there was no specific kind of *latros* (physician) who was specifically concerned with care for children. On the other hand, in *paideia*, or the care of children, the ancient Greeks possessed something on a par with contemporary child-welfare, but it was perhaps broader given that it included the bringing up of children. We know that in ancient Sparta, the city State claimed control over the children and decided which were to live and which were to die. Those who were to live were brought up with great care and received a special education in order to increase their usefulness to Sparta. Deformed children, on the other hand, were thrown off the Rupe Tarpea on Mount Taigeto. In the meantime Athenian society had begun to support a number of institutions which took care of children who had been rejected by their families.



In Rome it was the father (*pater familias*) rather than the State that was responsible for children. But children rejected by their parents became the property of the State and were mutilated so that they could become beggars or slaves. Emperor Augustus created a state grant for abandoned children and in the fourth century AD, during the Christian era, Emperor Constantine abolished infanticide and used state funds to give money to needy families with children so that these last could stay in their homes. As was the case with other ancient cultures, the Romans did not have physicians who dealt exclusively with children. However some physicians, such as Aulus Cornelius Celsus, wrote books on childbirth and on neonates. Another famous physician, Galen of Pergamon (131-200 AD), in his *Consilium, puero comitiali morbo laboranti scriptum*, espouses certain general principles on the diet of breastfeeding mothers, recommending that they should receive broth and crumbs of bread dipped in wine. In Rome, at the same time, figures such as Cicero, Quintillian and Plutarch, basing themselves on Greek wisdom, expounded in a clear way the anthropological and humanitarian principles that ought to have guided the upbringing of children in the Latin world.

Amongst the barbarian peoples, for example the Germanic peoples, the strength of neonates was tested by immersing them in cold water after childbirth, in line with the Spartan approach, and from this comes the well-known popular expression. Those that were less strong died – they were not ready for a hard life.

Islam

From the seventh century onwards, the teaching of Mohammed, like the teaching of Christianity before it, led to an improvement in how children were seen, first amongst the tribes and the cities of the Arab peninsula, from whence his teaching spread, and then in the countries that were conquered by Islam, namely Persia, Egypt, Palestine, Syria, Armenia and a large part of northern Africa.

With the rise of Islam, the Arabs translated, conserved and transmitted the knowledge of the wise men of antiquity such as Hippocrates, Soranus of Ephesus and Galen. One of the most important translators and compilers was Rhazes (Abu Bakr Mohammad Ibn Zakariya al-Razi, 865-925 AD), a Persian physician who was the first to describe the semiology of smallpox and measles and to discover the existence of papillary reflex. Amongst his many writings there was a book on children's illnesses, *De egritudinibus puerorum*, which at the time was very popular, and this dealt with hygiene and care for neonates and breastfeeding. It also has chapters that explain the various parts of

the body and the need to look after it. Lastly, in this work there is also a chapter on character formation and moral upbringing.

Another great Persian physician was Avicenna (Ibn Sina) (980-1037 AD) who in his books *Canons* and *The Book of Healing* paid a great deal of attention to children's illnesses. He is seen as one of the first figures of medicine in the history of mankind. At the same time we encounter precedents of value in the writings of the Arab physicians of Andalusia such as Averroes (born in Cordoba in 1126), Avenzoar (Seville, 1073-1162) and Maimonides (Cordoba 1135).

The Middle Ages

In Visigoth Spain we encounter the rules that were collected together in *Libro iudiciorum*. Here there are laws that protect motherhood and neonates. These legal precepts may be seen as an extension of the customs that had prevailed during the period of Roman domination.

The most significant legal document of Castile during the medieval period is the *Codigo de las siete partidas* of the thirteenth century. Amongst other things, it expounds the reasons why children should be brought up: because of the natural law parents should bring up their own children; the children of strangers should be brought up out of goodness; and abandoned children should be brought up for religious reasons. This codex laid down rules on the work of nurses, stated that parents who had abandoned their children could not subsequently claim them back, and imposed punishments on parents who punished their children in a cruel way.

Works that are more literary than medical in character are *Libre de Doctrina Pueril (*1279) by the Majorcan Ramon Llull and *Regimen Sanitatis Salernitanum* by Arnau de Vilanova (1233-1312).

Singular testimony to the concern that sick children provoked during the Middle Ages is offered by the instruction *Pare d'orfans*, the forerunner of *Defender of the Child*, which was created by King Peter IV of Aragon and was in force in Valencia until the end of the eighteenth century.

A child born in Europe during the fifteenth century had a life expectancy of about thirty years. During the Renaissance there was increasing interest in children. St. Thomas More (1478-1535), Erasmus (1469-1536), Lluis Vives (1492-1540), Jan Amos Comenio (1592-1670), John Locke (1632-1704) and François Fénelon (1651-1715) were humanists who belonged to a shared Europe whose thought, which had a Christian basis, had a strong influence on the way in which children were seen. This would later flourish with the Enlightenment.

Hospitals

The first hospital exclusively for mothers and children was founded in Paris in 1638 by St. Vincent de Paul. The *Hospice des Enfants Trouvés* admitted teenage mothers and their children. In 1788 Mastalier founded the first institute for children's illnesses in Vienna. Later, in 1802, and once again in Paris, the *Hôpital des Enfants Malades* was created and this was the first hospital exclusively for children. In 1830 the first paediatric department of the *Hôpital de la Charité* in Berlin was opened, and in the same year clinical teaching began, which was the responsibility of internal doctors or obstetricians who dedicated a part of their time to care for children, at the Hospital of St. Petersburg (1834); at the Hospital of Niño Jesús (1897); and at Barcelona at the Hospital de San Juan de Dios (1897).

The scientific history of paediatrics was already following parallel lines to the history of hospitals and universities. The first book on children's diseases was an incunable written entirely in Latin in 1742, after the invention of printing, by Prof. Paolo Bagellardo of the University of Padua. This work was entitled *Libelus de aegritudinibus infantium*.

The first Spanish tract on children's medicine is held to be that of Jacobo Diaz de Toledo and this was published in 1538 with the title *Opusculum recens natum de morbis puerorum*, although in the best works of medicine of the time there were interesting chapters on children. One may cite here the works of Francisco Lopez de Villalobos (*Sumario de la medicina*, 1498) and Cristobal de Vega (*Liber de Arte Medendi*, 1564).

The consecration of paediatric studies as a form of independent knowledge took place with the work of Jeronimo Soriano (*Método y orden de curar las enfermedades de los niños*) and one of the works held to be the most important in the history of paediatrics, namely l'*Anweisung zur Kenntnis und Cur der Kinderkrankheiten*, was published by the Swede, Rosen von Rosenstein, in Uppsala, in 1765. Before this the *Boke of Chyldren* by Thomas Phaire had been published in London.

During the seventeenth century many medical writings appeared on children as well as the descriptions of many infectious and general diseases. In 1748 Fothergill established a diagnosis which distinguished between streptococcal and diphtherial tonsillitis. In 1759 F. Horne established that measles can be transmitted from one human to another and calculated that its period of incubation was two weeks. In 1765 Fothergill engaged in a detailed description of chicken pox and diphtheria in his *An Inquiry into the Nature. Causes and Cure of the Croup*. In 1764 Jean Jacques Rousseau (1712-1778) published *Emile*, a work that represents a milestone in the upbringing of children for that epoch and subsequent epochs. In this work he says: 'Nature wants children to be children rather than adults. If we wanted to invert this order we would produce early fruits that would be neither ripe nor with taste, and they would soon rot'. These words clashed with the dominant view that had been held up to that date that a child was a little adult, indeed one had to accept that an adult was a survivor from childhood.

In 1767 the Englishman George Armstrong (1720-1789) published his *An Essay on the Diseases most Fatal to Infants* and this was one

of the first epidemiological tracts of the period. In 1769 he founded the Dispensary for Poor Children in London and in 1777 offered the first clinical description of hypotrophic stenosis of the pylorus. In 1784 Underwood described neonatal scleredema and in 1789 he did the same in relation to congenital heart malformations and polio. In 1796 the English physician Edward Jenner (1749-1823) produced the first vaccination against smallpox, and thereby began a new way of fighting disease – prevention. It should be observed that up to that time smallpox had been responsible for 20% of all deaths.

With the advent of the Enlightenment and the French Revolution (1789), other authors wrote on the nutritional, social and educational aspects of children of the epoch. Thus it was that in 1748 Cadogan wrote his *An Essay upon Nursing and the Management of Children, from their Birth to Three Years of Age.* A Swiss educationalist, Johann Heinrich Pestalozzi (1746-1827), created in Zurich an educational centre without punishments where the children were guided by 'love'. This pioneer of pre-school education expressed his ideas in a book published in 1803 – 'How Gertrude Teaches Her Children'. One of his disciples, Frederick Froebel (1782-1852), in 1840 founded his kindergarten in Blackenburg which had children of between the ages of three and four. Later he would be followed by Maria Montessori.

The first medical doctor whom we could see as a paediatrician in the modern sense of the term was a Frenchman, Dr. Charles Michel Billard (1800-1831), who in 1828 published in Paris his *Traité des Maladies des Enfants Nouveaunés et à la Mamelle*. In 1826 Dr. Billard engaged in an assessment at *Le hospice des Enfants Trouvés* of 5,392 children, of whom 1,404 died (26%). All of this information was transformed into a book in which are described, amongst many other subjects, colic in children, congenital urethral atresia, and kernicterus and pulmonary illnesses in neonates, with a relative clinical-pathological correlation. For this reason he is seen not only as the first paediatrician in history but also as the pioneer of neonatalogy, and this publication of his is considered the point of departure for modern paediatrics.

In 1848 the eminent English obstetrician Dr. Charles West published his *Lectures on the Diseases of Infancy and Childhood* which had a wide dissemination (it was published in seven editions) with translations into various languages. We owe to Dr. Watt the description of a disease from which one his five children suffered.

In 1834 in Stockholm was published the first review in the world (Analenkten ubre Kinderkrankheiten) to be devoted exclusively to paediatric subjects. In 1843 Frederic Rillet (1814-1861) and Antoine Barthez (1811-1891) published their *Traité Clinique et Practique de Medicine des Enfants*, a book that was published in a number of subsequent reprints and which was composed almost exclusively of clinical cases. In this work we have one of the first descriptions of tubercular meningitis.

The concept of '*puericultura*' introduced by the Frenchman Caron in 1865 was received favourably in paediatric circles and spread rapidly throughout the world. In Italy Maria Montessori (1870-1952), the first woman medical doctor and psychiatrist who had been trained in her country and had studied with interest the observations of Pestalozzi of Switzerland, founded in Rome the *Casa dei Bambini* ('Children's Home') and outlined an innovative multi-sensorial educational method where children are seen as real persons. Still today, the school she founded is considered to be advanced.

Some of the first paediatricians distinguished themselves in the field of bacteriology. Worthy of note amongst these is Theodor Escherich (1875-1911) who isolated the Escherichia coli in 1886. In 1896 the New York paediatrician Koplik described those marks that appear in oral cavities before the appearance of measles exanthema which bear his name. In the same year Georges F. Still described juvenile rheumatoid arthritis, whose systemic form bears his name.

Clemens von Pirquet (1874-1929) began his first studies on allergies in 1907, described blood disease and in 1911 outlined the fundamental principles of hypersensitisation. Three years earlier (1908) Sir Archibald Garrod had published his classic work on the errors of metabolism, a work that he had begun in 1903.

I could cite very many people who made valuable contributions to our understanding of children through different disciplines. Jean Piaget (1896-1980), for example, with his work on child psychology and the development of intelligence in children, or Arnold Gesseil, with his studies on growth and development, or Erick Ericsson with his theories on psycho-social development in humans.

Another German, Heinrich Finkelstein (1865-1942), in 1912 introduced fortified milk in order to improve the nutritional conditions of children. To him is attributed the spread of paediatrics in Cono Sur in Latin America, some of whose schools achieved world fame.

Universities

The year 1858, with the foundation of the first chair of paediatrics in Berlin, marked the birth of the specialisation of paediatrics. Its growth as a specialisation was slow because as late as ten years later paediatrics was taught in only two universities – the University of Berlin and the University of Wurzburg. In Germany the study of children's illnesses developed in a particular way thanks to Eduard Henoch (1820-1910), a disciple of Schönlein. Dr. Henoch was appointed Extraordinary Professor of Paediatrics in 1858 but he did not have an independent clinic until 1872. In 1874 he described the syndrome that bears his name, as well as the syndrome that bears the name of his mentor Schönlein (purpura anaphylactoid). Otto Heubner (1843-1926) succeeded him in his professorial chair in 1894 at the Charité of Berlin. In 1896 Heubner managed to isolate for the first time the meningcoccus of the cephalorachidian liquid.

The first hospital in the United

States of America for the care and treatment of children's illnesses was opened in 1869 by Professor Abraham Jacobi who was born and had been trained in Germany. In 1861 he was appointed Professor of Infantile Pathology and Therapeutics at New York Medical College and is rightly held to be the father of North American paediatrics. The first chair of children's medicine in Spain was created in 1886 and provided the people who would later hold chairs in Madrid, Barcelona, Valencia and Granada.

In 1888 Harvard University appointed Professor Thomas Morgan Roth who was also a German. At the beginning of the twentieth century Von Pirquet moved from Vienna to Johns Hopkins and a little later to Bela Shick where he was appointed to a chair at the School of Medicine of Mount Sinai in New York. In this way German paediatrics, whose hegemony had replaced that of the French, passed the torch of progress to North American and more generally to Anglo-Saxon paediatrics. In 1902 only eight German universities out of twenty had a chair of paediatrics but at the end of the First World war (1918) paediatrics was an integral part of European university programmes.

Paediatric Associations

In 1865 the Society for the Protection of Children was created in Paris. In 1871 the American Medical Association (AMA) organised an internal section for obstetrics and women's and children's illnesses. In 1879 the AMA created a specific internal section for children's illnesses. When paediatrics had already been created as a medical specialisation, in 1884 the first International Paediatric Conference was created during the Fifth International Medical Congress held in Copenhagen. It was chaired on that occasion by the famous surgeon Harald Hirschprung who was later to describe the ganglion megacolon. In 1888 the North American Paediatric Society came into existence. The International Association of Paediatrics was founded in Paris on 28 June 1910 and the first International Congress of Paediatrics was held in the same city in 1912. In 1926 the *Societat catalana de Pediatria* was founded. The North American Academy of Paediatrics was not created until 1930. The Spanish Association of Paediatrics had been established in 1849.

The Rights of Minors

Important social advances, the great leap forward in relation to the rights of minors, took place very recently, that is to say during the twentieth century. From 1940 to 1950 international organisations were created which fostered an objective advance in the legal protection of minors (FAO, UNICEF, UN, UNESCO). The outcome of this was the Universal Declaration of human Rights (1948). This, together with the Universal Declaration of the Rights of the Child and above all the Convention on the Rights of the Child (1989), has been a fundamental instrument in defining the aspiration to a world in which the historic neglect and brutality towards minors (many of which still persist in various forms and in forms that are even masked by modernity) can be overcome at a global level.

Christianity

I would like to emphasise, before finishing this paper, that the real work of protecting children began, developed, matured and continued with Christianity, and it could not have been otherwise.

I do not wish to dwell further on this subject which will be addressed in detail by other speakers but we have already grasped how behind a great deal of generous devotion and pure self-sacrifice in relation to children, behind a great deal of study and research, behind the foundations of hospitals and universities, behind the '*gotas de leche*', and behind nurseries, maternity wards and a great many of the institutions for the protection of children, which, duly modified, still continue, there has been Christianity and in a special way the Catholic Church. Note that the very word infancy – *infans* in Latin – means etymologically he who has no voice and it appeals for a voice to be given to him. And He who has given him that voice is the Word, He whose name should not be pronounced in vain, the Jehovah of the Old Testament, Jesus Christ who said 'let the children come to me', and the Holy Spirit

St. Giuseppe Calasanzio (1556-1648), St. Ignatius of Loyola, St. Jean Baptiste de la Salle (1651-1684), St.Vincent de Paul (1581-1660), St. John of God, the blessed Catalan Mother Rafols, and many others, each one with their own charism, have been the most romantic figures of this history, which began with culture, with action for the littlest, the most innocent, those whom, according to the Gospel, we should all resemble.

I would like to remember in particular the Blessed Pere Tarres, a medical doctor and priest of my country who said 'the sick person is Christ, his bed is the altar, and the doctor is the priest', and the paediatrician St. Gianna Beretta, an Italian, from a town near Milan, a saint for life, who gave her own life for the sake of the fruit of her womb. Both of these saints demonstrate that our dedication to children is a pathway of holiness.

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MARINA CUTTINI

2. The Demography of the Juvenile Population in the World and Mortality

Introduction

Exactly thirty years ago the Declaration of Alma Ata established the principles for the promotion of health in the world of the development of primary care.[1] Beyond the very well known slogan with which it was publicised ('Health for All for the Year 2000'), this Declaration contained certain innovative principles which are still valid: the definition of health as a fundamental human right; the recognition of the importance of socio-economic conditions and political decisions; the role of local communities; and above all the emphasis on fairness in access to care and efficiency in the use of resources.

More recently, under the aegis of the United Nations, the eight key goals for the development in critical areas of global interest, the so-termed 'Millennium Development Goals, were established.[2] Three of these goals concern health and two (MDG 4 and 5) refer directly to mother-child health: to reduce mortality during the paediatric age (by the age of five) and to improve the health of mothers.

This paper seeks to offer a survey of the conditions at birth and the mortality of children in the world with especial reference to the first five years of life, describing the factors that influence them and the inequality that still characterises them.

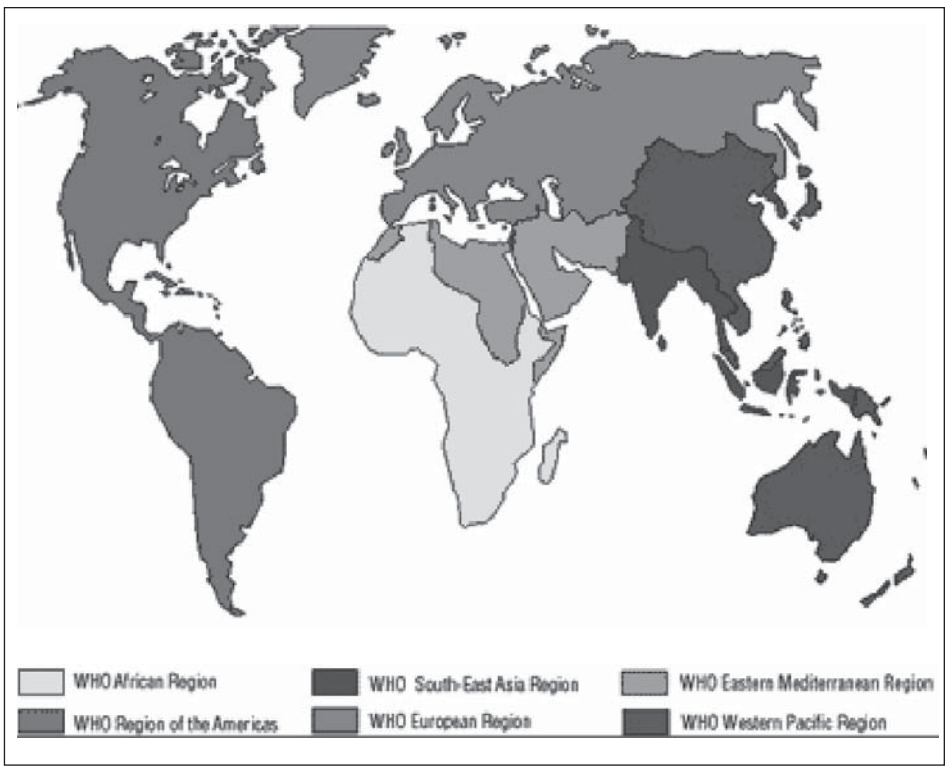
Methodological Notes

The data in this paper come from official publications of the World Health Organisation (WHO), of UNICEF and of the World Bank – the sources are quoted in turn and are listed in the bibliography. Priority has been given to the most recent available data, even though they do not always refer to the same year. The quality of the data, however, is not the same for all countries and calculations can vary according to the sources that are used.[3]

In general, the data are presented with reference to the six regions defined by the WHO (Figure 1): Africa, the Americas, the eastern Mediterranean, Europe, South-East Asia and the Western Pacific. These are very large regions which include countries that are very different in terms of development, availability of resources and health-care organisation and as a consequence in terms of demographic and mortality statistics as well. One need only think of the differences that exist between Canada and the United States of America, on the one hand, and the countries of Central America and South America, on the other, and yet all these countries are included in the region of the 'Americas'. In the same way, the region of 'Europe' includes both the industrialised Western countries of the continent and the countries of central and eastern Europe where socio-economic conditions are rather different.

For this reason, the classification proposed by the World Bank is also used – this classification groups countries in four bands according to the gross national income (GNI) of 2004: high income, medium-high, medium-low and low.[4]

Figure 1. Regions according to the World Health Organisation



Mother-child Demography in the World: how many Children are there, where are they Born and in what Conditions?

28% of the world's population is made up of children who are under the age of fifteen. But this percentage is not the same for all countries and varies from 18% in Europe to 43% in Africa.[4]

The level of fertility in 2006 was 1.6 in Europe, 3.5 in the regions of the eastern Mediterranean, and 4.7 in African countries (Table 1).

Every year about 136 million children are born (data from the year 2004) but more than 20% are dead at birth: a figure that varies from 7% in the Americas to 29% in Africa and rises to 31% in South-East Africa.[5] As regards live births, the conditions of babies at the moment of birth, the kind of care that they receive, and the survival of their mothers all condition in an important way their probability of survival and their future health.

16% of newborn children have a low weight at birth (< 2500 grams): a condition that can indicate a premature birth (that is to say before the thirty-seventh week of pregnancy) or a delay in growth within the womb, or both. In both cases one is dealing here with the newborn children who are the frailest and are most at risk to illness and early death.

The percentage of births helped by health-care personnel (medical doctors or others) varies from 44% in Africa to 96% in Europe.

Every year about half a million women (400 for every 100,000 live births) die at childbirth or for reasons connected to childbirth (maternal deaths). In the poorest countries the death of the mother places the survival of her baby at great risk.[6]

Neonatal Mortality and Infant Mortality Before the Age of Five

According to the Save the Children report published in May 2008 [7] for the first time since documentation on the questions had existed the number of children who died before the age of five fell below the figure of 10 million a year. This is a victory for those countries that invested resources to improve the health and the survival rates of their children, but, as the report itself says, 'the lives that were saved were the easiest to save'. The greatest benefits accrued to the wealthier countries and within these to their most disadvantaged population groups.[8] As a consequence, the differences between the various areas of the world have become more pronounced, and a child born in Sub-Saharan Africa today has a risk of dying before the age of five which is twenty-seven times greater than if he or she had been born in an industrialised country. In 1970 this risk was 'only' nine times greater and in 1990 nineteen times.[7]

99% of deaths before the age of five take place in developing countries and particular in Sub-Saharan Africa (4.4 million deaths every year, equal to almost 50% of total deaths) and South-East Asia (3 million).[9] As one can see from Table 1, in terms of levels (that is to say the number of deaths in relation to live births in the same area), neonatal mortality, infant mortality and mortality before the age of five are all higher in Africa and the eastern Mediterranean.

Table 1. Births, care and conditions at birth, and mortality by WHO regions

	Africa	The Americas	South-East Asia	Europe	Eastern Mediterranean	Western Pacific	Total
Fertility (for each woman)*	4,7	2,3	2,7	1,6	3,5	2	2,6
Life births each year (in thousands)§	28.572	16.137	37.842	10.462	15.306	24.556	132.874
Births helped by health-care personnel (%)*	44	92	48	96	63	92	65
Mortality at birth (‰)§	29	7	31	9	23	16	22
Low weight births (%)*	14	9	26	8	17	8	16
Maternal mortality (for every 100,000 live births)*	900	99	450	27	420	82	400
Neonatal mortality ≤ 28 days (‰)*	40	11	35	10	38	17	28
Infant mortality < 1 year (‰)*	94	18	52	14	62	20	49
Mortality before the age of 5 (‰)*	157	21	69	16	84	24	71

Sources : * World Health Statistics, WHO 2008 [4].
§ Neonatal and Perinatal Mortality. Country, Regional and Global Estimates 2004. WHO 2007 [5]

Figure 2 shows the rates of neonatal mortality (before 28 days), infantile mortality (before the age of 1) and mortality before the age of five by classes of income established on the base of GDP [4]. It is obvious that the more the wealth of a country increases the lower the levels in such categories of mortality.

Within the same country, however, the children that die are the poorest of the poor. They live in communities where health care is deficient and they often belong to ethnic or religious minorities which leads them to be discriminated against. And it is more often the case that one is dealing with girls.[7] The poorest children have a greater probability of being born underweight, of developing malnutrition and of contracting infectious diseases. They are more exposed to the environmental risks derived from a lack of drinking water, from low levels of hygiene, and from inadequate housing conditions. Often their parents do not have the most relevant knowledge by which to protect their health nor do they have ways of gaining access to health care. For that matter, the quantity and quality of health-care services in the most disadvantaged countries are inferior to those to be found in wealthy countries.

The Causes of Death

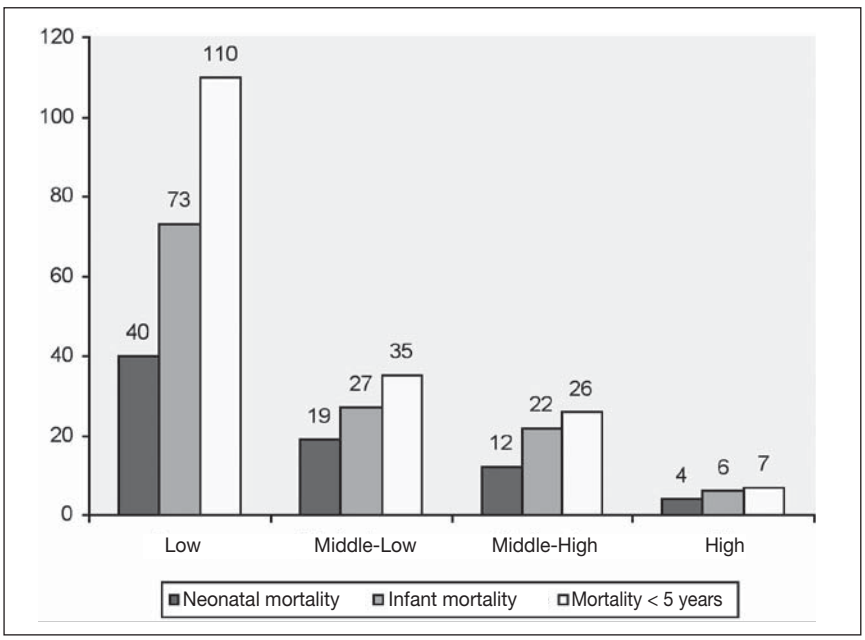
A few preventable and/or treatable infectious diseases are responsible for about 50% of the deaths of children under the age of five (Table 2): pneumonia (17%), post-neonatal diarrhoea (16%), malaria (7%), measles (4%) and HIV/AIDS (2%).[10] An important proportion (37%) is due to neonatal causes, amongst which stand out premature birth or low weight at birth (28% of neonatal deaths), neonatal infections (26%) and asphyxia at birth (23%). [10]

Table 2. Distribution of causes of death during the first five years of life and during the neonatal period (<28 days)

Causes of death	< 5 years %	< 28 days %
Pneumonia	17	
Post-neonatal diarrhoea	16	
Malaria	7	
Measles	4	
HIV/AIDS	2	
Other infectious and parasite diseases	9	
Non-transmissible diseases	4	
Accidents	4	
Neonatal causes	37	
Premature birth/low weight		31
Neonatal infections		25
Asphyxia at birth		23
Neonatal tetanus		3,4
Congenital malformations		6,7
Neonatal diarrhoea		2,6
Altro		8,7

Source: The Global Burden of Disease. 2004 Update. WHO 2008 [10]

Figure 2. Levels of neonatal mortality, infant mortality and mortality before the age of five by classes of national income (for every 1,000 live births)



Source: World Health Statistics, WHO 2008 [4]

When the distribution of causes of death is examined by income band (Figure 3), one observes how the increase in the wealth of countries is matched proportionately (but certainly not absolutely!) by an increase in deaths caused by neonatal causes, in parallel with a reduction and disappearance of deaths caused by infectious causes: pneumonia, diarrhoea, malaria and measles. The deaths caused by accidents, and those brought about by other causes, which probably include chronic paediatric illnesses, also increase.

This classification of the causes of death is based upon the 'international classification of diseases' (ICD10) which attributes every case to the 'illness or accident which gave rise to the chain of pathological events which led directly to death'. This is a correct system which avoids the total of

causes of death going above 100%. But this approach can be a little simplistic in developing countries where various grave illnesses can combine more often than happens in the industrialised world.[11] For example, measles can by complicated by pneumonia or diarrhoea, which increase the risk of death. Malnutrition and low weight also cause a reduction in the defences of the organism and should perhaps be seen as the principal cause of death, even when they are associated with an infection which constitutes its terminal cause. It has been calculated that about 53% of deaths before the age of five can be attributed to malnutrition.[12, 13] More recent calculations, however, carried out using the updated growth curves of the WHO and more sophisticated statistics, have produced a more conservative figure (35%).[14]

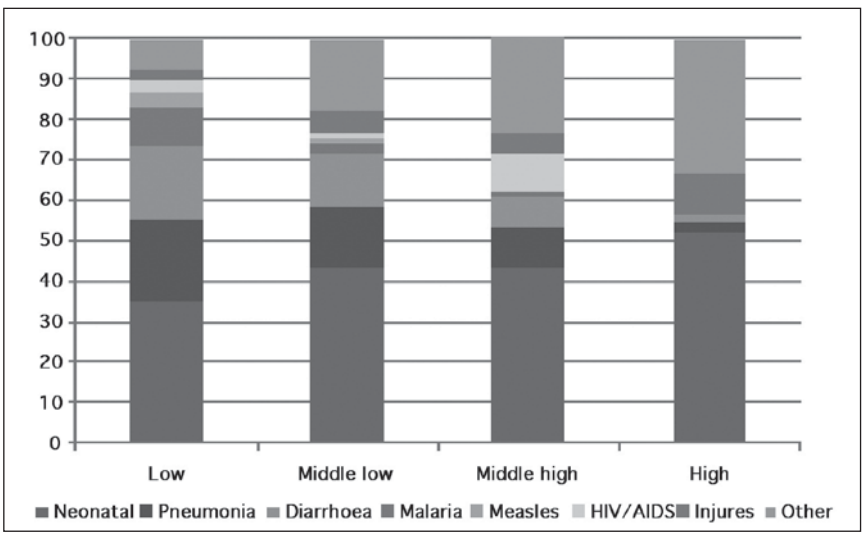
Given that most child deaths can be attributed to six preventable causes, care and healthcare 'coverage' play a very important role. By 'coverage' is meant the number of people who receive specific treatment expressed as a percentage of those who need such treatment.[15] At the present time, it is calculated that more than two million children under the age of five do not receive necessary primary care.[7] The index of coverage, once again, increases with income, and is significantly correlated with mortality under the age of five.[16]

Final Observations

The fourth Millennium Development Goal calls on countries to reduce the mortality of children under the age of five to two-thirds of the 1990 levels, and this reduction should take place by 2015.[17] Hitherto there have been advances but the reduction has been too slow for the goal to be reached, or it has been limited to certain countries. The deaths of children, and of mothers, are increasingly concentrated in certain more deprived areas. Sub-Sahara Africa is responsible, as has been pointed out, for about a half of deaths of children of paediatric age, despite the fact that this age band makes up only 11% of the world's population.[17]

Various studies demonstrate that the health and survival of children are inextricably linked to the well-being of their mothers.[6] In the poorest countries the death of a mother is not only a personal tragedy – it can also have important consequences both for her children and family and for the whole community. Possible solutions exist.[7, 10] The results obtained in very poor countries, such as Indonesia, Nepal and Bolivia, and also some countries in eastern Africa,[18] show that progress, and indeed rapid progress, is possible.

Figure 3. Distribution of the causes of deaths before the age of five by classes of income (PIL)



Sources: World Health Statistics, WHO 2008 [4]

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3. The Definition of Disability in the Principal Illnesses that Afflict Children

Children's Illnesses and the Epidemiological Transition

Any process of development in the health of populations must be based upon an identification of the factors that determine health itself and must be sufficiently broad to assess all the causes of premature death and of disability, as well as the risk factors that underlie most illnesses (Lopez and Mathers 2006).

During the last century we witnessed a steady increase in chronic pathologies within the scenario of medical care and treatment and this brought about the need to focus attention on the *consequences* of illness rather than exclusively on the illness itself. We are thus now witnessing a shift from episodic and brief diagnostic and curative actions to the need to organise social/health-care systems and public health-care policies which are able to organise the taking on of responsibility for people over a long period. Aspects connected with the consequences of illness are thus acquiring greater importance, that is to say the reactions to the illness of the person involved, of his or her family relatives, and of those who provide care and treatment. At the same time environmental factors are becoming increasingly relevant.

Reference is made to an 'epidemiological transition' in order to define this shift from a scenario made up for the most part of transmissible diseases to a scenario largely made up of chronic non-transmissible illnesses. Thus there is an increase in the need to have available information and data on morbidity and on the non-fatal outcomes of illnesses, and not only on the death rates of a population. Death rates, in fact, were used for a very long period of time as one of the principal indicators of health, thereby diverting attention away from all those invalidating chronic illnesses which, even though they have low mortality rates, involve high disability levels – for example neurological diseases, psychiatric illnesses or the condition of being HIV-positive. The number of deaths, the mortality rates of a population, tell us nothing about the outcomes of a non-fatal illness and incidence rates on their own do not take into account the gravity or the length of an illness (Leonardi, 2005).

Diagnosis alone, in addition, is not in the least able to predict the needs involved in services, the length of hospitalisation, the levels of treatment that have been received, and the functional levels of people. The use of traditional indicators, in fact, led to a grave underestimate of invalidating chronic illnesses in developed countries and in developing countries and they did not allow a full consideration of the burden involved, that is to say the impact that they have on an individuals, on systems and on policies (Leonardi, 2005).

The Principal Children's Illnesses and the Burden of Illnesses During the Paediatric Stage of Life

In order to reduce the impact of children's diseases it is of crucial importance to recognise that paediatric illnesses in both developed and developing countries are an important cause of disability, of death and of economic and social costs. We should have data on the incidence and distribution of the various illnesses of childhood that are as accurate as possible, and it is of fundamental importance to recognise that the disability of a child should be identified, managed and combated, given that no country can ignore the fact that disability in children is the result of interactions between pathologies and environments that do not protect children.

The impact of the environment in the assessment of the burden of illnesses is without doubt more evident in children than in adults: poverty, poor social/health-care conditions, socio-political instability and malnutrition affect children more than adults and all of these environmental factors have relevant effects on the health of children (Pronczuk, 2008).

Observing the scale and the nature of the illnesses that afflict the world of children one can identify two categories. There are illnesses that are characteristic of the paediatric stage of life alone and there are others that afflict both children and adults, including chronic illnesses that afflict children who continue to have them as they grow up. It is undoubted that the second category of illnesses has the greatest impact on health and it is upon these illnesses that this paper will focus. The need to draw up instruments by which to classify certain aspects of health and disability in a population arises first of all from requirements of clarity and should be seen in the light of certain criteria such as the criterion of scientific rigour in the drawing up and application of classifying instruments, the criterion of their reliability, the criterion of their effectiveness and the criterion of their usefulness.

Hence the need to have instruments of measurement in order to compare levels of health in various populations, and within the same

population, over different periods; the need to draw up instruments which take into consideration not only the cause of illnesses and conditions of health but also the importance and the impact that illnesses can have on the health of a population. This new awareness allows a step forward to be taken in the definition and the identification of priorities at the level of action.

In 2001 the World Health Organisation (WHO), after a long process of revision involving a great deal of work, approved the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The WHO recommended that the member States used this ICF for research, for population studies and in their reports. The ICF classification is an instrument that can constitute a possible response to the emerging needs of contemporary society which require comparable instruments that are also able to take into account the impact and the disability caused by illnesses during the different stages of life. But what are children's disabilities in the world?

As Orne-Gliemann *et al.* show in their review of the priorities of developing countries, these remain malnutrition, diarrhoeal illnesses, respiratory illnesses, perinatal pathologies, AIDS, malaria, TB and measles (Orne-Gliemann, 2003). According to the WHO, infectious diseases are the diseases that cause the highest levels of death in children (63% of the causes of death), and amongst these the most serious and fatal are acute respiratory illnesses (including influenza and pneumonia), AIDS, diarrhoea, tuberculosis, malaria and measles (Black, 2003). In many parts of the world infection by HIV-AIDS is a phenomenon that is now out of control and at the present time it is the greatest health problem of the planet together with malnutrition; naturally, this is one of the objectives of the strategy defined as the Millennium Development Goals.

The significant successes obtained with the introduction of the clinical use of the new and highly effective antiretrovirals induced in public opinion the idea that this epidemic was undergoing a rapid decline. Unfortunately, the reality is very different. There has been a steady fall in the attention paid to this pathology and in fatal fashion the results obtained in terms of prevention have declined. Children with HIV must be treated and receive therapies in line with international protocols. Forty million people in the world are HIV-positive; three million people die every year because of this disease; and it is calculated that fifteen million children have been made orphans because of it.

In the more developed countries the impact of these pathologies is lower and pathologies prevail that have a lower death rate but high morbidity levels. Amongst these, asthma is a growing problem, above all in the industrialised countries, followed by mental and behavioural pathologies which afflict between 10% and 20% of children and are often underestimated. In addition, scientific and technological advance has enabled us increasingly to identify the genetic and molecular bases of various children's illnesses which often give rise to malformations. Diabetes and obesity are emerging pathologies in the main in developed countries but they are also to be found in developing ones as well, and the disability caused by these pathologies is very high (Rudan *et al.*, 2005; Flynn *et al.*, 2006). It is also of fundamental importance when considering childhood to take into account the burden caused by various illnesses that afflict millions of children, provoking disability that then has an impact on systems in a very relevant way.

What Definition for Disability in Children?

Today, indeed, the question of the definition of disability constitutes an ineluctable problem in the definition and identity of the welfare state. Both the epidemiological transition and the increasingly chronic character of illness have brought about a radical transformation in the meaning of health and of welfare policies in general, in large measure in Western countries, but the same phenomenon can be observed in developing countries as well (Iezzoni *et al.*, 2003 and 2008).

The ICF classification has brought about a series of important changes at a cultural level as regards the concepts of health, of functioning and above all of disability, and in 2007 the WHO published a version for children and adolescents – the ICF-CY (WHO, 2007) – which was the result of five years of work and experimentation in the field with experts from more than eighteen countries in order to adapt the ICF to childhood, with a focus on codes able to best capture the complexity of disability in children. For a long time, indeed, the concept of health was subordinated to the concept of absence of illness, a model specifically of a medical-organicistic kind which has been recently expanded with other components. Health, however, is not only the absence of illness; it can be summarised as a state of the entire person. Thus it is wellbeing strictly linked to human functioning at all the levels – the biological, the psychological and the social. The inclusion of the environment in the definition of a state of health is of primary importance: the health of an individual directly affects his or her context of life (implying changes in his or her habits, work, and relationships),in the same way as these interact

'with' and influence 'the' health of the individual (for example attitudes, barriers, environmental pollution or situational stress) (Michaud *et al.*, 2001; Gavidia, 2009). This definition of health in a broad sense has been accepted since 1948 by the whole of the scientific and non-scientific community as a point of reference on which to base policies and plan initiatives.

The definition of disability, in contrary fashion, has not experienced such a simple journey given the multiplicity of meanings that in different countries in different contexts at different times it has had, and has, and there is no agreement on the meaning of disability. For this reason, in the international context and through the WHO an attempt has been made to find a possible answer to what is still unresolved and discordant in the sphere of the definition of disability in the strong belief that it is important to have a definition of disability on which there is broad agreement. According to the bio-psycho-social model defined by the ICF and the ICF-CY, disability 'is a universal experience, it is a difficulty in functioning at the level of the body, of the person and at the level of society, in one or more spheres of life, as experienced and undergone by a person with a condition of health in interaction with contextual factors' (Leonardi *et al.*, 2006).

Emerging Needs: Every Child is What He or She is and is What He or She Lives in

The ICF classification and the ICF-CY classification for children and adolescents constitutes a conceptual framework of extraordinary importance specifically because, in conformity with the principles of international conventions for the protection of the rights of children and people with disabilities, it stresses the fact that the body, the mind and the life environment are the three factors on which one must focus. The use of the ICF, and this is even more the case in the CY version, allows us to work with and for an individual from a bio-psycho-social perspective in a way that takes into account the dignity of the person and it also allows us to draw up strategies that seek to reduce the burden caused by illness. The publication by the WHO of this instrument constitutes the point of arrival of a cultural and scientific pathway which in recent years has witnessed the continued establishment of the concept of the defence of health understood as care for the 'wellbeing' and 'quality of life' of the individual. These requirements are necessary not only in the health-care world but they are also, as the WHO itself has declared, fundamental for the economic development of every country. Illnesses, disabilities and non-self-sufficiency constitute a burden for social and economic development and thus there is a need to promote the concept of 'health above all'. But by what route should this development advance? With the ICF a new horizon is opened up: one begins to understand the concept of 'participation' and the concept of 'interaction with the environment' as fundamental parameters by which to measure any objective of an intervention. The *context*, therefore, takes on an essential role in determining health and disability in the sense that it can facilitate or obstruct the functioning of an individual. And the fact that there is a close relationship between the individual and his or her environment means that a person can function in different ways in different environments.

Every child is what he or she is and is what he or she lives in. One of the greatest innovations brought about by the ICF model of classification as regards the definition of disability is the introduction of environmental factors. By this term are defined all the characteristics, the aspects and the attributes of objects, structures and organisations available to the services and agencies present in the physical or social environment in which people live out their lives. The problem is one of approach or culture and requires social changes which at a political level become a question involving the defence and promotion of human rights. Disability becomes, in short, also a political question.

The importance of grasping the value of the support of the environment in which each child lives and grows is by now well established in the paediatric field, above all in those cases where complete knowledge of state of health becomes an ineluctable fact. A child with disability, indeed, needs 'overall' care which is centred on the needs of that child and which takes into account the context in which the child himself or herself lives.

The Bio-psycho-social Model and the Disability of Children as a Political Question

The ICF stimulates new reflections because it takes questions of health and disability to the level of the concrete problems of people, their needs, their functions and their activities. The ICF provides a map, a way of working. The ICF, as has already been pointed out in this paper, sees disability as a universal human experience and provides an innovative and revolutionary definition of it. It stresses the importance of an overall approach to disability which for the first time also takes into account environmental factors because it classifies them in a systematic way. The fundamental idea of the 'person' changes: the person is not defined according to the qualities that he or she possesses but is in line with his or her being a person as such at all the stages of his or her life (Leonardi, 2005). The advantage of the ICF as regards the practical purposes of multidisciplinary actions lies in bringing out the importance of environmental and personal factors from a bio-psycho-social perspective and stressing the need for the action to take account of all the factors at work. The ICF defines the functioning of a person not in negative terms, with reference to 'residual abilities', but in a propositive approach, as an indicator of the interaction between the individual – in his or her habitual condition of health – and the contextual factors in which he or she is inserted which can be environmental or personal in character. The concept of disability refers, instead, according to the ICF, to the negative aspects of the interaction between the individual and his or her environment. Disability, therefore, is defined, like functioning, both by the factors connected with conditions of health (for example the handicaps at the level of function and/or corporeal structure) but also by the conditions of limitation that the individual encounters in his or her interaction with a disadvantaged context which after a certain fashion represents an obstacle to the functioning of the person (WHO, 2001).

Appreciating a Child with a Pathology as a Subject of Human Rights

The ICF-CY belongs to the family of international classifications that were developed by the WHO in order to classify and measure different aspects of health in both adults and children. In international classifications, illnesses, disturbances and deformations are primarily classified in the ICD-10, an international classification of illnesses that envisages the provision of an aetiological framework, whereas functioning and disability, associated with a condition of health, are classified by the ICF for adults and by the ICF-CY for children and adolescents (from the ages of 0 to 17). These two instruments, the ICD and the ICF-CY, allow an adequate synergic description of the condition of health of a child with a disability (WHO, 2007).

The ICF-CY tries to promote an operational model that appreciates the condition of a child with a disability and which even before that recognises that he or she is a person with human rights. Many countries still do not engage in this recognition and this causes grave failings in the defence of children. In some countries, for example, if a family has a child which has some form of disability, he or she is the last to receive food, as long, that is, as there is some left over.

With the ICF-CY classification the WHO strives first and foremost to promote a culture that recognises in growth an intrinsic value and one that is well differentiated from the adult condition. Children are not little adults. Instead, they can be defined as a 'moving target' which varies notably according to age and level of development. The need for a specialist adaptation for children and adolescents, which is what the CY classification is, was based on the fact that the first two decades of life are characterised by rapid growth and by the emergence of significant physical, psychological and social changes. The expressions of functioning, disability and conditions of health in childhood and adolescence are different by nature, intensity and impact to what is the case on adults. To respond to, and to take into account, these differences, the ICF-CY classification was developed in order to be sensitive to the changes associated with growth and development. Within the age bands envisaged by the ICF-CY one goes from neonates (who have an evident need to be looked after and relationships which are strongly centred around their needs) to adolescents (who are able to engage in a variety of activities, are rather autonomous and at a stage when they are fully consolidating their identities).

The functioning of a child cannot be seen in isolation. Rather, it should always and only be seen within the context of the family life within which it takes place. This constitutes an important element as regards the observation of performance, ability and participation in life situations. A child in the context of the family develops through a dynamic process which advances steadily from absolute dependence through the development of the body to social relationships and psychological maturation which already begins to express itself in adolescence. In this dynamic process the functioning of the child depends on the constant interaction with the family relatives or other caregivers in the context of life to which the child belongs.

The influence of family interactions on the performance and functioning of a child is very important for his or her development of the subsequent stages of adult development as well (WHO, 2007). In children and young people there exist substantial differences in growth and development. A delay in the emergence of functions, of structures or of abilities may not be permanent and/or reflect a delay in development. There can be delays in each of the spheres described by the classifications (e.g. cognitive functions, language functions, movement functions etc.), these are 'age specific' and are influenced both by physical and psychological aspects and by environmental situations. Variations in the emergence of the corporeal functions, of the structures and of the performance that are expected for development

define the concept of delay in development and often constitute a useful basis by which to identify those children who at the level of prognosis display a risk of having – during the course of their development – various forms of disability (Leonardi, 2005; Simeonsson *et al.*, 2003).

Participation, defined as the level of involvement in life situations, constitutes the social level of the CY classification. As with the observations that have been described hitherto in this paper, the level and the typology of involvement in life situations are extremely diverse in children and adolescents in the same way as the social situations are diverse. With development, life situations change substantially, especially in terms of the complexity of relationships (from the caregiver to more complex social activities, schools and contemporaries). The ability to engage in social interactions develops beginning with family relationships and then extends to relationships with peers and siblings. The social context remains significant for the whole of the period of development, even though this varies in nature and complexity with the changes in the environment. Specifically in the light of these considerations, interactions and relationships at both a social and psychological level constitute an essential aspect of participation in children and adolescents, which must be taken into account (WHO, 2007).

Environmental factors, lastly, constitute the approaches and the physical and social environment in which people live and engage in their existence. Implicit interaction between people and the environment in the ICF paradigm shifts attention from the medical model to the bio-psycho-social model of disability. This requires special care, especially when we are in the presence of children and young people. Changes in the environment of children are associated with the development of skills in various spheres and by increasing independence (Simeonsson *et al.*, 2003; Gavidia, 2009).

The smallest children depend significantly on the people in their immediate life contexts. Games and access to those of the same age are essential components for the principal areas of the lives of children. For older children environmental factors are strictly connected with home and school, going on to broaden to more diversified contexts during the course of adolescence. Given what has been observed in this paper regarding the determining dependence of children on the environment, it appears clear that the latter has a significant impact on the functioning of children. The presence of barriers in the environment often has a grave impact on children as well as on adults, specifically because of the great influence that the environment has on the child and the child's dependence on it. Care and actions at the level of prevention promoted in the field of the health and wellbeing of children thus prevalently focus on the physical, social and psychological changes of the environment (Simeonsson *et al.*, 2003; WHO, 2007).

Conclusions

The first factor of international importance in the defence of health is a recognition of the dignity and rights of *children and adolescents as individuals characterised by special features*, as is recognised by various international conventions, which have been too often ignored or not yet ratified. All the contents of the ICF-CY have been developed in order to be in conformity with the international conventions and declarations designed to defend the rights of children (the UN Convention on the Rights of Persons with Disabilities (UN 2007); the UN Convention on the Rights of the Child (UN, 1989); Standard Rules for the Equalization of Opportunities, (UN, 1994); the Salamanca Statement on the Right to Education, (UNESCO 2001)). The conformity of the ICF-CY with these conventions and declarations has been made in order to assure that the documentation derived from the codes and categories of classification can be a useful instrument in the defence and upholding of the rights of children and adolescents and in planning that is marked by specific goals. From a philosophical point of view, it was essential that the classification defined the health and the functioning of children and young people by including aspects inherent in the defence and recognition of human rights as recognised in the UN Convention on the Rights of Persons with Disabilities (UN, 2007). The taxonomy, which derives from the ICF and the ICF-CY, describes functioning and health through very detailed codes that refer to various aspects of development. The rationale of the ICF-CY, connected with public health, is based on the fundamental idea of preventing functional limitations and disability in childhood by seeing it as an instrument that allows an identification of the various sphere of intervention, or the person or the environment in which he or she lives.

The centrality of planning based upon the needs of the person also allows a better management of services in terms of management and the allocation of resources, interventions involving control and quality assessment, the allocation of forms of treatment to different conditions of health, and the measurement in the field of treatment and the costs of treatment.

In developed countries as in developing countries the bases should be established for the spread of a culture of a 'caring community' which gives important points of reference to children during their growth stage and which can be the 'red line' that unites an identity that is often fragmented and dispersed in various services. All the (health-care, educational, family etc.) figures involved should provide individuals through their specific skills with all the support that is necessary, but each skill should be joined and integrated with the others. It is of fundamental importance for children that their conditions of health, whatever these may be, do not coincide with their identity: their identity, rather, includes and incorporates also their health and what that health involves. A social/health-care network linked to an informal network that is well constructed around the child and

his or her family can be the strongest answer to health problems that could create loneliness and marginalisation and a failure to develop capacities.

We can thus state with certainty that no analysis of disability is useful and clear unless one takes into account persons, both adults and children, as such: disability is a subsequent problem, Without this fundamental fact a person with a disability is seen as 'another' compared to other human beings. If the problem of disability remains the problem 'of others' we will never manage to understand that it is nothing else but part of the complexity of being human.

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SALLY SMITH

4. Children's Diseases and Globalization: Risks and Opportunities

I am delighted to join you here today, and especially to thank His Eminence Cardinal Javier Lozano Barragán for his invitation to Dr Peter Piot, Executive Director of UNAIDS to attend this conference. I bring greetings from Dr. Piot. He sends his regrets that he is not able to join you to discuss this important topic. It is a privilege to attend the meeting to represent UNAIDS today and to share with you some perspectives on the specific issue of the global HIV epidemic, how it affects children in particular and what are some of the challenges and opportunities before us as a global community in seeking to mount an effective response to this pandemic.

This is an important conference and the timing is very significant. Dr. Piot has recently reminded us that we are at the beginning of a new phase in the AIDS response: 'There are a number of voices today that would tell us that AIDS is yesterday's issue – they could not be more wrong. AIDS is a complex, long-wave, intergenerational event, and responses must take account of children'.

There is good news in the new Global AIDS Report, which shows that since 2003 deaths among children have declined by 16%. Since 2001, new infections have declined by 20%. Thus there have been improvements but still 1,200 children under age 15 years were infected each day in 2007. We still have a long way to go.

We must have renewed resolve to prevent HIV among children, and support those who are affected and infected. At a recent meeting in Dublin hosted by the Government of Ireland, UNAIDS reaffirmed our commitment to work with UNICEF to rally a UN-wide effort for children and AIDS as a system-wide effort working with many partners including the Joint Learning Initiative on Children and AIDS. Faith-based organizations were represented at the meeting and this is reflected in the wording of the final communiqué.

The Joint Learning Initiative on Children and AIDS has been an exceptional initiative to reassess the evidence of what is needed for successful responses to HIV for children. It has galvanized learning across different communities, analyzed the data, consulted with communities and maintains a methodological rigor. I know that Catholic groups have been a part of this consultation and have brought rich data and experience to the discussion.

Churches and communities of faith are at the heart of the response and are leading the way in many communities – providing care and support to families living with HIV. Throughout this presentation, as I present some of the challenges I will also highlight ways in which Churches are responding to these challenges in partnership with others.

There is now a consensus that the Global Community knows what needs to be done and an agreement that we need to focus on how to ensure that vulnerable children can access the services and support they need. Children are becoming infected because we are not fully implementing the proven means to stop mother to child transmission, because we are not treating women, because we are not involving men, because we are not providing young people with the knowledge and skills they need, and because we are not coordinating services. More effort is needed to keep children and parents living with HIV alive and well.

Some stark findings from the recent round of global reporting indicate that: only 18% of pregnant women in low- to middle-income countries received an HIV test in 2007; without HIV diagnosis, prevention of HIV transmission to the child is difficult. Only 21% of pregnant women who attended ANC in 2007 were offered an HIV test. Only 33% of pregnant women living with HIV worldwide received anti-retrovirals to prevent mother-to-child transmission in 2007.

In 2007 only 12% of HIV-positive women identified during antenatal care were assessed for their own eligibility to receive full-course anti-retroviral therapy. Without preventing infection among women and providing treatment for those who are infected, children will continue to be at risk to HIV infection. Protecting the lives of mothers is critical to the wellbeing and survival of children and families.

If we have learnt anything in the past twenty-seven years it is that there is no single way to tackle AIDS, and that no single organization or sector can do the job alone. Partnerships are the key to success, including partnership with the Catholic Church and other faith-based organizations.

In 2007/8 the Unions of Superiors General of Religious Orders of Men and International Union of Superiors General of Religious Orders of Women (USG UISG), in collaboration with UNAIDS and Georgetown University, conducted and published a mapping exercise of their responses to HIV: 190 service delivery outlets were directly providing antiretroviral medication and 104 providing PMTCT services. This is a significant contribution, and is likely to

be an under-reporting of overall service provision by Catholic health care facilities.[1]

Children are not getting treatment – we need to increase the effectiveness of programs, services and funding. Few children receive timely HIV testing: in 2007, only 8% of children in low- to middle-income countries were tested for HIV within the first two months of life. Yet without treatment, disease progression among infants is rapid and half die within the first two years, nearly all by the age of five. Few receive cotrimoxazole, an affordable, widely available, effective and well tolerated antibiotic treatment recommended for all HIV-exposed children. In 2007, only 4% of children born of HIV-positive women were initiated on cotrimoxazole by the age of two.

Access to ARV treatment for children is improving but we have a long way to go. At the end of 2007 fewer than 200,000 children worldwide received AIDS treatment – 60% more than the year before but still little more than 10% of those who need it – and only a third of the treatment access of adults.

The USG-UISG survey reports that 23% respondents were directly providing ARV services but only 17% had pediatric formulations of ARV's available for treatment.[i] This is a reflection of a broader problem, namely the lack of antiretroviral medications for children.

Caritas Internationalis has worked extensively over the last few years with the Ecumenical Advocacy Alliance (EAA) and other Christian partners on a campaign to increase access to antiretroviral medications for children. Caritas Internationalis and the Catholic HIV AIDS Network (CHAN) have endorsed the WHO "make medicines child friendly campaign." These are some examples of the ways that the Catholic Church-related organizations have been, and continue to be, heavily involved in work to increase access to medicines for children living with HIV.

Comprehensive support for affected children, families and communities is badly needed. According to household surveys in eleven high-prevalence countries, only 15% of orphaned children live in households receiving some sort of assistance. For many children, AIDS is not an emergency any more; they have never known anything else.

For them, programs addressing structural factors must be added to those expanding prevention and treatment. Especially in sub-Saharan Africa, this requires a unprecedented national mobilization of resources and a paradigm shift on how we respond. But these programs are not expanding as fast as they could.

The Dublin communiqué highlights the role of community and faith-based organizations, many of whom are playing a critical role in caring for, protecting and supporting families. More support and capacity is needed however, and better coordination between government and civil society responses.

The USG-UISG survey has again demonstrated something of the extent of the response by religious orders to this problem; 43% of respondents were providing extended services to support women and orphans in the community. Many of these activities were integrated into the longstanding programs that religious men and women were organizing in the communities in which they serve [1]

Children are affected by HIV directly and indirectly – we are shortchanging children unless human rights for vulnerable children are protected. Children who are infected have to deal with HIV testing, treatment and care where services are available. Management of other infections such as TB, and the burden of stigma and discrimination are complications leading to poor life prospects for many children.

When parents are infected children are often orphaned (today there are 15m children under the age of eighteen who have had lost one or both parents to HIV), and instead of being care-receivers children are forced into being caregivers, and eventually breadwinners. When communities are affected, so are children as teachers, health care workers caregivers and public servants are lacking. And when children become young adults and start to become sexually active, they must be able to protect themselves against the risk of HIV infection; I will come back to this point later.

In February of 2008 a joint mission to Swaziland was organized between WHO, UNAIDS and Caritas Internationalis to explore some of the possibilities for increased collaboration between the Church and the government in the provision of combined TB/HIV

care. Faith-based health service outlets are often well placed to provide integrated service delivery for HIV and related infections. Msgr. Robert Vitillo presented a report of this joint mission to the UNAIDS coordinating board, demonstrating to other governments the importance of partnership between governments, UN agencies and faith-based organizations.

We know how we can avoid 90% of infection in children, and we know how to respond in the case of those who are infected. The principles known as the "Four Ps" are supported by UNAIDS and UNICEF:

1. To prevent mother-to-child transmission of HIV.
2. To provide paediatric HIV treatment.
3. To prevent infection among adolescents and young people.
4. To protect and support children infected and affected by HIV.

We know what can be done to prevent HIV among children. We need to do better what we already know what to do:

1. To prevent mother-to-child transmission of HIV to children. We can do this, and we have significant successes in Argentina, Belarus, Botswana, Bahamas, Moldova and Thailand, where coverage has met UNGASS goals, as well as the rest of the industrialized world.
2. To provide paediatric treatment (ARVs, cotrimoxazole or both).
3. To prevent infection among adolescents and young people – after nearly 30 years into the epidemic only 40% of young people have comprehensive HIV information.
4. To protect and support children infected and affected by HIV.

We have a clear idea of what makes programmes addressing children successful: strong government commitment and fully coordinated efforts with government and non-government partners; quality maternal, newborn, child health and sexual and reproductive health care services; HIV testing and counseling in antenatal care settings; effective and age-appropriate HIV and sex education programs, delivered before young people become sexually active; and family-centered HIV care which links maternal, newborn, child health and sexual and reproductive health care.

We must focus especially on protecting and supporting children affected by HIV because that is still a neglected part of our agenda. We know that AIDS is breaking up families, fragmenting communities and challenging traditional safety nets. Yet larger organizations do very little prevention work with families, and only limited work around structural and long-term development. More emphasis needs to be given to structural prevention, including physical and social protection policies that lie beyond the typical policy focus of HIV but which address the fault lines that underlie vulnerability to the AIDS and its impact. This is again where the Church is strategically placed to respond, and in many areas is already doing so

We know that the impact on household welfare is greater on the poor than on the better off. We know that gender inequities make girls more vulnerable than boys. We are aware that it is threatening children's rights – whether civil, political, economic, social or cultural.

The issues faced by children provide a lever to promote broader development-oriented responses to HIV/AIDS: rolling out social protection to poor families, including cash transfer schemes, supporting children in highly impacted areas is one such example.

But we are not yet on track to creating these successful programs because of: poor coordination between, on the one hand, maternal and child health programs, and, on the other hand, HIV programs; a lack of financial and human resources; stigma; a lack of male engagement and a failure to tackle gender violence.

We also know how to tackle the prevention of sexual transmission of HIV as children become adults, but to do so needs political courage to talk honestly with our children about sex, interpersonal, sexual and family relations. Adolescents continue to be denied information and services, even though research has shown that sexuality education programs do not increase sexual experimentation, and may increase the likelihood that sexual debut is protected.

As I mentioned earlier, still only 40% of young people globally have comprehensive and correct knowledge about HIV (slightly fewer girls than boys) – less than halfway to the global goals set in 2001.

Fortunately, young people are also leading the way by changing their behavior in a way that has led to the downturn of the epidemics in several countries such as Burkina Faso, Cameroon, Ethiopia, Ghana, Kenya, Malawi, Tanzania, Zambia and parts of Zimbabwe. But we have to get much more serious about making sure that girls in particular are not faced with choices where sex seems the only way to survive.

The key words to success are "integrated services" and "family and community centered approaches". These are areas of service delivery and community care that the Catholic Church is well placed to address. The Dublin communiqué "Encourages partnerships between civil society, and government, including parliamentarians by building civil society capacity to participate in national responses. Supports civil society engagement and accountability in channelling funds to communities'.

UNAIDS has been collaborating with the Catholic Church in a range of activities for some years now and is keen to build on this partnership. A Memorandum of Understanding between UNAIDS and Caritas Internationalis already exists and areas of collaboration include "promoting activities to mitigate the social and economic impact of the epidemic on individuals, families, communities and nations, keeping the human person at the centre of the response".

UNAIDS worked with Caritas Internationalis, the Catholic Medical Missions Board and the Southern African Catholic Bishop's Conference AIDS office to produce a Best Practice Case

Study – "Choose to Care". Based on the work of the Southern African Bishops Conference, this documents some of the ways the Church is already responding and demonstrates models that can be replicated by other groups. Copies are available.

This year UNAIDS and FBO partners including Caritas Internationalis have worked together to develop a framework for UNAIDS engagement with religion and FBOs in the response to HIV. Again, copies are available for you to see. This is still a draft framework, but it outlines the many areas for collaboration between UNAIDS and FBOs, a separate section on working with children is currently being drafted and will be included in the final text. Perhaps colleagues from this meeting might be able to provide technical inputs in this new section. Another important issue stressed by the Dublin communiqué that UNAIDS will include in this section of the framework is the importance of strengthening care options such as kinship care, foster care, and domestic adoption so that institutional care is the last resort. I would be delighted to talk with you afterwards about the framework if you have any questions.

To conclude: we need therefore to put children right at the centre of our thinking and our action, to make sure we surround them with the loving, strong and resilient families and communities they need to flourish. You are already a part of the partnerships that are leading this work and we look forward to strengthening and continuing that partnership as we commit together to put children at the heart of the response.

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GUIDO CASTELLI GATTINARA

5. Lifestyle and Health in Children

The impact of individual lifestyle on health is well known in the case of both adults and children. Alimentation, but also the environment in which people live and work, the social and family context, conditions of hygiene, physical exercise and prevention are all directly involved in determining physical and mental well-being or, vice versa, in causing illness. The lifestyle of a child depends almost completely on the environment that his or her parents create around him or her, from the moment he or she is living in his or her mother's womb and then throughout childhood and adolescence.

When in the West reference is made to 'lifestyle' one assumes on the whole a freedom of choice, based upon knowledge of the basic rules of healthy living, upon the existence of social/health-care services, and upon the economic means of a family unit. This is a choice which in evolved countries adults can exercise freely and responsibly: in order to improve the conditions of personal health and their own children, parents can choose, if they want, a healthy and balanced alimentation, not to smoke or to consume alcoholic beverages, to practice sports and to engage in physical exercise, to enjoy necessary rest, and to intervene to prevent illness with the support of health care which in most cases is free.

This does, however, apply to the great majority of the populations that live in developing countries where choosing a correct 'lifestyle' to defend one's health is in reality a luxury. Poverty, cultural backwardness, and environmental difficulties connected with climate, with conflicts, with social deterioration, with the presence of grave illnesses within families and with the absence of education do not allow the *choice* of a healthy life, even where its rules are known about.

Let us now see in general terms what the causes, the lifestyles, are that involve consequences for the health of children.

Those in Western countries are relatively well known: excessive alimentation or a diet overly rich in fats and carbohydrates, a sedentary life linked to the replacement of the activities of social interplay and those in the open air by solitary recreational activity at home, videogames and the TV. But Western children are also exposed to the risks of domestic accidents caused by electrical or dangerous equipment, to swallowing toxic products, to road accidents, to passive and active smoking, to drugs and alcohol, not to speak of the danger of weapons, which are in some countries are to be found in every household. However in the advanced West there also exists a more hidden level of poverty which afflicts children who are often forced to live in an environment that offers few stimuli or a low level of moral support. This condition can be attributed as well to a part of the middle or upper classes, for whom there are no risks at the level of material privation but whose youngest members run up against strong possibilities of emotional and spiritual impoverishment.

The illnesses linked to lifestyle in advanced countries are thus prevalently asthma, diabetes, obesity, heart disease, depression and the consequences of domestic or road accidents.

In developing countries we have very different problems that derive from very different lifestyles. One of the first is malnutrition, followed by deficiencies in hygiene, drinking water and prevention; the unhealthy character of the environment; sexual exploitation,; child labour; and the traumas caused by conflicts and the death of parents. Poverty, social degradation and illnesses are inextricably linked. Most of the diseases associated with poverty are infectious diseases such as diarrhoea in various forms, malaria and tuberculosis.

Malnutrition

Throughout the developing world, one child in every four under the age of five – about 146 million children in all – is underweight. At a regional level, infant malnutrition is at its worst in southern Africa and to a lesser extent in Sub-Saharan Africa. In the case of children with nutritional deficiencies, the common illnesses of childhood, such as diarrhoea and infections of the respiratory system, can be fatal. Malnourished children who survive the first years of childhood often have low protein and energy levels, low iodine and iron levels, and these can contribute to chronic illnesses such as arrested growth or below-average height levels, as well as a compromising of their social and cognitive development.

Lack of Water

Drinking water and safe hygiene services can change the lives of children. Impure drinking water, a lack of water in which to wash and cook, and a lack of access to hygiene services together contribute to 88% of deaths due to diarrhoea illnesses, that is to say over 1.5 million deaths every year. An improvement in hygiene/health-care services alone could reduce the morbidity associated with diarrhoea by over a third; improved hygiene services associated with more hygienic forms of behaviour could reduce such morbidity by two-thirds. The washing of hands with soap or ashes would avoid 0.5 million to 1.4 million deaths every year.

Tribal Practices

Unfortunately, in many contexts social/religious practices survive which involve sufferings and risks for the health of children. One need only think of the mutilations of the female genitals, a practice above all of the sub-Saharan Africa, the Middle East and North Africa and in parts of East and West Asia. It is calculated that over 130 million women and girls who are alive at the present time were subjected to the mutilation of their genitals, and this is something which can have grave consequences for their health, such as the risk that the wound will not heal, a greater predisposition to HIV infection, complications during childbirth, inflammatory illnesses, and urinary incontinence. Haemorrhages and infections can lead to death.

Amongst the traditions that are a cause of suffering for children we may include early marriages and early motherhood. At a world level, 36% of women marry as children or adolescents, above all in East Africa and sub-Saharan Africa. The consequence of this phenomenon is early pregnancies and early motherhood. Every year fourteen million adolescent girls between the ages of fifteen and nineteen give birth. Girls under the age of fifteen have five times more probability of dying during pregnancy and childbirth compared to women between the ages of twenty and twenty-nine. If a mother is less than eighteen, the probability that her child will die during the first years of its life is 60% greater than in the case of a child born to an adult woman. And even if the child survives, it is more probable that it will be underweight, undernourished and will have retarded physical and cognitive development.

Sexual Abuse and Exploitation

It is calculated that 1.8 million children are involved in the commercial sex industry. Many are forced to do this because they are sold as slaves by extremely poor families, or kidnapped and trafficked in places of exploitation. These children are neglected, exposed to sexual violence, physical and psychological abuse, and infections of all kinds – for example HIV.

The Condition of Orphans

Every year over 1.5 million women die because of complications during pregnancy and childbirth, and newborn children without a mother have a three to ten times greater probability of dying than newborn children whose mothers survive. Thirty-nine million people, of whom a half are women, are infected with HIV and run the risk of dying: it is calculated that by the year 2010 there will be 15.7 million children made orphans as a result of this in sub-Saharan Africa alone. A series of strongly invalidating illnesses impoverish families or cause the death of parents. To this should be added the deaths caused by armed conflicts or their consequences.

Then are tens of millions of orphan children in the world and at times they themselves are ill (about 2.3 million children under the age of fifteen are infected with HIV), they have to support themselves and their siblings or they have to contribute to the expenditure of the families that have adopted them. They abandon schooling and thus become excluded from fundamental information about health, alimentation, practical skills and protection against violence and abuse. Research carried out in Addis Ababa in Ethiopia revealed that 28% of the children interviewed who worked as domestic servants were orphans, and in Zambia one study on children forced into prostitution showed that a third of such children were orphans of one or two parents.

Child Labour

It is calculated that 8.4 million children work in inhuman conditions. They are forced into slavery because of debts, into prostitution and into pornography, or are forced to take part in armed conflicts or other illicit activities. Slave-children work in the gravel pits of Latin America, in the brick factories of South Asia, and in the stone quarries of sub-Saharan Africa. This work is very dangerous and severe for these children who are, for that matter, malnourished and housed in unhealthy accommodation. Grave accidents are frequent, with mutilations and deaths as a consequence, but also lung afflictions…

It is useless to dwell upon the problem of boy soldiers. They are exposed to risks of all kinds, drugged, and traumatised by the most terrible experiences.

The Role of Mothers and Schools

A child, as we know, and above all when it is small, is not an independent entity, and does not determine its own life on its own. We should always see it as being within its family and above all in a vital link with its mother. The wellbeing of a child depends on the wellbeing of its mother and the women of its family. It has been amply demonstrated that when women can decide children benefit in terms of nutrition, health and education.

If we want, therefore, to imagine a positive relationship between the lifestyles and the wives of children, we should state with conviction that this is connected to the promotion of the equality of women.

We may think of microcredit, the practice that is spreading in developing countries with excellent results. Its success is linked to the fact that the loan in the vast majority of cases is given to women, who do not waste it but use it to promote their own activities and this to the exclusive advantage of their families. It is calculated that when they

obtain an income from their work, women on average spend 74% of their resources to increase their food reserves whereas the figure with men is only 22%!

But the education of women also brings many benefits to children and improves their survival rates, nutritional states and school attendance. Educated women have less probability of dying at childbirth and more probability of sending their children to school. The statistics indicate that the infant mortality rate is halved in the case of children whose mothers have an elementary education.

And this is not all: for children, school is a valuable place not only to learn to read and do sums and socialise but also to receive useful information on their lifestyles, hygiene, alimentation, and the prevention of illnesses.

But I want here to return to women and their crucial role in the health of children: it is always mothers who are the first to detect the illnesses of their children and have them treated. This is true throughout the world and this is something that we paediatricians well know. However, in some areas women have not been able to decide whether to take their children to a doctor; they cannot pronounce on how much should be spent on medicines or health care because they do not have their own resources and they do not have the same rights as their companions. The situation is even more serious in rural areas and urban slums where women are in large part illiterate and have to face up to barriers of a socio-cultural character, such as restrictions on being able to leave their homes or interacting with strangers. Often they do not have access to a health-care centre or a clinic. In Afghanistan women are prohibited from receiving health care in hospitals which have a medical staff that is exclusively male, and cultural norms impede women from working and receiving an advanced instruction in medicine.

While awaiting the reaching of the objective of the equality of women, every year 2.3. million children are born dead, more than four million die during the first weeks after childbirth, and another 6.6. million children die before their fifth birthday. Twenty-six thousand children die every day as a result of avoidable causes, and because of poverty and illiteracy.

But let us turn our minds back to our Western world where our children fall sick because we give them too much food, because we consume too much, because we have replaced our affectionate presence as parents with that screen babysitter known as the TV and their friends with videogames. It is difficult to find even one connection between the lifestyles of our children and the lifestyles of orphan children who are exploited, or of boy soldiers.

And yet there is a connection, that connection is all of us, we adults who are called with the little that we know how to do and can do, to contribute to thinking, because this is possible, of a more just world, for our children and other people's children.

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PAOLA ROSATI

6. The Realities and Origins of Children's Illnesses from a Personal Point of View: Alimentation

Introduction and Framework

A definition of a neonate which I remember was used at the Paediatric Clinic of the La Sapienza University of Rome when I was engaged in specialisation studies in the late 1980s offered a description which described its physiognomic features with exactitude – a neonate was defined as a macrosplanchnic brachytype.

Our attention as students was thus directed and concentrated on the physical constitution of a new born child which on being inspected was shown to be short in height, with slight limbs and an abundant trunk and abdomen. In my eyes as an aspirant paediatrician, who outside that lecture hall had stopped in front of the Latin motto '*In Puero Homo*', there immediately appeared the organicist vision of that little being who in himself presented all the mystery, the wonder and the fullness of a human being who had just been born and of his future, still to come, as a man.

Subsequently, during my professional years, as takes place in every profession, even though I had of necessity acquired that jargon that characterises medical language and allows a professional relationship in those authoritative high spheres that are dedicated to the medical profession, I always tried to concentrate my attention on a different vision of human nature, from the professional point of view of a medical doctor and from the point of view of a patient. This was difficult to reconcile, both because of the various languages that were involved, and, above all, because of the different priority objectives identified by the medical doctor, who is very often afflicted by a pre-eminently organicist vision of illness, on the one hand, and by the patient, on the other, who experiences the discomfort of the examination and a lack of health as sources of pain and tribulation, feelings that are closely accompanied by unexpressed worries and ones that are difficult to contain or overcome.

The subject of alimentation which has been entrusted to me allows me at a high level to reflect on this reality and on the constant research that is directed towards a continual improvement in communication between doctors and patients, on which is based a correct anamnestic approach for alimentary recall and its diagnostic-therapeutic contextualisation. A clinical history and conversation are, in fact, the only valid and practically necessary arms that we have to emphasise the emergent problems in the alimentary sphere. We do, indeed, often encounter the fact that the child and his or her family unit almost never think about the need to call a doctor if there are alimentary problems, and an eating disturbance runs the risk of coming out by chance during an examination or remaining underestimated for years until a critical clinical sign appears or the problem becomes unsustainable. In both cases it is often very difficult to focus the attention of the child and his or her family relatives, who are disorientated because of this initial question which had led them to the examination, and frequently an eating problem runs the risk of still being denied or remaining underestimated. It is at this point that our professional capacity is called into question, and this should not be directed towards treating but towards taking care of, without rigid, authoritarian or paternalistic positions, directing ourselves towards an open dialogue directed towards the search for the formation of the awareness of parents as regards alimentary problems and the justification of the recommendations that we will make in order to overcome the problem, directing the attention of the family towards authoritative sources that support the recommendations that have been made. The aim of the solution to the alimentary problem, like many other problems of health, will not, therefore, be compliance, that is to say a passive and often incomplete following of the medical prescriptions, but, rather, concordance, that is to say an understanding of the problem and cooperation in providing a solution to it (shared decision-making).[1] [2] Specifically through a consideration of the values and beliefs of patients, two distinctive figures have been identified in the literature in the field of good and great medical doctors. Here a predilection has been observed, above all as regards alimentary problems, for a good medical doctor who patiently listens and observes.[3]

'What is the role of conscience in man's moral development? How do we determine, in accordance with the truth about the good, the specific rights and duties of the human person?'[4] (John Paul II). In addition to technical-professional training we need a formation of conscience, which should not remain silent but which calls on us constantly in every conversation with a child and his or her

family. John Paul II defined the relationship of communication between a doctor and a patient as an encounter between trust and conscience.[5] This relationship has an actor in a non-starring role, which is often wrongly held to be passive, namely the child himself or herself.

To this end, I drew up during the first two decades of my work at the Baby Jesus Children' Hospital an operational pathway[6 7] that allows an expansion of the vision of medical doctors, which has been traditionally directed towards a rapid and rigorous act of prescribing, towards the point of view of the patient, whose way of seeing and understanding things, although it is incomplete and often inadequate as regards comprehending the cryptic medical vocabulary, more resembles human nature, which we medical doctors rediscover when we find that we ourselves are patients. The simple operational standard of this model of communication allows various levels of approach to an integrated talk: welcoming, empathy and readiness to listen, clarity and completeness as regards the information that is provided, and a relationship that involves mutual trust and joint work with the patient.

The basic principles are captured in the SMILE technique:

S Smile
M Mind
I Interview
L Listen
E Empathise

The systematic application of this model of communication to the relationship between a doctor, a mother and her child, also allows us to address the new further daily challenge of the contemporary globalised world – at least a third of those we take care of in our hospital come from distant cultural and religious realities, with different dietary traditions. This obliges us to engage in communication through a special figure, the cultural mediator, who is often an improvised and not trained figure, with evident worsening and confusion as regards the quality of the dialogue and understanding. In all of these cases, if we manage to offer a smile, our gestures and our empathy, which do not need to be translated, we can keep the talk at a clear and understandable level which allows us to take on board and to gather the anamnestic data.

In addition, increasingly often we enter into communication with parents who, although they come from our country or cultures similar to our own, speak the electronic language of Internet, a universally variegated virtual country where there is no serious and rigorous Virgil who directs the choice to go to safe, authoritative and predetermined sites. These modern and technological parents ask us for confirmations and insistently ask us about their sources, thereby forcing us to move towards new horizons, on the one hand imposing on us a constant updating and, on the other, inviting us to satisfy their questions with more careful and detailed information that should clarify and justify what we propose to do in practical terms.

The words nutrition and alimentation are not synonyms and are marked by a subtle difference of meaning:[8] by nutrition is meant the function by which living beings take from the outside world substances that are useful in developing and engaging in vital activities; alimentation, on the other hand, is the act or the effect of giving food, that is to say substances that contain various nutritive principles that can be used by living organisms. In English the translation of the Italian word '*alimentatazione*' differs from mere 'nourishment' and intimately identifies the relationship between a man and his nutrition and in a child his or her dependency on the mother who feeds him or her. Alimentation is the consequence of a series of conscious and voluntary activities: the mother provides the food that is produced by her own body and in subsequent months, after the birth, chooses the food that is suitable for the child, assesses it, throws away the part that is not edible, transforms it by cooking it or treating it and, lastly, gives it to the child.

Cultural, racial, religious and social differentiation issues are connected with food,[9] as are the needs of health, and with the lack and constant search for sustainable funds for a fair distribution of resources in relation to needs.[10] Alimentation is one of the factors that determines the growth of individuals and their physical and mental health and bears upon the performance and the productive a capacity of human beings, thereby influencing the development of peoples and their human destiny. Indeed, it is easy to notice that the nutritional status of children clearly reflects the socio-economic condition of a specific population[11] and that numerous characteristics of certain peoples, which are held to be normal and linked to race, are often the result of an unbalanced diet that has been deficient for generations or which is due to choices in relation to food that have been forced on them by climatic or environmental factors or a prolonged local shortage of nutrients.[12 13 14]

Alimentation, therefore, is a vital need for an individual: food, on the one hand, produces the sources that are needed for the production of energy, which is indispensable for life, and, on the other hand, the nutritive principles or 'nutrients' that are required for the maintenance of a harmonious biological equilibrium that ensures good health. This is obtained completely when the alimentary input, the calorie input and the nutrient input, and the needs of the organism (which vary according to numerous factors such as age, sex and kind of activity engaged in) are balanced and met completely. Alimentation and this meeting of needs are, therefore, complementary and overlapping elements and the meeting of the needs of mothers and their children also allows the needs of medical doctors to be met.

A little neonate, a macrosplanchnic individual, constantly seeks satisfaction at his or her mother's breast: he or she eats, sleeps and governs his or her life on the basis of hunger pangs,[15] and quickly and easily absorbs the milk that is given to him or her, even after intestinal operations.[16] The word 'satisfaction', therefore, is the natural and fundamental consequence of good alimentation.

Around this relationship between alimentation and satisfaction I will now analyse the subject

that has been proposed to me and I will try to link my liking for communication with that of satisfying the stomachs of those little patients we help and their needs.

Notes on International Law and Food Security

The close connection between peace and wellbeing was stated by the Charter of the United Nations which was adopted and entered into force in 1945 in San Francisco (for Italy it became binding in 1955, the year when Italy joined the UN). Article 55 of this Charter maintained that in order to create conditions of stability and prosperity it was necessary to have peaceful relations between the peoples of the world and thus the United Nations 'promotes a higher standard of living'.

This simple declaration of intent, which was without binding legal force for the States that signed the Charter, has been restated over the years on a number of occasions and has been upheld by international law, with clear references to the right to food and freedom from hunger[17] (in 1949 two Conventions of Geneva were drawn up, one for the protection of civilians in wartime, involving the free transport of food for children, pregnant women, women that have just given birth, and for the provision of food aid to occupied areas, and the other for the provision to prisoners of war of suitable food rations).

It was only in 1966, however, that the General Assembly of the United Nations declared the right to freedom from hunger in its International Pact on Economic, Social and Cultural Rights (article 11, first section, recognition of the right to adequate level of life…that includes food). This entered into force in 1976 and has hitherto been ratified, and has thus become legally binding, by the 138 States who adhere to it. The right to be free from hunger thus became a fundamental right of mankind, placed amongst the third-generation rights, that is to say both collective and individual rights, which involve activation by public powers.

The World Food Conference on 1974 solemnly proclaimed that 'every man, woman and child has the inalienable right to be free from hunger and malnutrition so as to be able to develop completely and maintain their physical and mental faculties'. The structure of action of FAO and other non-governmental organisations is essential if one wants to achieve the ambitious goal of the FAO summit that was held in Rome in June 2002, that of halving the number of hungry and malnourished people in the world (from eight hundred to four hundred people) by the year 2015. This goal, which was, for that matter, contested by the developing countries and a large number of non-governmental organisations which were present in a parallel forum, seems in reality to be already difficult to achieve. Indeed, on the horizon new heavy scenarios and imperatives at the level of programmes have emerged – these relate to food safety and to the so-termed obesity epidemic. Later in this paper I will examine the very large number of problems connected with this subject that have not been solved.

In 1992 the International Conference on Nutrition adopted a World Declaration on Nutrition[18] in relation to food safety by which the plenipotentiary ministers 'recognised that access to nutrionally adequate and healthy food is the right of every individual'. The right to adequate nutrition means that every man, woman and child, whether considered individually or as a part of a community, must at every moment have physical and economic access to adequate alimentation, or through the use of appropriate resources to hand, in a way that is suited to human dignity. The implementation of this right requires food that is available, free from adverse substances, culturally acceptable, and in quantity and quality suited to meeting the nutritional and dietary needs of individuals for their nutritional wellbeing.[19] The implementation of the right to adequate alimentation is inseparable from social justice which requires the adoption of appropriate political, economic, environmental and social policies at both a national and international level that are directed towards the elimination of poverty and the meeting of primary needs. To this end, the new concept of food sovereignty has been formulated as the right of peoples to determine, on their own, their own choices in the sectors of the production, distribution and consumption of food, in a way that respects the criteria of environmental, cultural and social sustainability, and in order to assure the right of every individual to sufficient and healthy alimentation.[20]

Despite these international efforts, the lack of adequate political control as regards food safety recently brought about in China the scandal of the 'melamine epidemic'.[21] The first episode involving the contamination of milk with melamine, a substance harmful to man and used to produce plastic and fertilisers, came to the attention of international organisations on 11 September of last year (a sad date). Both WHO and FAO used the international network INFOSAN (the International Food Safety Authorities Network)[22] to inform and update national authorities about the crisis, one of the gravest of recent years. In China, according to the data that has been re-

leased, 54,000 children had to resort to medical treatment because of the consumption of powdered milk and about 12,900 children are at the moment in hospital and four have died.

Why was milk contaminated by melamine? Because it increases the nitrogen content and in this way allows an apparent increase in the protein content of milk. The devastating effect of this on the working of the kidneys takes place when, added to sulphuric acid, melamine forms crystals that are deposited in stones to the point of obstructing the renal tubules and causing anuria, bringing about death in a short period of time. The level of melamine found in powdered milk produced by Chinese companies, who control 60% of the local market, was 2,560mg for every kg of the ready to consume product, although the level of sulphuric acid remains unknown. This was a devastating alimentary disaster that could have been avoided. Now the whole world is called upon to achieve international political cohesion and food control, together with constant initiatives in defence of health against the immoral policy of profit rather than the defence of children.

Some Specific Food Disturbances

For reasons of time and clarity, I have chosen not to list the numerous problems connected with alimentation and children but I have preferred to choose to reflect upon the four characteristic examples of food disturbance in children which for various emergent social reasons impose themselves on our attention: anxiety in the case of children who have no appetite; illnesses brought about by food deficiencies; mental anorexia; and obesity. Some of these disturbances are very frequent, others are very difficult to diagnose, but often they involve the mass media and require a multidisciplinary approach to be dealt with. The clinical pathways are often incomplete or even ineffective and a large number of operational difficulties of a diagnostic-therapeutic kind remain unresolved. Thus in relation to each one of these food disturbances I will identify the problems that remain open and the practical choices involved as regards communication and meeting needs in order to achieve best clinical practice.

Anxiety Caused by Children who do not have an Appetite

A typical phrase used by nearly all mothers who are worried because their child does not have an appetite is 'I do not know what to do. My child does not eat for *me*'. In that 'me' we find clearly identified their state of frustration, their symbiotic relationship with their child, and their feelings of guilt at their inability to deal with the problem. A paediatrician also feels frustrated when he or she suggests, ineffectively, that the mother should not force the child to eat, or when he or she identifies a rigorous list of nutrients which should be taken every day, something that expresses all of his or her participation in this problem which for a long time remains unresolved in a clear way. A lack of appetite can last for many months or for years, beginning during weaning (common opposition anorexia of the second six-month period) or concealing, although this takes place in very few cases, and with gastroenterological or systemic pathologies.[23] A protracted lack of appetite and an inadequate quantity of food introduced into a child can involve tiring days around the child at home, with the involvement of the whole of the family unit, including grandparents, in putting food into his or her mouth or distracting him or her with games and television programmes during meals. It can also involve the almost maniacal search for forms of treatment to stimulate the appetite of the child (this may include homeopathic remedies) and the carrying out of allergy tests, even ones that have not been validated, which often identify various forms of intolerance that then give rise to rigid diets involving the exclusion of certain kinds of food which do not produce a cure and which are, indeed, often accompanied by nutritional deficits (which are also denied by the mothers!). Lastly, after various examinations along the lines of medical shopping there often arrives, with varying degrees of concealment, a state of depression and self-blame on the part of the mother because of her feelings of inadequacy and anxiety caused by frustration. In these cases, mothers, who are nearly always involved in work that keeps them out of their homes for a large number of hours, display a natural and remissive subordination to the anarchic demands of their child who is nearly always lively and dissatisfied, and when by chance an alimentary problem is discovered during a paediatric examination that has been requested because of seasonal infections mothers can turn out to be adversarial and untrusting. In this way it may be impossible to change the family's 'political' management of the case in a short period of time. Of use here is a calm and communicative dialogue in order to acquire the trust of the mother, a taking on board of the problem, and the setting in motion of a multidisciplinary relationship (involving a paediatrician, a dietician, a specialised nurse or a psychologist) in order to exclude physical pathologies and identify the objective characteristics of the child which are often very different from the consolidated perceptions of the mother.[24]

Deficiency Illnesses

In the Western world nutritive deficits can be seen in selected parts of the population who limit the intake of nutrients for reasons of age, because of cognitive or metabolic disturbances, or because of psychological and social problems. Our present globalised world has also enabled us to learn from close at hand about cultural and religious realities that are often very different from our own and to encounter difficulties in making emblematic diagnoses that are only studied and assessed in academic texts. I will dwell here upon two cases where I encountered difficulty in diagnosing an illness derived from food deficits – one of scurvy and the other rickets. In the first case, the child, who was about eight years old, had had, ever since his birth, a modest cognitive deficit and for some months he had had bleeding of the gums, pains in his bones, asthenia and weight loss. After various days in hospital and a large number of blood tests, echograms and x-rays, a bone biopsy was carried out with the hypothesis of cancer which identified a clinical picture of diet deficiency because of an absence of osteoblasts (the cells used for bone remodelling). After a dietetic recall had been carried out, followed by a long conversation with the child's mother, a total lack of vitamin C in the child's diet was identified, which was the result of a choice made by the child and one that had never been obstructed by the mother whose attitude had been remissive.[25] This clinical picture was confirmed by an haematic absence of vitamin C and the condition was rapidly cured over subsequent months through the oral administration of vitamin C.[26] [27]

The second case recently concerned a child aged one year and six months who had been born in Italy to Hindu parents. The child came to the hospital because he was suffering from pains in his bones and painless tumefaction to his metatarsus and carpus associated with thinness of the lower limbs. The child lived in an embassy with his parents, his mother always never went out of her home and was still breastfeeding the child, without using milk or milk substitutes in her diet. After a diagnosis had been made of rickets caused by a diet deficiency, renal and hormonal causes were excluded. This diagnosis was then confirmed by an x-ray of the skeleton which showed pathognomonic lesions and the child began a diet of vitamin C supplements and exposure to sunlight with the expectation that he would fully recover within a few months. The following groups are currently at risk as regards rickets caused by deficiencies: dark skinned races who because they are more pigmented have a lower ability to produce vitamin C endogenously; women who wear clothes that cover large parts of their bodies our of tradition and religion; and individuals who undergo lengthy and often not recognised alimentary deficiencies.[28]

Anorexia Nervosa

This is characterised by a fear of gaining weight, by a denial of low body weight, and by amenorrhea in women who also have a low body mass index (BMI, which is obtained by dividing body weight in kgs by height squared in metres).[29] The incidence of this illness is very high in Western countries: anorexia nervosa in Italy afflicts between 0.2% and 0.7% of teenage girls and bulimia afflicts from 1% to 5% of the same category.[32]

This illness can occur in individuals with similar genetic, biological, familial and socio-cultural factors and often it is accompanied by psychiatric and personality disorders such as depression, anxiety, obsessive-compulsive disorders, and perfectionism.[28] A female adolescent with mental anorexia is nearly always female (M/F relationship=1/4),[30] develops a food disorder characterised by an obsessive following of her own weight, strange behaviour in relation to food, which is broken into pieces and eaten in small quantities and then often expelled through induced vomiting, does not take her meals with her family relatives, often denies that she has any appetite, and subjects herself to constant sporting activities. With a rapid and multidisciplinary treatment of both a nutritional and psychotherapeutic/medical character most of the people afflicted by anorexia nervosa recover, but it is estimated that 5% die from the illness and 20% develop a chronic food disorder.[28] In order to find a solution to anorexia a self-help approach[31] has recently been studied which has the aim of autonomously motivating the individual to go through the steps proposed and to engage in a relaxed conversation (the easy-going or relaxed approach)[32] without a stringent imposition of behaviour and associated with the choice of treatment through a clinic rather then through admission to a hospital. In this way, the pathway by which a recovery could take place within one to two years is assessed.[33] The use of anti-depressants has not been confirmed through clear evidence as being effective[29] and in women who have already had anorexia there is an increased risk of bone fractures which appear in old age.[34]

Obesity

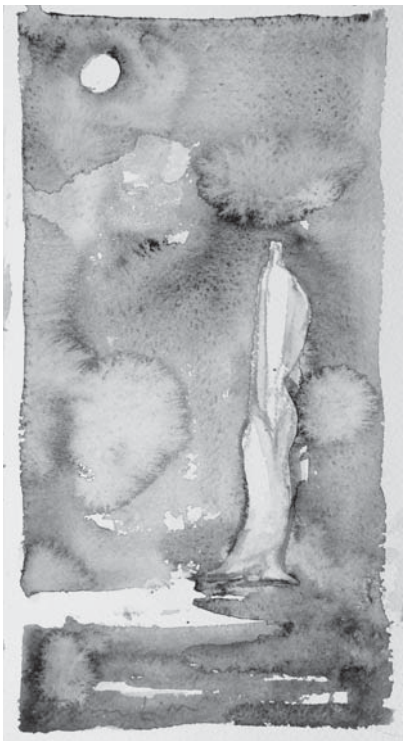
The prevention of obesity at the paediatric stage of life constitutes a priority in national public health plans.[35] [36] The prevalence of excessive weight and obesity is constantly increasing in adults as well as in young people and children (WHO, 1997). The definition of being overweight and of obesity varies in the various epidemiological studies and at times this makes comparisons between the various countries difficult. Recent calculations obtained from surveys in thirty-four countries on children of school age have 25% overweight rates and 7%-8% obesity rates in Malta and the United States of America, and 5 % overweight rates and 1% obesity rates in Lithuania (Janssen 2005). This phenomenon has increased exponentially over the last decade – the results of a vast survey carried out in England on children between the age of 0 and 4 showed that there has been an increase in overweight children since 1990 (Bundred 2001). From information on lifestyles, it emerged that 40.1%

of children spent about two hours a day in front of a screen (television, play station, computer) and 24.7% 3 or more hours. 32.2% of children declared that they did not spend more than one hour in the open air, only 24% of children went to school on foot, and 34% declared that they did not engage in any physical exercise after school. A statistically significant correlation between obesity, fast food and a feeling of being sated has also been recently demonstrated.[37] According to a survey carried out by the Italian Society for the Study of Obesity in Children, 25% of Italian children of the school age are overweight and the trend is upwards; at the level of trends the regions of the South have a higher level of excess body weight than the regions of the North. Various protocols regarding alimentary practice have been implemented but none of them have produced lasting results or results with a high capacity for reproduction. MEND (Mind, Exercise, Nutrition, Do it) is the most widespread method for combating paediatric obesity in Great Britain. WATCH IT! was developed to combat obesity in children in disadvantaged areas and allows a simple schema of communication and support based upon a structured approach that is called HELP (Healthy Eating Lifestyle Programme).[38]

The international epidemic of obesity in children[39] affects every paediatric age band and most ethnic groups, even those with good economic conditions. In an effective summarising fashion and with appropriate concepts, in response to the call to arms to fight the epidemic of obesity made by Dietz, a Scottish doctor, Guthrie, published in the *British Medical Journal* a small poem that summarises with gentle irony the justified need to receive and listen to mothers in order to identify problems and together with her to try to solve them (Childhood lies dying: Globalization, Some price to pay. Environmental pillage. No place for kids to play. Mothers out working, Neglecting their broods, Filling their children with all the wrong foods[40]). Excessive weight and obesity have a negative effect on a person's state of physical health and psychological growth and development: hyperlipidaemia, hypertension, reduced tolerance to glucose, a feeling of inadequacy and frustration are amongst the most serious possible complications in adults.[38] Despite the efforts and funds that have been brought into play hitherto, none of the hundreds of programmes that are available in Great Britain and other countries have enabled us to achieve optimal and permanent results.[41] At the present time the Institute of Education of London is completing a systematic revision from a different perspective based upon a survey of the problem and the needs of obese children in order to identify their individual motivations and thus to make those corrections that are necessary in order to provide a new methodological pathway that is based upon the expectations of obese children (available from 2009 onwards).[42]

Conclusion

With openness and a comforting welcome, with a solid, concrete and daily cooperation with the staff responsible for care, and with an individualised and available therapeutic continuity, the family receives from the paediatrician the help that it needs to obtain a solution to its food problem. A full concordance in relation to the proposals and advice that emerge, adapted to the individual situation and events, allows a containing of worry and the joint planning with the parents of the best and most effective pathway for the recovery of the full health of the child. The presence of cultural mediators for families who have different languages, cultures and religions is fundamental in filling that space of linguistic and social incomprehension which otherwise would remain unfilled, Side by side with this, however, the medical doctor must add his or her own affectionate and caring presence which emerges from his or her face and gestures, in addition to the words that are used, and which families understand without needing to understand what the words mean. When parents feel that discrimination is present it is very easy to restore the relationship with a gesture or a touch, in the absence of oral expressions: the sincerity that emerges from a hand that heals cannot be translated but is always understandable and does not need mediations. Good training in communication and the use of a simple and comprehensible language (plain language) is a fundamental guide for the conscience of the medical doctor and an improvement in the understanding of the treatment that has been proposed. The use of brochures, graphics or pictures, which accompany the oral explanations, also allows a full understanding of the prospects that are held up both in the short and the long term and allows the child and his or her family to be constantly motivated to engage in a constant and gradual review of the solution to the eating problems involved.



That 'first talk' involving communication, and the feelings that comes from it, is a fundamental milestone and will always remain impressed in the child and his or her family. The satisfaction that is experienced as a result of that meeting will modulate all the subsequent contacts between the medical doctor and the family and

the child, and will bear upon mutual understanding, the subsequent choices, and the achievement of success at the level of diet and therapy.

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ANDRZEJ SYSA

7. The Technological and Scientific Origin of Diseases Afflicting Children: Technological Change, Industrial Change, Capacity for Rehabilitation

The Holy Bible
Genesis 1
'[27] So God created man in his own image, in the image of God created he him; male and female created he them.
[28] And God blessed them, and God said unto them, Be fruitful, and multiply, and replenish the earth, and subdue it: and have dominion over the fish of the sea, and over the fowl of the air, and over every living thing that moveth upon the earth.
[29] And God said, Behold, I have given you every herb bearing seed, which is upon the face of all the earth, and every tree, in the which is the fruit of a tree yielding seed; to you it shall be for meat'.

We and our children have the earth with all its "fruits", the fruits of our human activity as well. Right now we do not live in paradise but in partially polluted earth and air. This environment is a place of birth for our children. Some children are affected by different diseases with many origins. Part of the whole population of children manifests symptoms of congenital defects with a high percentage of cardiovascular anomalies. Congenital malformations may be caused by endogenous, genetic or family factors, as well as by exogenous comprising maternal or environmental elements. The exogenous environmental factors are air and earth pollution. In the air, there is outdoor diesel exhaust, emissions from combustion and industrial processes, powered pesticides and such particles as carbon monoxide, nitrogen dioxide, ozone, and exposure to such environmental factors as paints, solvents and degreasers, and pesticides. There publications shed light on the problem of the increased risk of malformations in children of women who work in pesticide factories and the leather industry.

The increased risk of congenital anomalies caused by earth pollution was proven by a multicenter study on families living at a distance of about 3 to 7 km from waste-disposal sites. A striking proof of the impact of air pollution caused by the burning of oil fields is based on the observation of a threefold increase in congenital heart defects after the Gulf War in Kuweit.

The respective proportionate influence of these two exogenous and endogenous (genetic) components is not precisely established mainly because some overlapping of both components exists. Most common congenital defects demonstrate multifactorial inheritance and are determined by a combination of genetic and environmental factors. Major congenital defects are mostly developed by teratogenous agents acting during organogenesis between the third and the tenth week of gestation. Severely affected embryos are spontaneously aborted during the first months of their lives. Anatomic and structural abnormalities are present at birth but may be not diagnosed until later on. They are responsible for approximately 20% of deaths in the perinatal period, the differences depend on the level of health service in the analyzed countries. Approximately 3-4% of all live birth newborn children will have major malformations; in them around 1% are cardiovascular defective

Epidemiologic studies carried out during the 1970s presented a rough spectrum of the group of congenital heart defects: about 50% involved defects with left to right shunts; approximately 25% involved cyanotic defects (this means complex anomalies with right to left shunt); and the rest had mainly stenotic malformations. During the last decades a specific change in proportions has been observed. There is an increasing number of complex and very complicated cardiovascular defects with a great deal, around 20%, of so called ductus-dependent anomalies.

In the field of congenital heart defects the advent of new and highly sophisticated technologies and techniques is bringing progress in diagnosis and treatment.

Contemporary visualization using computed tomography enables us to see malformations of vessels coming out of the heart such as coarctation of the aorta and collateral vessels omitting the places of narrowed vessels.

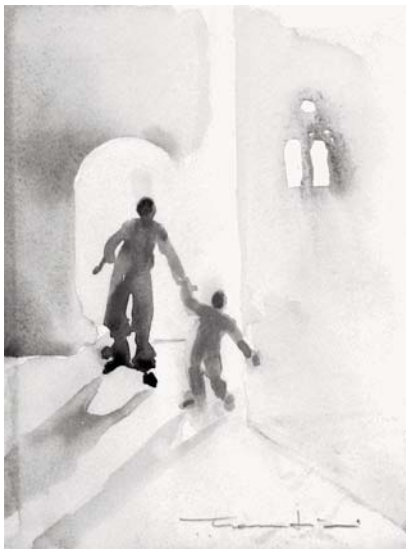
Ultrasound techniques give us the means to diagnose structural changes in the inside of the heart and the origin of great vessels, and the use of a color-coded Doppler makes it possible to discover pathologic flows inside them and to estimate the level of severity. This especially concerns those defects that do not manifest themselves in the first days or weeks of

life in clear acoustic symptoms (a specific murmur or prominent pathological heart sounds), for instance the hypoplastic left heart syndrome (HLHS), and the transposition of the great arteries (TGA). These diagnostic techniques have a great influence on ability to assess methods of surgical and interventional treatment and the results of these procedures. Optimal results from their surgical repair take place when operations are performed during the first ten days of life. In this way, we can abandon for such children invasive techniques such as catheterization and angiocardiography which in some newborn children can have dangerous complications. In older children echocardiography with a color coded Doppler enables the visualization of such mute (acoustic) heart malformations as the atrial septal defect (ASD). Decisions as to closing are based upon ultrasound examination.

On the other hand, the progress in techniques of catheterization and the technology of material production used in medicine allows the avoidance of surgical methods of treatment by using the percutaneous intravascular pathway. This is called interventional cardiology. Using this technique several malformations can be repaired. This involves closing such defects as the ventricular septal defect (VSD), the atrial septal defect (ASD), and the patent arterial duct (PDA) or several collateral vessels which are not necessary but disturb the circulation of blood. Interventional procedures, on the other hand, are available in the treatment (dilating) of both congenital and postoperative stenotic vascular lesions. A spectacular relief of symptoms can be obtained by balloon valvuloplasty in neonates who have a critical stenosis of the aorta or pulmonary artery.

The same releasing effect can be achieved in the case of coarctation of isthmus of aorta (COA) by performing balloon angioplasty using special high pressure balloons. Sometimes it is necessary to maintain this effect, supporting the wall of the artery by introducing a special stent bar or a covering of a special artificial textile.

The use of interventional procedures as medical support involving several groups of problems. From one point of view, a lot of distending techniques have temporary effects and should be repeated. On the other hand, the possibility of using artificial materials in the form of implants in cardiovascular system has different consequences. In some implants there is a need for prolonged anticoagulation therapy, which is very inconvenient in children, and sometimes impossible to do quickly.



There are also several noxious reactions. The most common are: metal toxicity, fibrogenic reaction, allergy, and the autoimmune response (to homo or heterograft valve implants).

While using implants, according to Gillon we have to take into consideration four principles of medical ethics: 1.respect for autonomy; 2. not doing harm; 3. beneficence; 4. the function of judgments.

Respect for autonomy means an obligation to respect the decision-making capacities of an autonomous person. Not doing harm means an obligation to avoid causing harm. Beneficence means the obligation to provide benefits and to balance benefits against risks. The function of judgments – the obligation to act without prejudice, fairly, without any bias, with justice in distribution, respect for the rights of other persons, and respect for the moral accepted law.

The progress in the technology of medical equipment, anaesthesiology and operative techniques provides us with an opportunity to treat children with very complicated cardiovascular anomalies with surgery. The number and forms of contraindications ate being gradually limited.

This progress has caused a change in the age of children operated on for cardiovascular anomalies. My country – Poland – could serve as an example. In 1990s the largest group was that treated surgically during the first year of their lives, mainly in the pre-school period. Now most of cardiosurgical procedures (two-thirds) are performed during the first year of life, and more than a half of them during the neonatal stage.

Simultaneously, the progress in techniques of neonatal care has increased the chances of survival of very small premature children who have congenital defects, often of a multiple kind, and who have organs that are not completely developed and are very susceptible to injury to their central nervous systems. Infants who require open-heart surgery and reach the school age are sometimes at risk to developmental, psychosocial and academic difficulties. These children need some educational and rehabilitation services.

As mentioned above the main cause of malformation is genetic disorders. They have different characteristics. Of the about 3% of all newborn children who have significant congenital defects, 1% have multiple anomalies or syndromes. Only 40% (!) of them can be diagnosed as having specific, recognized syndromes and 60% have unknown conditions that need to be further delineated.

Diagnostic techniques enable us to diagnose the deletion of the arm of chromosomes linked to some cardiovascular defects: trisomy of the 14, 18, and 21 chromosomes. Trisomy of the 18 chromosome (the Edwards syndrome) is connected with a bad prognosis for long survival. Trisomy of the 21 chromosome (the Down syndrome) has a good prognosis for survival but it is imperative not only to treat their cardiovascular system but to support their quality of life by a different form of physical

and mental rehabilitation. The some concerns more subtle chromosomal disorders such as microdeletions.

There are several known forms diagnosed by a new FISH technique which manifest as different syndromes connected with different organs and tissues. Two of them should be stressed because of their possible frequency and the clinical consequences for children who have this anomaly as a syndrome: it is microdeletion 22g11.2 (the Di Gorge syndrome, or the VCFS syndrome) and 7q11.23 (the Williams syndrome)

The first (known also as the velo-cardio-facial syndrome) consists of several abnormalities – cardiac (conotruncal anomalies), abnormal facies (bulbous nasal tip), thymic hypoplasia (immunodeficiency), cleft palate (abnormal soft palate function), and hypocalcemia.

The clinical problem for these children with a cardiac defect is a defect in their immune responses for the whole of their lives.

The second, the Williams syndrome, is characterized by so called elf-face, a progressive narrowing of the aorta and/or pulmonary artery, and light/moderate mental retardation. In both syndromes, interventional and surgical treatment of heart defects prolongs life but these children need rehabilitation and the support of their parents.

As a result of progress in the technology of diagnosis and in the treatment of cardiovascular defects some new problems have appeared which have many consequences. The change of proportion between simple and complex, mainly cyanotic defects, a doubtfull total/final correction of most of the defects and an increased proportion of patients with multiple malformations, including genetic disorders.

All of us are responsible for the consequences of the progressive influence of developed techniques which help to solve the main problems of cardiac-affected children, namely their survival, but they simultaneously involve new unfavourable developments. It is our duty to create a system of rehabilitation for these handicapped children whose lives are saved but whose quality of life needs to be improved constantly.

'The recent stage of human history, especially that of certain societies, brings a correct affirmation of technology as a basic coefficient of economic progress; but, at the same time, this affirmation has been accompanied by and continues to be accompanied by the raising of essential questions concerning human work in relationship to its subject, which is man. These questions are particularly charged with *content and tension of an ethical and an ethical and social character.* They therefore constitute a continual challenge for institutions of many kinds, for States and governments, for systems and international organizations; they also constitute a challenge for the Church' (John Paul II, Encyclical *Laborem Exercens*, n. 5).

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8. The Paediatric Sciences

At the beginning of the last century infectious diseases constituted throughout the world the greatest danger for health and for the lives of children. Infant mortality then oscillated in Europe at 10-20% and was caused for the most part by infectious diseases, Gradually, above all after the end of the Second World War, improvements in standards of living, vaccinations and the use of antibiotics drastically reduced illness rates and death rates in young people in industrialised and economically emerging countries. Today infant mortality in Italy is a little above 5 cases for every 1,000 live births. In developing countries as well, infant illness and death rates are decreasing but unfortunately to a much lower extent.

On the other hand, the diagnostic and therapeutic developments made possible by technological innovations and in particular by the biotechnology revolution, by the extraordinary advances in imaging technology, by the availability of new pharmaceuticals and by important innovations in the field of surgery and intensive care have enabled paediatrics in industrialised countries to save the lives of a large number of sick children who in the past would have survived for a few months or at the most for a year. However, as Hugo Heymans has well emphasised: 'It is difficult to overestimate the successes of paediatrics over the last fifty years. We know how to treat conditions which at one time were fatal such as leukaemia, diabetes, congenital heart disease, immunity deficits… many children who did not survive yesterday, today become adults. But we should also ask ourselves: have we really defeated these illnesses? No, we have not defeated them, we have transformed them into chronic illnesses'. Today the central problem of the paediatric sciences as a discipline is that of their biological and clinical bases, their therapeutic approach and the organisational approach employed in the treatment of children with chronic illnesses. As a rule, chronic illnesses are complex because they do not involve one organ or apparatus alone but, in general, end up by effecting the organism in the totality or almost totality of its anatomical and functional component parts. They are, in other terms, authentic systemic illnesses. It is therefore necessary to develop a new approach to care based on integrated multi-specialist care and on what is called 'case management', that is to say on the integration of the process of care of a large number of specialists that is coordinated by a 'case manager' who assures the efficiency and efficacy of the intervention and places the child in the integrity of his or her person at the centre of the care and treatment that is provided and thus within the context of his or her family life as well.

Given that a growing number of children are being saved, in developing countries as well, the problem of chronic illnesses has by now become a global problem. In developing countries the burdens of care are increased by the persistence, side by side with chronic illnesses, of high death and illness rates in children, a phenomenon caused by simple acute infectious diseases such as measles, pneumonia, meningitis, meningo-cocchal and pneuomo-coccal sepsis, and bacterial and viral gastroenteritis. On the other hand, the availability of anti-viral HIV treatment of an increasingly effective nature has also transformed paediatric AIDS from being a rapidly fatal acute illness to being a chronic illness. The cost of this antiviral treatment, which at the outset was very great, is progressively falling and as a result in developing countries there has been an increase in care programmes for children infected by HIV whose success in these countries is destined in a substantial way to increase the number of children with chronic illnesses, with a consequent social/health-care impact that it would be difficult to overestimate.

H.R. Wulff, one of the pioneers and founders of modern evidence-based medicine, has identified four fundamental components of this clinical paradigm, and thus of the paediatric sciences as well: the biomedical and physiopathological bases of illnesses, clinical experience, empathetic comprehension and ethical judgement.

Faced with the new and emergent questions and issues of a biological character, the paediatric sciences are drawing up a new model of clinical physiopathology that is integrated with cell biology and molecular biology. Concrete examples of this, amongst many others, is the development of increasingly effective technologies for the diagnosis and treatment of rare illnesses. Equally significant in the treatment of many onco-haematological pathologies and numerous genetic diseases is the development of increasingly effective therapeutic strategies that are based on the transplanting of somatic stem cells taken from the same sick individual or from voluntary donors. The transplanting of haematopoietic stem cells, in particular, has allowed the lives to be saved of an extremely high number of children with leukaemia, as well as children afflicted by genetic diseases. The application of biotechnologies to the production of pharmaceuticals has made new vaccines become available for the prevention of grave and widespread infections as well

as what are termed 'biological pharmaceuticals' which have been shown to be extremely effective, even and above all in the case of children, in the treatment of certain kinds of cancer, numerous anti-immunity illnesses, and chronic bone and intestinal inflammatory illnesses.

Clinical experience was based until the last years of the last century on the memory of the individual medical doctor and on the authoritativeness of particularly capable and authoritative clinicians. From the 1980s onwards evidence-base medicine developed as an authentic discipline, defined by David Sackett, one of its founders, as an 'approach to clinical practice where clinical decisions derive from the integration of the experience of the medical doctor and the conscientious, explicit and judicious use of the best scientific evidence available, mediated by the preferences of the patient'. Medical experience, therefore, moves out of the sphere of subjectivity and becomes subjected to the tests of efficacy and rational criticism. This radical change in the meaning and role of clinical experience has had an extremely significant impact on the paediatric sciences and is finding increasingly broad and pervasive application thanks to the rapid evolution and spread in clinical practice of the instruments of information technology as well.

As regards the last two components of this clinical paradigm of Wulff, namely empathetic comprehension and ethical judgement, I would like to offer an illuminating reflection formulated by Richard Behrman in 2006: 'In the interaction between the paediatrician, the child and his or her family, sensitivity, aptitudes, values, traditions and faith come into play. This interaction is strictly intertwined with medical science and technology but, in fact, it dominates the process of providing care and treatment to the sick child'. It may be surprising, but at the same time extremely significant, that the person who wrote these lines, which uphold the primacy of the human person in the context of the contemporary paediatric sciences, is a great paediatrician of the United States of America, the heir to a school marked by the most rigid form of molecular reductionism. Fortunately enough, rational reflection is shown to play a determining role in the present and the future of the paediatric sciences as well.

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PAOLO RIZZINI

9. The Development of New Pharmaceuticals and Children

Children, boys and girls, and teenagers are very different from adults from various points of view – the social, the psychological, the behavioural and the medical. More than a hundred years ago Dr. Abraham Jacobi, the father of modern American paediatrics, recognised the importance of, and the need to provide, a specific pharmacotherapy that was appropriate to the various stages of life when he wrote: 'paediatrics has nothing to do with miniature men and women, with reduced dosages of pharmaceuticals and the same kinds of illnesses in smaller bodies…rather, it has it own spheres and horizons'.[1] However, only recently has pharmacology began to take into account the profound modifications that growth and development involve for responses to pharmaceuticals as well, and has there been a better understanding of the need specifically to study new and old molecules in the various stages of the paediatric age, thereby overcoming the traditional empirical methods of adjusting the dosages (for example Young's rule and Clark's rule), but also calling into question or testing, above all in the case of forms of treatment for chronic illnesses, the adjustment and 'normalisation' of dosages according to weight or body surface. It should, indeed, be borne in mind that human growth is not a linear process and that the changes in the composition of the body and the working of organs are dynamic and can be variable, in particular during the first ten to fifteen years of life. Today it is evident that a modern approach to the development and dynamics of the ontogenesis of the processes involving the absorption, distribution, metabolism and excretion of pharmaceuticals is required. In addition, as regards the mechanisms of the action of new molecules and their pharmaco-dynamics, one should assess the evolutionary aspects during the various stages of the interaction between the pharmaceutical and the receptor, including the ontogenic changes in the number of receptors, in their affinity, in the coupling of the receptor and effector, and in the modulation and regulation of the receptor system or any other molecular target of a new pharmaceutical. Indeed, the International Conference on Harmonization (ICH) issued its 'Note for Guidance on Clinical Investigation of Medicinal Products in the Pediatric Population' which was later partially modified by the European Committee for Medicinal Products for Human Use (CHMP). This divides up the paediatric part of the population on the basis of age into six categories, derived from physiological and pharmaco-kinetic differences (such as metabolic capacity, the maturation of organs and the clearance of pharmaceuticals): premature neonates, neonates (0-1 years of age), little children (1-2 years of age), pre-school children (2-6 years of age), boys and girls of school age (6-12 years of age), and adolescents (12-16/18 years of age).

Despite these advances, hitherto pharmacological studies on children have been relatively low in number and often pharmaceuticals are administered which are without specific paediatric information. There has thus been a consolidation of a significant off-label use of many of the therapies that have been registered after studies carried out on adults alone, and this goes from use in the case of non-registered instructions or in different age bands, to unforeseen dosages, or different frequencies of administration or paths of administration, to counter-indicated or non-envisaged uses or combinations, and on to the use of extemporary formulations without data on bioavailability or physical-chemical stability. Some studies have tried to ascertain the range of this phenomenon and in thirty of them, carried out between 1985 and 2004, the percentage of very young patients who had received at least one off-label prescription was between 16% and 97%, with greater incidence in neonatal hospital departments (80%-97%) compared to paediatric hospital wards (36%-92%) and community paediatrics (16%-56%).[2] Not much is known about the risks associated with this kind of use of pharmaceuticals in paediatrics but some studies have nonetheless demonstrated a greater risk of adverse reactions.[3-5] Finally, it should not be forgotten that history teaches us that there are adverse events that appear only in children. We may recall here the deformations caused by thalidomide, the colouring of teeth caused by tetracycline, the 'grey baby syndrome', and Reye's syndrome caused by aspirin in children with viral infections. The need for specific pharmacological studies in paediatrics is therefore high but the list of pathologies where there has been clinical research on children is not long and is confined to certain illnesses typical of childhood, in particular in the oncologic sector. And yet it should be acknowledged that clinical experimentation in paediatrics has led to significant improvements in the conditions of health of children: between 1971 and 1985, as regards the survival rates up to five years of age for certain infantile tumours, there was a rise from 37% to 70% for acute lymphoblastic leukaemia, from 22% to 70% for non-Hodgkin's lymphoma, from

15% to 43% for neuroblastoma, and from 17% to 54% for osteosarcoma.[6-7]

The importance of the scientific development of pharmaceuticals in paediatrics has been recognised in recent years by regulatory and legislative initiatives which with partial success have also sought to increase the quantity of paediatric clinical studies. In the United States of America, in 1998, the Food and Drug Administration (FDA) issued its 'pediatric rule' which compelled the production of scientific evidence before new therapies or new instructions were approved for use in paediatrics and at the same time the American government encouraged the pharmaceutical companies to carry out studies on children with an extension of six months of the exclusivity on the patent (FDA Modernisation Act, Pediatric Exclusivity Provision, prorogued in 2002 as Best Pharmaceutical for Children). Subsequently the 'pediatric rule' was eliminated and in 2003 the Pediatric Research Equity Act became law in the United States of America. This laid down that all the requests for registration (new molecules, new therapeutic instructions, new dosages, new systems of administration, new paths of administration or new formulations) had to bring with them information gathered from the paediatric part of the population, unless the applicant had obtained from the FDA a waiving of a test or its postponement. These legal measures only apply to pharmaceuticals and biological products developed for the treatment of pathologies or conditions to be found in both adults and the paediatric part of the population.

More recently, the European Union also recognised the need to carry out pharmacological experimentations with children and in December 2006 the European Parliament and the European Council approved the 'Pediatric Regulation'[8] with the aim of promoting research and development in the field of pharmaceuticals in paediatrics and improving the availability of information for their use in children. In the United States of America the above-mentioned legislative measures have led to an increase in data provided on pharmaceuticals in paediatrics with consequent substantial modifications in information on the use of pharmaceuticals (see Table 1). This demonstrates that a specific paediatric dose is needed (in different ages) which reflects the growth and stage of maturation of children, which cannot be simply determined by normalising the dosage of the adult, and that such pharmaceuticals which have a specific spectrum of tolerability in adults can be ineffective or less tolerated in children.[9]

Tab. 1. Modifications of information (tot. 165) on 108 pharmaceuticals (of which 7 are new molecules) following the new paediatric data presented to the FDA between 1998 and 2005.(9)

Type of Modification	%
Modifications in dosage	21.3
New data on tolerability	31.5
Demonstration of lack of effectiveness	17.6
New formulations	11.1
Extension of limits of age in children	71.3

Of the pharmaceuticals approved in Europe between 1995 and 2005, only 33% provided data to support a paediatric indication, and this percentage falls to 9.4% and to 23.4% if one considers respectively the neonatal age band and the infant age band.[10] It is therefore clear that pharmacological research has been lacking overall in paediatrics for a variety of reasons which go from practical and ethical difficulties in carrying out studies on the paediatric part of the population to the high costs of these studies and on to the lower economic return on the use of pharmaceuticals in very young patients. It follows from this that often 'new pharmaceuticals' developed in paediatrics has involved molecules whose use had been consolidated in adults but specifically studied for children's pathologies and pathologies in children. To encourage this kind of research, which is certainly fundamental in paediatrics, Europe has provided a new authorisation for the market in the form of its Pediatric Use Marketing Authorization (PUMA), with ten years of extension of patent protection for old pharmaceuticals studied in children and only for use in paediatrics. The European Medicinal Agency (EMEA) has also published a Priority List to indicate the principal needs as regards experimentation with pharmaceuticals in paediatrics and this contains twenty-five pathological conditions for which there exist non-patented pharmaceuticals without information and data in paediatrics.[11] A survey of the literature in the field has recently analysed the paediatric pharmacological studies that are underway or were published in Europe between 2004 and 2007. Most of them were carried out in the field of infectious and parasite diseases (21.4% and of these 41% on malaria), followed by the area of neoplastic illnesses (18.2%), of the nervous system (10.3%), and endocrinal-metabolic and immunity illnesses (9%). When these data are compared with the Priority List of the EMEA only four of the twenty-five pathologies were addressed in the research studies; neoplastic diseases (18.2% of the total of studies carried out), asthma (3.2%), sedation (0.8%) and pain (0.8%)[12] (see Table 2).

Tab. 2. Paediatric clinical studies in the EU between 2004 and 2007 (EPL - European Priority List). (12)

Pathological Condition	%
Infectious and parasite diseases	21.4
Neoplastic diseases (EPL)	18.2
Illnesses of the nervous system	10.3
Endocrinal-metabolic and immunity diseases	9
Asthma (EPL)	3.2
Sedation (EPL)	0.8
Pain (EPL)	0.3
Other non-EPL	36.8

It should also be emphasised that amongst the three principal areas, that area indicated by the WHO in its 'Burden of Disease for the European Region'[13] as being the most needed as regards research for children between the ages of 0 and 14 was neonatal illness, which remains the primary cause of death and is still an 'orphan' of research. On the basis of this evidence, we can thus state that despite the fact that in recent years there has been an increase in pharmacological studies in paediatrics, the need remains to direct such studies more towards the therapeutic areas that are really short on the ground or without research or new information.

Lastly, there should be an increase in research into the development of new formulations that are appropriate for administration to children, in particular during the first years of life. These must take into account the following characteristics: sufficient bioavailability, the safety of the recipients (some are safe in adults but have high toxicological risks or risks of inducing hypersensitivity in little children or children with metabolic disorders typical of childhood), palatability and other elements of acceptability, accuracy of dosage and possibly uniformity of dosage in the various stages of childhood, a simple and safe administration, and information on the use of the formulation which is precise and clear.

I will now briefly analyse the principal pathological conditions in the paediatric sphere where in recent years the need for research or the effective study of new pharmaceuticals has been most focused.

Paediatric Antiretroviral Therapies

UNAIDS estimated that in the year 2007 the number of children in the world under the age of fifteen (average age 2.3) who had HIV/AIDS, the great majority of whom were in Africa, had an annual growth rate of 420,000 infections. Of these only 15% received the necessary treatment and 40% were less than eighteen months old.[14] Some of the principal problems involved in making available these therapies with greater effectiveness, and in particular antiretroviral therapies, include that of a lack of formulations of therapies which can be easily dosed and administered (such as, for example, disposable pills) and the scarcity of studies in small children on the tolerability and effectiveness of available and new molecules, regarding the development of resistances as well, and in particular in relation to the impact that situations of malnutrition and contemporary pathologies (such as tuberculosis and malaria) have on the principal parameters of clinical results and safety. I will now summarise the priorities of research to optimise the therapies for HIV in children (HAART- Highly Active Anti-Retroviral Therapy; PMTCT – Prevention of Mother To Child Transmission)[15]:

1. Therapeutic aspects of HAART: optimisation of the first-line regimes after exposure to PMTCT measures; optimal instructions for the beginning of HAART; optimal instructions for the move from first-line to second-line therapies; the assessment of long-term results; optimisation of treatment in adolescents; optimisation of prophylaxis with cotrimossazol during HAART; and optimisation of the schedules of immunisation and re-immunisation during HAART.

2. Pharmacological aspects: development of combinations of a fixed dose for children; improvements of thermal stability for paediatric formulations; pharmacokinetics of HAART in neonates, little children, malnourished children, and children being treated for tuberculosis and malaria; and the pharmacokinetics, tolerability and effectiveness of new anti-HIV therapies in the various paediatric ages.

Paediatric Oncologic Illnesses

As has already been observed, paediatric oncology has today reached good cure percentages, but much has still to be done and in particular as regards that third of patients who have a relapse of their illness. It should indeed be taken into consideration that about 80% of anti-tumour pharmaceuticals used in children do not have paediatric instructions and are thus used off-label, and that less that 15% of pharmaceuticals approved for adults are used in paediatrics. There is therefore a great deal of absent information both about the pharmaceuticals that are used and about those that have not yet been experimented with in paediatrics. In particular, we need data on their pharmacokinetics, long-term tolerability and effects on the growth of organs and apparatuses, on the low effectiveness levels that are connected with questions of under dosage in children, and on mortality linked to the toxicity of treatment in particular in childhood. Lastly, new pharmaceuticals with a specific biological target whose presence should thus be ascertained in the neoplastic cells of the various forms of cancer

in children should also be experimented on. Support pharmaceuticals for cancer therapy should also be studied more, for example the new anti-emetic drugs, the factors of marrow growth such as filgrastim for neuropenia induced by chemotherapy, and zoledronic acid for the hypocalcaemia induced by cancer. In the next table (Table 3) are listed the principal molecules being studied for some of the cancers of childhood[16-17]:

Paediatric Psychopharmacology

Suicides and murders are the second and third causes of mortality in adolescents and are connected with emotional and behavioural disturbances, with symptoms of impulsiveness, depression and aggression. The use of psychoactive drugs in childhood has been studied very little and their use is prevalently off-label. The problem of the safety of these pharmaceuticals in the case of a nervous system that is at a stage of development is extremely relevant, as is the testing of their effectiveness in situations that are substantially different to those of adults from the anatomical-physiological, neurochemical and psychological point of view. As regards safety, one need only remember the sudden deaths in children treated with desipramin, a tricylic anti-depressant, or the greater risk of suicidal behaviour in children and adolescents who have been treated with selective serotonin reuptake inhibitors (SSRI). The treatment on which research has begun to concentrate the most are ADHD (Attention Deficit Hyperactivity Disorders) and autism, but pharmacological experimentations on mood pathologies (depression), anxiety syndromes, and above all on the development of new pharmaceuticals for epilepsy, have increased.[18]

ADHD: this is a common neurobehavioural disorder characterised by symptoms of lack of attention, hyperactivity and impulsiveness, the standard pharmacological treatment of which is made up of stimulant molecules (methylphenidate and amphetamines), or by a non-stimulating compound – atomoxetin. Research has been directed towards the study of formulations which allow a control of symptoms throughout the day (MTS, methylphenidate transdermic system, bipentin, and pro-pharmaceuticals such as lisdexamphetamine), and the study of new molecules such as modaphenyl, a cortical selective activator; guanfacin, an agonist of the Alpha-2A receptors of the prefrontal cortex; cholinergic agents that are activators of the nicotinic receptors such as donezepil, galantamin and other nicotinic agonists or analogues; the use of zinc sulphate as a metabolic co-factor that influences the metabolism dopamine; and the new inhibitors of reuptake of dopamine and noradrenalin (GW320659) or selective inhibitors of the noradrenalin sola (reboxetin).[19] However we do not have data on the efficacy and safety over the long term of these compounds that have been studied, and in particular we lack data on the risk of abuse of these molecules with stimulating characteristics in chronic treatment and the reduction of risk when one moves on to non-stimulating ones.

Autism: there is no treatment for autism and hitherto none of the few pharmaceuticals that have experimented on with children with autism have demonstrated any effectiveness in relation to the principal symptoms of social disability typical of this syndrome. Retrospective studies have indicated the effectiveness of memantin on the symptoms of irritability and lack of attention of autistic children and adolescents, and an important trial showed the efficacy of the anti-psychotic drug risperidon on manifestations of aggression and self-inflicted injuries in patients between the ages of five and sixteen.[20] Other pharmaceuticals initially experimented with in non-controlled studies are mood stabilisers (valproate and levetiracetam) for affective instability and aggression, and SSRI (fluoxetin, citalopram and venlafaxin) for anxiety and mood disturbances. Then there are various empirical approaches that are at times used both with diets with chelating metal substances and at times with various other molecules, but the information that is available today is too limited to allow an assessment of the efficacy of these forms of treatment and their generalised use. Given the low number of effective instruments that are available for the treatment of autistic patients every potential indication of benefit must be considered and adequately assessed. This can take place only in a scientific context with formal and recognised

Tab. 3. Principal molecules studied for tumours of the paediatric age

Type of paediatric neoplastic illness	Molecules being studied in paediatric patients
Acute lymphatic leukaemia Acute positive Philadelphia chromosome	Imatinib
Acute lymphatic leukaemia	Clopharabin (nucleosid analogue)
Acute lymphoblastic leukaemia	Imatinib
Chronic lymphoblastic leukaemia	Alemtuzumab
Acute myeloid leukaemia	gemtuzumab ozogamicin; inhibitor of the proteasomes; inhibitor of the deacetylasis histone; inhibitor of the kinesis tyrosine
Follicular lymphoma	Rituximab
Cerebral tumours	Erlotinib (inhibitor of the EGFR)
Neuroblastoma	Inhibitor of angiogenesis (bevacizumab); phenretinid (retinoid)
Adrenergic cortical carcinoma	Mitotan
Rhabdomyosarcomas	topotecan, irinotecan, docetaxel; ixabepilone (inhibitor of the microtubules); inhibitors of rapamicin
Other sarcomas of the mol tissues	gefitinib (inhibitor of the EGFR); ET-743 (inhibitor of gene transcription); gemcitabina+docetaxel

methodological approaches, otherwise the decisions will be based not on evidence but on sensations which, however much they may be important, are not in the interests of patients and their families. To have bases from which to begin to develop pharmacological research, it is necessary to know the mechanisms that have to be corrected or modified. And one cannot get to this if one does not know the seats where the mechanism has been altered. Today, however, there are clear instructions that the full clinical expression of the autistic disorder reflects complex interactions between genetic vulnerability and other biological and environmental factors. Indeed, genetics plays a fundamental role in the outbreak of autism but it should also be said that the autistic disturbance is multigenic and thus of a complex character. The Smith Kline Foundation has promoted in this direction a project of genetic research with various studies that can be engaged in, starting with a large patrimony of eternised DNA and data gathered in a standardised way by families of autistic patients in order to contribute to the discovery of the causes of autism and thus the discovery of therapeutic solutions.

Rare Diseases

These are diseases with a low incidence rate within the population (less than five out of every 10,000 people). They are very heterogeneous and it is calculated that there exist between 5,000 and 7,000 of them. Of these, almost 50% appear in or are exclusive to childhood. Table 4 lists the principal molecules that have been studied and have been shown to be active in rare diseases of the paediatric age.[21]

Despite the fact that American and European legislation has tried to encourage research into, and the development of, molecules for these diseases, over the last four year only a few pharmaceuticals have been studied in a sufficient way, albeit with problems of a methodological character which still have to be solved. There thus remain thousands of rare diseases, and not only of children, which await an effective and secure therapy. This is certainly a problem of public health which should not in any way be neglected.

Vaccines

The appropriate vaccination of all healthy children would increasingly reduce over time the risk connected with the outbreak of various infectious diseases which have a morbidity and mortality that are higher in that age band, and in particular in children who, because of concomitant pathologies or malnutrition, have a reduced immunity response capacity. For this reason as well, an assessment of a correct initial dose and the frequency of possible boosters over time, in addition to an assessment of the safety of the vaccine, are of fundamental importance in paediatrics. For these reasons, new vaccine research seeks to reduce the quantity of antigens per dose, to use inactive antigens or inert recombinants rather than live attenuates, to increase immunogenicity, thereby reducing the necessary quantity of the antigen, through new adjuvant systems, to choose easier and more effective systems of administration as regards the immunity compartment that one wants to stimulate (for example mucosal rather than humoral), and to study new fixed combinations of vaccines to simplify and optimise vaccine schedules in the paediatric age. With the acquisition of new knowledge about the immunity response, and in particular on the innate immunity response, research into new helpers has become of fundamental importance because these induce a powerful and persistent immune response with the advantage of reducing the need for an antigen and the frequency of administration. In addition, the targets of new vaccines often require the inducing of a strong cellular response, which includes the helper T lymphocytes, side by side with the classic antibody response induced by old helpers such as aluminium salts. The new vaccines thus require inert antigens of a recombinant type (ones that are safer), combined with formulations on the basis of aluminium salts, emulsions, liposomes or micro-particles, and immunostimulants as the agonists of various receptors present on the cells that are used to recognise the pathogenic microorganism (PRR – pathogen recognition receptor), in particular the various types of toll like receptor (TLR).[22] These developments are changing the research on vaccines by allowing us to identify them and develop them anew for a multiplicity of various targets, both viruses (HPV, HIV) and parasites (malaria) and bacteria (TB), but also neoplastic cells (melanoma, lung cancer) and cell components (angiotensin receptor II, amyloid). It becomes of fundamental importance to specifically study the impact of these new molecules that act on various points and patterns, including regulatory ones, of the immunity system during the various stages of the paediatric age, in parallel, therefore, with the various moments of maturation of a child's immunity system.

Table 4. Pharmaceuticals for rare children's diseases

Rare disease	Name of pharmaceutical
Tyrosinemia type 1	Nitisinone
Essential trombocytemia	anagrelide hydrochloride
Wilson's disease	dehydrated acetate zinc
Patent arterial duct in premature births	Ibuprofen
Mucopolisaccaridosis type 1	Laronidase
N-acetylglutammate synthetase deficit	N-cabamyl-L-glutammic
Gaucher's disease	miglustat, imiglucerase
Acromegalia	Pegvisamant
Fabry's disease	Alpha agalsidase, beta agalsidase

Conclusion

In this summarising analysis of the development of new pharmaceuticals for paediatric use I have tried to show how this research is unfortunately recent and how often studying new pharmaceuticals means engaging in specific pharmacokinetic, pharmacodynamic and clinical research in the paedi-

atric age with old molecules or with new dosages, formulations and instructions of old compounds that are already used in adults or are often used without additional informative data in children. The new American and European legislation has begun to modify this situation, encouraging and promoting studies with old and new vaccines in paediatrics, also trying to direct research to those paediatric areas which most need it. Research in paediatric pharmacology has been more directed to certain sectors, such as that of infectious diseases (and in particular the treatment of HIV and vaccines), oncologic illnesses, psychiatric illnesses connected with development, and some rare pathologies, thanks to the law's encouragement of the development of 'orphan' pharmaceuticals. Stress should also be laid on the need for the development of adequate formulations that allow a paediatrician to prescribe pharmaceuticals that are really taken by very young patients in a complete way with the correct posology, easily and safely. Lastly there is a need to experiment with the new forms of biological treatment in the paediatric age as well. These are being shown to be extremely effective in adults as regards pathologies that also affect children. I may cite by way of example the anti-TNF monoclonal antibodies in Crohn's disease and in idiopathic infantile arthritis. For these new and promising types of therapy as well it is of fundamental importance to verify their (probable) impact not only on effectiveness but above all on safety in the long term in the various paediatric age bands.

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The Origins of Illness in Children: the Political Perspective

The Health of Children in the World Today

It is rightfully claimed that a great deal has been achieved in our world over the last decades with respect to the health of children, not least the improvement in their chances of achieving (more or less) healthy survival and then entrance into productive and meaningful adolescence and adulthood.[1]

However, the health of the world's children nowadays is far from perfect. Quite the contrary. Despite the progress that has been achieved, the situation is not at all satisfactory. Children that could be living healthy lives are not healthy; instead they suffer from illnesses that are preventable, and they are even dying in very high numbers. The numbers from the less well-off countries are alarming. However, even in generally well-off countries there are communities, especially on the outskirts of great cities or within certain ethnic groups, that live in abject poverty and bad health. Children who are born there have low life expectancies and also little opportunity to escape their misery.

A great divide runs across the globe, affecting many aspects of families' lives today, as well as the lives of their children and their children's happiness, perspectives and health. Details may be found in other papers throughout these proceedings and in the relevant literature.[1, 2, 3] I will discuss here only some of the most striking paradoxes of today's situation, and try to see at least some of the causes, especially those that can be seen as 'political' ones, albeit only in a very brief and sketched form.

Children are dying in armed conflicts. They are vulnerable, unprotected, sometimes even killed intentionally before of the eyes of their parents or together with them. They are being made orphans in great numbers; their ordeal they face is a life of poverty, struggle and grim prospects. Children are dying in combat. It is estimated that about 300,000 children under the age of 15 are forced to be involved in various abominable ways in combat units in the battlefields around the globe. These children are abused in many ways, and are left – if they survive – with incomprehensible memories, unhealed or wrongly healed wounds, and various mutilations conferred on their bodies and souls.

Children are dying from hunger and from malnutrition. The deaths of 3.5 million children each year (more than one third of all children under five who die) can be attributed to the effects of malnutrition.[4] The damage done by malnutrition can start when a child is still in the womb, an indirect consequence of the poor nutritional intake of the mother, and globally 18 million babies are born with a low birth weight each year. Malnutrition weakens a child's immune system, making him or her more susceptible to disease and less able to fight off infection. A particularly critical period for cognitive and physical development is from the first few weeks in the womb until the second year of life. If a child is chronically malnourished, or stunted, during this time, the effects are irreversible. He or she falls easy prey to illnesses caused by malnutrition, to infectious diseases, and also to developmental retardation and abnormalities.

Children are dying from preventable or easily treatable diseases.[1, 2] More than 50% of all children's deaths are caused by just five communicable diseases, which are preventable and can be treated: pneumonia, diarrhoea, measles, malaria and HIV/AIDS. Malnutrition is an underlying factor that increases the risk of dying from these diseases. Children are particularly vulnerable during early life. Perinatal mortality accounts for more than 20% of deaths in children under the age of five, and includes birth asphyxia, trauma, and low birth weight.

Children are dying from exploitation, abuses and injuries suffered at the workplace.[5] It is estimated that 158 million children aged 5-14 are engaged in child labour – one in six children in the world. Millions of children are engaged in hazardous situations or conditions, such as working in mines, working with chemicals and pesticides in agriculture, or working with dangerous machinery. They are everywhere but they are invisible, toiling as domestic servants in homes, labouring behind the walls of workshops, hidden from view in plantations. For example, in Sub-Saharan Africa around one in three children is engaged in child labour – 69 million children; in South Asia the figure is about 44 million. Children living in the poorest households and in rural areas are most likely to be affected.

Innumerable children born to the poor families of the underdeveloped countries, or to the families of impoverished communities living in better-off countries, are today losing their lives, their health, everything that belongs to a 'normal', happy childhood. They are the victims of hunger, bodily and mental injuries, deadly diseases (to a large extent preventable ones!); they are the victims of suffering, pain, hatred and death.

On the other hand, rather paradoxically, children in the devel-

oped countries also suffer from preventable diseases or illnesses, or they develop habits and lifestyles that prevent them from living healthy and happy adult lives. The most striking children's health issues today in these quite well- off countries are overeating, which leads to the 'epidemic of obesity' with subsequent health problems; alcohol and drug abuse; early initiation into sexual life, teenage pregnancies and abortions; the rise in sexually transmitted diseases; mental health problems and suicide; and loosing the perspective and meaning of live with a resulting passivity, apathy, a recourse to 'virtual reality' and 'virtual life' or to various forms of aggression against things, people or against themselves, including 'gang life' and other forms of crime. Many of these are interrelated and embodied in today's 'post-modern' culture which impregnates all aspects of the life of contemporary 'post-modern', technically, technologically and economically highly developed societies.

The Health Paradoxes of Children and their Causes

The health paradoxes of children, some of which have been briefly outlined above, as has been pointed out already, are far from having only medical or public health causes. On the contrary: the causes of the poor health and the deaths of today's children are most commonly found outside the health-care realm, and therefore they cannot be tackled effectively and efficiently within the health area alone. The roots of those distortions, injustices and forms of negligence have to be identified and tackled if any serious and sustainable change is to be achieved.

In the underdeveloped countries of the third world the causes of bad health and the early death of children are frequently horrible and disastrous political situations (those of war, international and national terrorism, a lack of basic living and health resources, or the channelling of the country's wealth into very inappropriate and unfortunate areas such as the purchasing or development of weaponry, sustaining large combat armies, etc.); the pursuit of bad and inhumane policies; and also a terrible lack of a development and implementation of good policies. The situation is made worse by the inability of suffering countries or regions to receive and use effectively the international aid that is brought to them – be it necessary goods, human resources, or technical and technological 'know how'. Greedy corruption; power struggles; the totally reckless attitudes of governments towards their own people; crude totalitarian dictatorships that offer no care or mercy to their people and even steal international aid from their most needy citizens; pitiless guerrilla wars that give rise to groups of ruthless warriors who have nothing to loose except their lives and despair and who rob people of their last food and necessities; and many, many other 'horrors of day and night' – these are all making these desperate situations seemingly helpless.

In developed countries the attacks on children's health and life are much less visible at first sight. Those are killing children's souls and lives from within, bringing the invisible poison of 'post-modern' culture and lifestyles. Children, paradoxically enough, are suffering because of an overwhelming presence of enormous, glittering offers and unmanageable quantities of otherwise possibly useful 'goods for life' – such as food, clothes, toys, virtual means of communication (internet and mobile phones), entertainment and leisure opportunities, information over/flows, the strong voices of the sirens of various today's 'must-have' pseudo-cultures, and last, but not least, absent or distorted family and social relationships, those that are necessary for the formation of networks for the healthy development of children's mental, social, and psychological capabilities and capacities.

All in all, we can see here that many of today's causes of children's diseases, illnesses and death are more of less directly coupled with a bad or insufficient governance, bad, distorted or insufficient policies, and, clearly, with bad, inhumane or reckless policies.

Politics and Policies towards Children's Health

Usually, politics is referred to as the process by which groups of people make decisions. The term is generally applied to behaviour within civil governments, but politics has been observed in all human group interactions, including corporate, academic, and religious institutions. Politics consists of 'social relations involving authority or power', and can refer to the regulation of a political unit and to the methods and tactics used to formulate and apply policies.

A policy, on the other hand, is 'a deliberate plan of action to guide decisions and achieve rational outcome(s)'. While law can compel or prohibit behaviour, policy merely guides actions toward those that are most likely to achieve a desired outcome. Policy may also refer to the process of making important organisational decisions, including the identification of different alternatives, and choosing from them on the basis of impact they will have. Policies can be understood as political, management, financial, and administrative mechanisms arranged to achieve explicit goals. They are typically instituted in order to avoid some negative effect that has been noticed or worried about, or to seek some positive benefit. Policies, however, may rather frequently have side effects or unintended consequences. Because the environments that they seek to influence or manipulate are usually complex adaptive systems (e.g. governments, societies, ethic groups, large companies etc.), making a policy change can have counterintuitive results. Therefore, the policy formulation process should include an effort to assess as many areas of potential policy impact as possible.

Health policies are an important part of the pool of public policies. Because of their 'vital' importance for individuals, families and various groups within society, they are also quite high on the political agenda, either in a purely declared and formal fashion, or in a more substantial way in the form of tackling and solving health problems. They are also an issue in po-

litical battles, especially during election campaigns. A lot of fine promises are thrown to the crowds – either literally or through powerful mass-media outlets. Unfortunately, those declared promises rarely survive to become a concrete health policy measure that is pushed up a legislature's or a government's approval ladder. However, even between elections deciding on health policies can rightfully occupy the 'hot spots' of municipal, regional, or national politics. The question is, however, how 'children-friendly' these policies really are, and how effective and efficient they become when implemented in practice.

How Can 'Bad Politics' or Wrong Policies Cause Illnesses in Children?

It is a paradoxical in itself to observe that a policy, or politics – which should, in principle, seek and promote the common and individual good – may inflict bad things, even ill health, diseases and death, upon a society's most cherished members, its children.

First of all, as has already been observed, this may be due to the lack of good policies as regards health issues connected with children, or the mere impossibility of implementing good health-related measures because of a disastrous situation in the country, region, or population or ethnic group in question (e.g. situations of war or natural disasters; groups of displaced or totally marginalised people; homeless people; illegal migrants etc.). This is also the case when the state or a particular community fails to establish laws and policies designed to protect the lives and health of its children.

The next possibility is situations where good laws or policies are not implemented; they remain in the realm of empty promises or wishful declarations. Though even to declare something in a public square as a good, recommendable or necessary issue should be seen as a positive move in itself, it does not suffice to make a real difference in improving the impoverished situation.

An even more subtle but nevertheless strongly impacting situation is faced when a law or a policy that establishes or promotes apparently good things is poisoned at the same time with issues, aspects or activities that are either bad in themselves or may lead (intentionally or not) to sinister consequences. Situations where good goals are believed to be achieved by bad means are not at all rare. On the contrary. People are made to believe that it might be good to decide for the 'lesser evil', or that it might be possible to adhere to distorted laws or policies for the sake of presumed political or social progress, or just to enable a (wrongly understood) 'constructive dialogue' among ideologically or morally adverse parties which are usually strongly entrenched in their typical positions. This is, however, as is seen in many instances, and possibly more clearly nowadays and in recent decades, 'the straight path to (at best) nowhere'.

Although dialogue between differing parties is a good thing and an opportunity that should not be lightly lost, it is necessary, for real progress to be achieved, to have one's own position clearly defined, embedded in a real good and well understood, clearly articulated and strongly held, and the interlocutor should be carefully listened to: he or she may throw a lot of useful light on the problem and sometimes a mutually acceptable solution may indeed be found. A 'moral identity' (e.g. of a Catholic institution, group, person or programme), however, cannot be traded for a tactical advantage or for seeming progress. This is even more important nowadays when the 'culture of death' is being promoted and fostered successfully at a local, national and global level by the use of obfuscating language, vague terminology, and 'intolerant claims for tolerance' of anything rooted in cloudy ambiguity and 'absolute relativism'. The duty of Catholic intellectuals, and especially of Catholic health-care professionals, is certainly to be able to distinguish 'good' from 'evil' and to offer the light of hope and wisdom in circumstances that are sometimes very complex, difficult to understand and unclear.

Some Examples of Dubious Policies Affecting Children

As an example of a poisonous and rather brutal state policy which inflicts harm and bad health on considerable numbers of children we may take the so-called 'one-child family' policy imposed upon the peoples of China.[6] This policy was instituted years ago (in 1979) at a time of the strong lobbying and support (including generous funding) of powerful international organisations such as the United Nations Population Fund (UNFPA) and wealthy funding donors. The aim of the policy, as frequently declared, is to achieve sustainable population dynamics in China (i.e. to contain its rapid population growth) and through this to attain an improvement in life conditions and a speeding up of economic and cultural development in the areas involved (that is to say the whole of the country). One should observe that this policy is based on some unproven claims (about the negative correlation between population growth and development), ones that have not hitherto been really substantiated by serious scientific research. Moreover, this policy is also deeply morally flawed in its intentions and its basic ap-

proach (i.e. an authoritarian enmeshing of the government in the lives and personal decisions of couples with regard to procreation). It is also dreadfully marked by the coercion measures that have been used in its implementation (e.g. forced abortions, sterilisations; the social and economic oppression of noncompliant couples or mothers, etc.). Among the bad consequences already apparent today, one may list the resulting demographic imbalance (i.e. the serious 'surplus' of boys); the high number of abortions and sterilisations (many of which have been involuntary or forced); the weakened social position and discriminatory treatment of 'girl children' (these are sometimes even abandoned by the parents and placed in a poorly equipped orphanages where they usually soon die from poor care and neglect). One can hardly estimate the 'invisible damages' that this policy inflicts upon fundamental social relationships and the 'fabric of society', especially upon relationships within families and local communities. And we are probably only beginning to understand the public health impact that such 'social engineering' is having upon the affected populations in a longer term perspective (e.g. the long-term population genetic effects are largely unknown).

Another seemingly child-friendly policy was pushed vigorously in the 'socialist' countries of the former Soviet bloc. Namely, a fashionable tendency, supported by the 'socialist ('communist') governments', that aimed at including children, from their early years of life, in collective care facilities (nurseries and kindergartens). Similar policies have been more recently fostered by the European Commission, e.g. by its Lisbon Strategy (the so-called 2002 Barcelona targets of childcare facilities for of 33% of children aged 0-3 and up to 90% of children aged 4-6). The aim, as was declared, is to enable women to join the workforce, i.e. the 'emancipation' and empowerment of women, and possibly also to improve the care and early education of children in children's collectives. However, although pre-school kindergartens may seem to confer some advantages on pre-school age children as regards their preparation for entering the schooling period (e.g. improving the language skills of immigrants' children), it has been shown that an early loss of the presence of a mother during the so-called bonding period, and even months later, may inflict serious damage upon a child's mental and personal development and health, which can even lead to social pathologies in his or her adult life. Moreover, bigger groups of children are more prone to 'share' various infectious diseases (especially those of the respiratory tract), so they are not healthier than their peers who are brought up in families or in families' small self-help groups.

More recently, various public health policies have been designed and fostered that have sought to prevent teenage pregnancies, as well as the containment of the worrisome spread of sexually transmitted diseases within this age group. Among the measures or activities pushed for implementation in public health and schooling domains, so-called 'sex education', the promotion of contraception (barrier methods and pills), securing teenagers' access to so-called 'safe abortion' and other 'reproductive and sexual health services', have been among the most prominent. Disregard of parents' involvement or authority (in the name of a child's or teenager's wrongly understood 'right' to privacy) has been a paramount feature of those programmes. Though the results achieved by these policies are 'culturally conditioned' (i.e. they differ between different countries, communities, ethnic groups etc.), they can hardly be seen so far as constituting an uncontested success. On the contrary, they may be seen more as contributing factors than as factors that bring solutions to these important public health problems. It becomes ever clearer that a healthier youth lifestyle is connected, instead, with the 'old good virtues' of chastity, faithfulness and 'true love' rather than with the novel 'inventions' of 'free love', 'living together as an experiment', 'safe(er) sex', 'sex-education' etc. that have been bequeathed to us by the champions of the 'sexual revolution' of the 1960s and by the ideologically-skewed research and abundantly funded social engineering projects of the decades that followed. More detailed analysis is, however, beyond the scope of this paper.

New Policies Regarding the Health and Lives of Children

When considering the great deficiencies and challenges that are piling up in this enormously broad and complicated area of children's health, disease and premature death, and when seeing how the lives of children are facing nowadays so many health dangers and threats, some of them inflicted upon children by wrong, distorted health and other key policies brought about by merciless or 'simply irresponsible' politics, sometimes following the brutal ideology of 'social engineering', one tends to ask: what could be done about this obvious misery, these unparalleled and unmet health and life needs, and these inescapable 'life-or-death' challenges? What, if anything, can be expected from today's politics? What can 'good politicians' do? What could be the role and responsibility of Christian (Catholic) health-care professionals?

Indeed, the questions are growing in numbers and clearly exceed the readily available answers. Easy, quick and simple solutions can probably not work here. Problems as complex as these, which are so deeply embedded in the very fabric and history of various societies and communities, problems that have sometimes had their own long existence throughout the development of a country or community (possibly including dark periods of suffering and oppression), such problems require thoughtful and systemic reflection and study. This study should take appropriate time and strive to go to the root of the matter (and to possible working solutions) where the problems are hidden.

'Mere thinkers', however, cannot bring about the necessary changes in the real world. This is why people of action are necessary – individuals, activists, concerned

groups, devoted non-governmental organisations, religious people and Churches, 'people of good will', acting political entities, and last but not least politicians who are able to foster and work 'vigorously and virtuously' for scientifically sound and morally acceptable (or rather, laudable) policies of change for the better. Many examples of such well established solutions are already contained in the available working materials of international or national organisations or institutions (although the ability to discern in a critical way the important aspects of the different options that are offered, including the possible differences at the level of their moral status, is certainly greatly needed here, always). When, finally, the desired health policy is got right, a political momentum for its approval and implementation should be created and sustained strongly for a necessary period. Thus, adequate 'popular' support should be rallied and kept alive at all levels – the municipal, the national, the continental and the global. Catholic health-care professionals certainly have an important role to play at the various levels of a society's political fabric. They should bring not only their unique professional expertise and 'grass roots' experience of real life but also, and even more importantly, an informed and sound moral orientation and stand based upon their deeply understood and faithfully lived Christianity.

Indeed, children are our future – and also the future's future. Surely, a nation, community, society or world without children is a nation, community, society and world without a future. So, let the children come, and let them be healthy, and happy, and blessed.

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Notes

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MARIA NEIRA

11. WHO Initiatives on Children's Health: Environmental Contaminants and Global Climate Change

Introduction

Every year, over three million children under five die from environment-related causes and conditions. This makes the environment one of the most critical contributors to the global toll of over ten million child deaths annually. Such a large burden is unacceptable.

Children's health problems arise traditionally from exposure to contaminated water, poor sanitation, indoor smoke, disease vectors such as mosquitoes, unsafe use of chemicals and waste disposal, from ultraviolet radiation, and degraded ecosystems. In addition, unsafe built environments and uncontrolled traffic may predispose to injuries in children.

Children are nowadays exposed to a wide and new range of environmental threats whose impact on health and development is important. Health problems linked to environmental hazards are multiplying and becoming more visible due to a rapidly changing global environment, explosive urban population growth, overcrowding, poverty and inequity, fast industrialization and uncontrolled pollution. Unabated waste-dumping, non-sustainable consumption of natural resources, unsafe use and contamination of chemicals, physical inactivity and poor nutrition, all contribute to affecting the environment and health of children from conception into adolescence. Some environmental pollutants, which are characterized by their persistence, and the effects of which are not fully known, may be linked to hormonal and developmental problems, as well as to certain types of cancer.

Health-damaging exposure to environmental risks can begin very early in life, even before birth when the mother (and father) live or work in degraded environments or under unsafe conditions.

Why "Children"?

Children are not "little adults": they have greater susceptibility to environmental risk factors, particularly *in utero* and in the first years of life. They are building a body for the future and, as they grow, they breathe more air, consume more food, and drink more water than adults do, in proportion to their weight. Children's central nervous systems, immune and reproductive functions are developing and may be exposed to the adverse effects of environmental pollutants during special periods, or "windows of susceptibility".

Children behave differently from adults and have different patterns of exposure. They may be exposed to hazardous substances as they crawl on the floor, taste what is inside attractive containers, play with soil or in recently pesticide-sprayed fields. Most importantly, children have little control over their environment. Unlike adults, they may be both unaware of risks and unable to make the right choices to protect their health.

The wide range of environmental threats that this vulnerable population is exposed to may have consequences that appear early in life, throughout their youth and even later, in adulthood – and may therefore have an impact on future health.

Environmental Threats to Children's Health

Indoor air pollution

Exposure to indoor air pollution from solid fuel use is one of the main risk factors for pneumonia among children under five years of age, and may also be associated with an increased risk of low birth weight and asthma. It is one of the major contributors to the global burden of disease in developing countries, and is responsible for more than 1.5 million deaths a year, mainly in children and their mothers. This is quite relevant, as we estimate that about three billion people worldwide cook or heat their homes with solid fuels, including biomass (wood, dung and agricultural residues) and coal for cooking and heating.

Another important indoor air pollutant is tobacco smoke, linked to a number of respiratory and other diseases in children. A report on *Tobacco and the Rights of the Child* (2001) highlighted the fact that in addition to the harmful effects caused by direct use of tobacco, children are also exposed to second-hand tobacco smoke and that nearly 700 million, or almost half of the world's children, breathe air polluted by second-hand tobacco smoke, and have no choice in the matter, as they are unable to protest or protect themselves.

Children breathing polluted air

may suffer acute respiratory infections or asthma attacks and end up with chronic respiratory disease.

Outdoor air pollution

Outdoor air pollution remains a serious problem in cities throughout the world, particularly in the megacities of developing countries. It is estimated that a quarter of the world population is exposed to unhealthy concentrations of air pollutants. Outdoor air pollution is mainly a consequence of the combustion of fossil fuels for transport, waste incineration, power generation and other industrial processes that release primary emissions (e.g. diesel soot particles, lead) and from products that are transformed in the atmosphere (e.g. ozone, sulfate particles). Children are particularly at risk due to the immaturity of their respiratory systems.

Water, sanitation and hygiene

Around the world, both biological and chemical pollutants are compromising the quality of water and causing a range of diseases. It has been estimated that 1.5 million deaths occur yearly from diarrheal cases, mainly in children and primarily in developing countries. Childhood diarrhea is closely associated with insufficient water supply, inadequate sanitation, water contaminated with communicable disease agents, and poor hygiene practices.

Repetitive episodes of diarrheal disease due to unsafe water and food may further cause chronic malnutrition and reduce the learning abilities of schoolchildren. Lack of adequate sanitary facilities and poor hygienic practices are common throughout the developing countries; the lowest levels of service coverage are to be found in Asia and Africa where more than half of the rural populations are excluded from any measurable progress in this area. Globally, more than 2.5 billion people, most of them in developing countries, still lack access to improved sanitation, including 1.2 million people who have none at all. Improving sanitation has the potential of saving 1.5 million children every year and improving the lives of many more.

Other important diseases are to be mentioned: arsenicosis and fluorosis, that result form high levels of these minerals in drinking water. For example, skeletal fluorosis emerges in early adulthood as a result of childhood exposure, and, although fluoride is effective in preventing dental caries, high amounts may alter the teeth and also the bones. A child's well-being is highly dependent on both the quality and the availability of water, and on how well this precious resource is taken care of and used.

Chemical hazards

The use of chemicals has increased dramatically due to the economic development in various sectors including industry, agriculture and transport. As a consequence, children are exposed to a large number of chemicals such as pesticides, solvents, lead, and also unsafely stored medicines. They are exposed virtually wherever they are and where different substances are in use: at home, in the school, on the playground, and during transport.

A recent episode of massive lead exposure in children who played in contaminated soil and lived in lead contaminated areas in an African country demonstrated how serious the effects may be in a developing child, as a result of the special vulnerability of their central nervous system. A good knowledge about, and sound management of, chemicals, particularly heavy metals, pesticides and persistent organic pollutants (POPs), is a prerequisite for the protection of children's health. Due to its importance, more action is required on preventing exposure to the so-called "intellectual robbers": lead, mercury and polychlorinated biphenyl, as well as on pesticides, but this by no means implies that other chemicals should be ignored. New evidence is emerging on the potential role of certain chemicals as endocrine disrupters, that could affect development as well as the immune, reproductive and neurological systems.

Disease vectors

The major global demographic, environmental and societal changes that have been occurring in the last decades contribute to the re-emergence of vector-borne and other diseases, many of which have an important impact, with varying severity, on children's health and development. A considerable proportion of the disease burden for four key vector-borne diseases: malaria, schistosomiasis, Japanese encephalitis and dengue

hemorrhagic fever falls on children under five years of age. Standing water near homes, ineffective irrigation management and water-drainage in urban areas and contamination of water bodies with human or animal feces increase the risk of vector-borne diseases.

Over 40% of the world's children live in malaria-endemic countries, and every year more than a million deaths in children under five occur, mainly in Africa. The environment is a key factor in the spread of malaria, which may be exacerbated by poor water management and storage, inadequate housing, deforestation and loss biodiversity. Most of these child deaths are preventable through effective management of the environment and use of treated bed-nets, among other measures.

Global environmental change

Large-scale and global environmental hazards to human health include climate change, stratospheric ozone depletion, loss of biodiversity, changes in hydrological systems and the supplies of freshwater, land degradation and stresses on food-producing systems. These processes have major influence on the risks of vector-borne diseases, water and food-borne diarrhea, and malnutrition, which are among the major burdens of disease in the developing world, and are disproportionately concentrated on children. In addition, as environmental degradation acts over a long-term and is potentially irreversible, children have the most to gain from measures to safeguard the integrity of natural ecosystems.

There is now widespread agreement that the earth is warming, due to emissions of greenhouse gases caused by human activity. In addition, the current trends in energy use development and population growth will contribute to climate change.

The changing climate will inevitably affect the basic requirements for maintaining health: clean air and water, sufficient food and adequate shelter. Each year, about 800,000 people die from causes attributable to urban air pollution, 1.8 million from diarrhea resulting from lack of access to clean water supply, sanitation, and poor hygiene, 3.5 million from malnutrition and approximately 60,000 in natural disasters. A warmer and more variable climate threatens to lead to higher levels of some air pollutants, to increase transmission of diseases through unclean water and through contaminated food, to compromise agricultural production in some of the least developed countries, and to increase the hazards of extreme weather.

Climate change also brings new challenges to the control of infectious diseases. Many of the major killers are highly climate sensitive as regards to temperature and rainfall, including cholera, and the diarrheal diseases, as well as diseases including malaria, dengue and other infections carried by vectors. In the long run, however, the greatest health impacts may not be from acute shocks such as natural disasters or epidemics, but from the gradual build-up of pressure on the natural, economic and social systems that sustain health, and which are already under stress in much of the developing world. These gradual stresses include reduced supply of fresh water, regional drops in food production, and rising sea levels. Each of these changes has the potential to force population displacement and increase the risks of civil conflict.

All populations will be affected by a changing climate, but some are more vulnerable. The initial health risks vary greatly, depending on where and how people live. People living in small island developing states and other coastal regions, megacities and mountainous and polar regions are all particularly vulnerable in different ways.

Health effects are expected to be more severe for children, elderly people and people with diseases or pre-existing medical conditions. The groups who are likely to bear most of the resulting disease burden are children and the poor, especially women. The major diseases that are most sensitive to climate change – diarrhea, vector-borne diseases like malaria, and infections associated with under nutrition – are more serious in children living in poverty.

How are children particularly affected by global climate change? They may suffer direct effects, such as respiratory problems from warm ambient air temperatures and fossil fuel generated air pollutants; injuries, psychological trauma and death from diarrheal and dehydration illnesses; and heat stroke under extreme weather conditions. They may be at a high risk of suffering skin can-

cer and cataracts in relation to stratospheric ozone depletion. Indirect effects are those related to food scarcity (e.g. malnutrition, growth retardation, developmental delay), compromised water supplies; malaria, dengue fever, and other vector-borne diseases; and asthma and allergies from increased allergens in air.

Ongoing climate change, coupled with globalization, will make it more difficult to contain infectious diseases within their current ranges. Health challenges arising from population displacement and conflict are unlikely to stay confined within national borders. Improved health conditions for all populations, alongside more rapid and effective international disease surveillance, constitute a vital contribution to global public health security.

Climate change can no longer be considered simply an environmental or developmental issue. More importantly, it puts at risk the protection and improvement of human health and well-being. A greater appreciation of the human health dimensions of climate change is necessary for both the development of effective policy and the mobilization of public engagement.

In the last decade, even though climate change has been increasingly acknowledged as an important risk to human well-being, its effects on health have received little research attention. In this respect, a recent WHO meeting held in Madrid, Spain (October 2008) agreed on a research agenda to develop an evidence-based framework for action on the human health implications of climate change.

The plan builds on a comprehensive review of what is already known about health risks from climate change and responds to the request made by member States about the need to strengthen the evidence base for policy action.

The plan will intensify climate change and health research to strengthen the evidence base for discussion at the *15th United Nations Conference of the Parties (COP15)*, to be held in Copenhagen in December 2009, where world leaders will forge a new global climate agreement to succeed the Kyoto Protocol.

The research plan identified five priority research areas, including a better understanding of how climate change does and will interact with other important health determinants and trends (e.g. economic development, globalization, urbanization, and inequities) and the effects of long-term changes such as increasing drought, decline in freshwater resources, and population displacement, ranging from mental health impacts to risks of conflict, with a particular focus on children and other vulnerable groups. Other research priorities address the effectiveness of interventions, assessing health impact of policies of non-health sectors, and strengthening public health systems to address health effects of climate change. Basically, more knowledge is needed to reduce not just climate change related threats but all environmental health risks.

The importance of interventions

Effective interventions to address children's environmental health risks exist. For instance, simple filtration, disinfection and adequate storage of water at the household level dramatically improves the microbial quality of water, and reduces the risk of diarrheal disease at a minimum cost. Similarly, improved stoves reduce exposures to indoor air pollution. Low-cost wood-burning stoves in East Africa lower pollution by 50% and plancha stoves in Latin America reduce indoor smoke levels by as much as 90%. Improved storage and safer use of chemicals at community level reduces exposures to toxic chemicals, especially among young children. Personal protection from malaria through the use of insecticide-treated mosquito nets and the environmental management of vector habitats will also contribute towards avoiding cases of malaria, especially in children.

In response to the many challenges identified, the WHO department of Public Health and Environment (PHE), in collaboration with relevant partners, promotes a number of activities on children's health and the environment, including awareness-raising, training activities, use of indicators, collaborative research and – overall – promoting successful prevention and education 'models' to provide healthier settings for children, their families and communities. Implementing these activities and turning efforts into action will have an important impact on reducing the burden of disease affecting children globally, therefore contributing towards achieving the Millennium Development Goals (MDGs) (WHO 2004).

Concerning climate change, strengthening of public health services needs to be a central component of adaptation to climate change. The international health community already has a wealth of experience in protecting people from climate-sensitive hazards, and proven, cost-effective health interventions are already available to counter the most urgent of these. Broadening the coverage of available interventions would greatly improve health now. Coupled with forward planning, it would also reduce vulnerability to climate changes as they unfold in the future. The diverse, widespread, long-term and inequitable distribution of health risks makes climate change a truly global challenge, calling for an unprecedented degree of partnership. An effective response will require actions from across society: from individuals, the health sector, and community and political leaders. A fair and effective response will require a sharing of responsibilities between the populations that make the greatest contribution to climate change and those that are most vulnerable to its effects, in order to safeguard and enhance global public health security.

The disease burden caused by the environment can be avoided if appropriate measures are taken through appropriate public health policies. However, for this to be done, recognition and assessment of the environmental burden of pediatric disease should be strengthened, both in industrialized and developing countries. This will enable all responsible sectors to recognize the main

problems and identify their specific roles in improving children's health through better environments.

Summary

There are over 600 million children under five in the world today whose health needs protecting. Over 30% of the global disease burden in children is attributable to modifiable environments. The recognition and assessment of the environmental burden of pediatric disease should be strengthened, both in industrialized and developing countries. To achieve this goal, it is important for all of us to join efforts in recognizing and addressing environmental threats.

All responsible sectors should know about the main threats affecting children's health and take action, identifying their specific roles in improving children's environments and "propose a future full of hope for the many children that are or may be affected during the initial stage of their life" as stated in the background document of the XXIII International Conference. Implementing these activities and turning efforts into prevention, education, policy-making and other actions will reduce the burden of disease affecting children globally, therefore contributing towards achieving the Millennium Development Goals (MDGs) and – overall – enabling every child to pursue their full development.

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Second Session

What Should Be Thought?

BRUNA COSTACURTA

1. Care for Sick Children in Holy Scripture

At this International conference on 'pastoral care for sick children' I was asked to speak about 'care for sick children in Holy Scripture'. This is a subject which touches on a neuralgic and very delicate point of the human experience, but it is difficult to find it in the Bible which, indeed, does not address this subject according to our modern categories. Scripture, however, well knows about the pain and also the inexplicable suffering of children and the innocent. In this short paper I will understand the idea of 'care' for sick children in the sense of 'taking care of', in a taking on and accompanying of that suffering, from which springs the need, for those who provide care to these children and those who help in various ways those who provide care to them or are at their side, for a problematic analysis of the scandal of innocent pain.

There are not many Biblical texts that speak about children or young people who are sick or in situations of suffering: the son of Hagar, Ishmael, comes near to death in the desert (Gen 21:9-19); the son of the widow of Zarephath falls ill and dies and is sent the prophet Elijah (1 Kings 17:17-24); there is also the son of the Shunammite at the time of Elisha (2 Kings 4:18-37); and there are the children that Jesus raises from the dead or heals: the son of the widow of Nain (Lk 7:11-17); the daughter of Jairus (Lk 8:40-56; cf. Mt 9:18-26; Mk 5:22-43); the daughter of the woman from Canaan (Mt 15:21-28; cf. Mk 7:24-30); the boy with epilepsy (Mt 17:14-18; cf. Mk 9:17-27; Lk 9:38-43); and the son of the king's official at Capernaum (Jn 4:46-53).[1]

In all these cases we have before us sick or dead young people and around them there are their parents and loved ones who suffer and ask for help. Their approach and their reactions (weeping, requests for help, tribulation) can begin to give us some indications about the reality of pain and how it is experienced. I would like in particular to examine, from those episodes that have just been mentioned, three which seem to me to be particularly significant.

The first involves Ishmael, the son of Abraham who was born to his servant Hagar. Because of Sarah's jealously, both the mother and the child are sent away. The drama takes place during the feast that should celebrate the weaning of Isaac, an important event that usually took place roundabout the age of three after the child had survived the dangerous time of early infancy. In a situation in which infant mortality rates were very high, this was an important stage, but it was also a delicate moment of passage from one stage to another which was often managed with difficulty, both for the child and for the mother, because a new stage in the life of the child was beginning which was more autonomous and marked by a detachment from the figure of the child's mother, an overcoming of dependency, and openness to new relationships. It was thus a particularly significant event, both for the family and for the community, which in our account in Genesis 21 is solemnised by a feast: this is shared joy, a way of celebrating a promise of life that has come true.

But Sarah introduces into the party a painful and possessive note of jealousy and rejection; she fears that the son of the slave will supplant her own son and wants Abraham to send Hagar and Ishmael away.[2] The preparations for the journey are narrated in a succinct way: 'So Abraham rose early in the morning, and took bread and a skin of water, and gave it to Hagar' (v. 14). These provisions are very little and can assure a very short survival; Hagar and her son are abandoned to their fate, without being accompanied by servants, without resources, in a difficult and hostile environment – the desert. The two wander alone and without help, in a desolate and uniform countryside: the woman disappears and when the water runs out the child runs the risk of dying, he is about to die from thirst and dehydration.

What interests us here is to see the reaction of Hagar, the mother, who understands that not much more can be done. Then, as the text tells us, ' she cast the child under one of the bushes' (v. 15). The boy is by now condemned to death and

she places him in the shade, in order to defend him against the burning heat of the sun, with a final gesture of tenderness which tries to protect her son until the last moment and to alleviate, as far as this is possible, his suffering. A mother does not give up in the face of pain, and she takes care of the life of her creature even when it appears that there is no longer any hope.[3]

Then Hagar moves away: 'and sat down over against him a good way off, about the distance of a bowshot; for she said " Let me not look upon the death of the child". And as she sat over against him, she[4] lifted up her voice and wept' (v. 16). Hagar has done what it was possible to do but now she cannot stand this torment, she does not want to see, and she moves off and stays there, not very far off, anxiously waiting. The child is now in the hands of God, she can no longer do anything. She can only weep, and her weeping is deep.

God, in fact, listens to that weeping: the God of Israel, who is provident and merciful, comes to the help of the poor child. Those tears proclaim the end, the absolute need for help, and God then intervenes: the eyes of Hagar open and she sees a well; the child has been saved, and she receives the promise that her child will give rise to a great people.

The Lord is the God that gives back life, and He does this in the desert, a place of death, where there is nothing. God takes care of His own, He makes water and food not be absent, as indeed was the case during the journey of the Exodus. Hagar is the figure of a woman without rights, without help, sent away by those who had used her; Hagar is a desperate mother, deprived of everything, who is also about to lose her child. But specifically because she is a mother she remains open to love and God gives life back to her son, but through her, making her see what can save her child. God answers by pointing to what can cure, opening her eyes so that they are able to see where to find what gives life.

And she sees the well and gives the child something to drink; the water is for him. The text does not say that Hagar also drinks. Everything is centred around the dying child, the pain of a mother who does not think of herself and wants only that her child will live, and the answer that God gives to that love and that weeping.

The second episode is narrated in the First Book of Kings, in the story of Elijah (chapter 17). The prophet, after announcing the drought that will take place in the country, in order to bring his people to conversion, finds hospitality and food at the hands of a poor widow, in Zarephath, in the territory of Sidon, and God recompenses the woman by insuring that she always has flour and oil. But then an unforeseen and dramatic event takes place: the son of the widow falls ill and dies. We have here the tragic and intolerable death of a child, which is all the more incomprehensible because it seems to contradict the promise of life that God had made to the widow and kept through His gift of flour and oil.

In this case, as well, it is important for us to see how those who surround the boy react, that is to say his mother and Elijah. The woman is overcome by desperation and gives voice to her bitterness, accusing the prophet: '"You have come to me to bring my sin to remembrance, and to cause the death of my son!"'(v. 18). These are hard words but they express all the rebellion that is born from an unacceptable pain; when a child dies one cannot remain calm, and the woman rebels and tries to find the person who is responsible, at whom she shouts her tribulation.

And these are words that express the paradox that Elijah, as well, has to address: the drought, indeed, acted to reveal the sin of the idolatrous people, but now the prophet finds himself faced with the death of an innocent. Elijah, too, after a certain fashion, suffers the scandal of this death, like the mother of the boy, and takes on this pain in prayer, addressing God with the following words: '"O Lord m God, hast thou brought calamity even upon the woman with whom I sojourn, by slaying her son?"' (v. 20). The prophet says '*even* upon the woman' and he seems to mean by this that there are other victims, that others have also suffered and that the Lord is in some way responsible. Elijah is not afraid to suffer the scandal, which should be accepted without fear, and he, too, allows himself to be invaded by pain, and he addresses and struggles with a mysterious God, who appears to be incomprehensible. But it is a struggle in faith because he says these words after taking the child that the mother clasped to her breast, thus engaging in a resolute gesture of trust in the God of life.

Since taking the dead child that she holds in her hands from her is hazardous, there is the risk that she will be disappointed and that she will be made to believe that something can still be done. And of God does not intervene in response to the prayer of the prophet? It would be a desperate disappointment which would add further pain to her pain. A great deal of faith is needed to take that child, just as trust is required on the part of the mother to allow him to be taken. It is faith that is needed to take care of those who suffer, accepting, as well, the risk of failure.

Then, after putting the body of the child on his bed, Elijah stretches over him, symbolically taking on the death of the boy, but remaining alive, a bearer of life.[5] And the boy comes back to life, through the intervention of God and through

the mediation of the prophet who prays and acts, and with a presence, Scripture teaches us, that is salvific because whomsoever takes care of a child enters into him, almost comes to be one with him, and does not leave him alone, sharing his fear and worry about death without fear.

We thus come to the third text, a passage from the Gospel, which narrates the episode of the resurrection of the daughter of the head of the synagogue, Jairus (cf. Lk 8:40-56). His daughter, his only daughter, a girl of twelve, is dying. Here it is the father and not the mother, as in the above episodes, who is the protagonist and who demonstrates his reaction when faced with the dramatic event of the illness of a daughter. And what the father does is to turn to Jesus and ask him to come to him: 'falling at Jesus' feet he besought him to come to his house' (v. 41).

This a request for simple help, a troubled request, without many words. The pain of the man is unspeakable and he does not express himself in long speeches; his cry for help is essential, succinct, because it arises from a heart tormented by suffering. His daughter is dying and he, the father, who is an important and influential figure, engages in a gesture of humility, he throws himself at the feet of the master and asks him to go to his home. Behind this request there is all the troubled loneliness of someone who feels powerless and the need for someone who, instead, knows that he can do something and indeed can do something, even though it appears impossible. The father clings to that thread of hope, he knows that the master performs miracles, and he does not allow him to go away, he stops him by throwing himself in front of him, and he asks, simply: come!

But the little girl dies. When they bring the news of the event it appears that Jesus' coming is not necessary, but instead Jesus goes to the home of Jairus and, ignoring the derisory incomprehension of those nearby, with tenacity he pursues life and reveals a new meaning to dying: '"Do not weep; for she is not dead but sleeping"' (v. 52). Death is like sleep, awaiting the final awakening. And taking the girl by the hand he makes her rise up with the command: "Child, arise"' And thus life returns, in obedience to the words of Jesus, and the girl rises and can eat, with an act that marks in an un unmistakable way the return of life.[6]

It seems to me that beginning with these texts it is possible to make certain short observations which perhaps can help in an analysis of the subject that this paper addresses. In them, in fact, we have seen how, in various ways, one reacts to pain and how God responds. I believe that one can say that faced with the illness and suffering of a child we should all adopt the approaches that we have encountered in these episodes.

In caring for a suffering child one should weep, as Hagar did in the desert, and struggle with God, as Elijah did, and like him enter into a state of crisis and pray, and, like Jairus, humbly ask and beseech with trust. And at the same time one should open one's eyes, as Hagar did, and intervene with courage to heal and comfort, as Elijah and Jesus did, using all means possible and all our capacities and expressing solidarity with the family relatives of suffering children. And all of this should be done having a strong faith in God who saves, bearing witness to the fact that death, even in mourning, can be a pathway of life, sleep from which God will awaken us. But it is not possible to elude the problem, one must allow oneself to be touched by pain, one must feel the scandal of innocent suffering, and share the weeping of those who love, in the ineradicable awareness that one is face to face with a mystery.

There is an entire book in the Bible that address the problem of pain that is inexplicable because it is innocent. This is the Book of Job, whose protagonist, an upright and irreproachable man, is struck by unmotivated misfortunes and who in the end, when sick, reaches the threshold of death.

Three friends who came to visit him try to make his suffering comprehensible and justify it as a way by which God is intervening in his life to make him aware of his faults. But Job, knowing that he is innocent, sends back the accusation and states that instead it is God who is blameworthy because He is unjust towards him. Men often give this accusatory meaning to suffering, or (like Job's friends) they interpret it as a sort of accusation by God who reveals through it man's sin, or (like Job) transform it into a reason to accuse God who is seen as being responsible for pain.

And Job, trapped between these two poles, struggles with God to understand and to rediscover a God who is different from how He appears, the good Lord in whom, despite everything, he wants to go on believing. And he finds answers, specifically in a new relationship with the divine, when he understands that he cannot understand everything and he accepts the mystery of life and death, and also of suffering.

Job is not a child but he raises the problem of innocent pain and the Lord, in answering him, educates him as though he were a child, whose father takes him by the hand and accompanies him in understanding the meaning of his suffering, on a pathway of self-awareness that confronts him with the specific truth of being a creature, with his smallness, with a specific need for God.[7]

And it is in the experience of nearness to God and a good and fatherly God that Job is able to accept his own reality and even reconcile himself with his own suffering. No longer accusatory, it becomes an opportunity for encounter with mystery. And though he is still suffering, Job can enter into the beatitude of blessing and say to the Lord: '"I had heard of thee by the hearing of the ear, but now my eye sees thee"' (42,5).

The scandal of pain, which has to be addressed by those who care for children, can be understood and overcome. But it requires a courageous approach which involves the taking upon oneself of suffering and an involved and participated accompanying, albeit without allowing oneself to be overwhelmed. What is needed is the technical that intervenes to heal and to bring relief; what is needed is the tenderness that reassures and attenuates fears; what is needed is love to respond to desperation; and what is needed is faith, which opens up a

new way of seeing pain, even discovering that it can be a possible pathway of salvation.

To take care of a sick child means 'to treat his' body, but also 'to take care of' the whole child and all his reality, in all its dimensions. It means to alleviate his pain, tenaciously to pursue healing, but it also means to walk with him (and with those who love him) in order to help him, like Job, 'to see God'.

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Notes

[1] Cf. also in Acts 20:9-19, the boy who has fallen from a window and Paul takes in his arms and brings back to life.

[2] The text explains Sarah's attitude with the fact that she sees Ishmael who is 'laughing' and 'playing' (v. 9). The verb used to express this contains the sound of the name Isaac which means 'he laughs', and which evokes the laughter of Abraham (cf. Gen 17:17) and Sarah (cf. Gen 18:12) when the conception of a child is announced for a woman is sterile and by now elderly, and then the happy laughter at the child's birth when the divine promise is fulfilled (cf. Gen 21:6). It is a name of joy and incredulity, which expresses the reality of this 'impossible' son who is a sign of the blessing of the Lord. But now, during the weaning feast, Ishmael also 'laughs', 'playing' the role of Isaac and becoming after a certain fashion similar to him (cf. here G.W. Coats, *Genesis, with an Introduction to Narrative Literature*, William B. Eerdmans Publishing Company, Grand Rapids, MI, 1983, p. 153). This troubles and alarms Sarah who sees endangered the rights and the prerogatives of her own son. For that matter, Ishmael was the first born of Abraham, and wanted as a child of the promise of the wife herself of the patriarch. The risk that her child will be supplanted appears real to Sarah, who thus decides to eliminate at the roots all possibility of this actually occurring.

[3] These are gestures of love that one often witnesses in the wards of hospitals, such as wetting the lips of a child with fever who is dying or continuing to speak to a child when he is already in a coma.

[4] In the Masoretic text, to which I refer, it is Hagar who cries out and weeps, whereas the LXX indicates that it is the child who does this. Generally, the tendency is to follow this version in order to harmonise what is then said in v. 17: 'And God heard the voice of the lad' (cf. on this point C. Westermann, *Genesis 12–36. A Commentary*, translated by John J. Scullion, Augsburg Publishing House, Minneapolis 1985, p. 341). One may, however, maintain the Hebrew text, which in this way, without being overt, unites to the two examples of weeping, of the mother and the child, in a single invocation for divine help.

[5] Cf. also the gestures of Elisha in 2 Kings 4:34-35.

[6] Within the episode about the daughter of Jairus we also find the account of the healing of the woman with a loss of blood (vv. 42b-48). The two episodes are related to each other: we have here two women who for different reasons are closed to fertility: the girl because she dies at the age of twelve, before being able to experience the joys of motherhood, and the woman because of the impurity of her blood impedes from having relationships with men and this has been the case for 'twelve years' although perhaps more accurately 'even since she was twelve', which is the age at which the daughter of Jairus dies and which marks the passage to adult and fertile life (cf. on this point R. Meynet, *Il Vangelo secondo Luca. Analisi retorica*, Edizioni Dehoniane, Rome, 1994, pp. 272, 273).

[7] On God's answers to Job and their educational function cf. B. Costacurta, 'Il libro di Giobbe: la scoperta di una diversa onnipotenza di Dio', in *Dio è amore ma può soffrire? Deus caritas est, ovvero il pathos di carità*, Giuseppe Cinà (ed.) (Edizioni Camilliane, Turin, 2008, pp. 19-30).

GABRIELE MARASCO

2. Care for Sick Children According to the Fathers of the Church

The establishment of Christianity also had very significant consequences for the field of care for children. In Greek society and in Roman society this task was entrusted almost exclusively to the family, obviously within the limits of its capacities and wealth.[1] The only exception was the case of orphans of men who had fallen in battle. At least in Athens, these children were raised by the state. To aggravate the situation, on the other hand, was infanticide and the exposure of unwanted children, which were both widely practiced and were generally tolerated.[2] The condition of children was thus rather grave and they could often be seen as just a burden and to such an extent that in recent times it has been asked whether the ancients were really saddened by the death of their children.[3]

A certain evolution took place only during the Antonine age. Indeed, because of Nerva, and above all because of Trajan, the *alimenta* were created. These were care institutions by which the Emperor provided sums to those private individuals who undertook to maintain boys and girls who had been made orphans. There has been much debate about the aims of this initiative: whether they were of a demographic or military character or whether they were a response to ethical requirements.[4] But their undoubted correspondence with ideals that were felt at that time seems to be clearly confirmed by the approach of a person who was near to Trajan, namely the historian Tacitus, who saw the condemnation of birth control and the killing of surplus live children as a demonstration of the good practices of the Germans which he held to be superior to the good laws of other peoples.[5] This approach must have remained rather widespread, at least amongst the intellectuals, and indeed to such an extent that during the Severian age the jurist Paulus thought that not only infanticide but also the exposure of babies deserved the death sentence.[6] But this had little effect, not only because this sentence was never effectively applied and infanticide and the exposure of children remained widespread, but also because the *alimenta* as well, after various vicissitudes, seem to have disappeared during the crisis of the third century.[7]

The approach to childhood in the Jewish world was very different. Here children were considered a gift from God and thus they were protected. Above all during the Hellenistic age, and during the age of the Romans as well, the killing or exposure of children was severely condemned.[8] Christian ethics were connected to this approach, being mindful as they were of the special affection that Jesus felt for children. As early as the *Didaché* we find a strong condemnation of abortion and the killing of children.[9] This is also to be found in numerous other sources,[10] on the whole together with the condemnation of the exposure of children, which was considered a crime that was even worse than infanticide[11] and widely employed for polemical purposes against the pagans.[12]

The prohibition on infanticide and the exposure of children was accompanied, on the other hand, by practical measures to help children in need. In the Epistle of Barnabas, which was written between the end of the first century and the first decades of the second century,[13] care for orphans and widows was seen as being an essential task of the Church.[14] This testimony is confirmed by Ignatius of Antioch, who was martyred under Trajan,[15] whereas Polycarp of Smyrna saw care for orphans as belonging to the essential tasks of presbyters[16] and Hippolite of Rome believed that it was the responsibility of the catechumens.[17] The role of the Church and the faithful in care for orphans was later emphasised by Clement, Tertullian and Origen[18] and remained one of the fundamental tasks of bishops, as is attested to in particular by the Fathers of Cappadocia.[19] The Council of Calcedonia forbade clerics who had relationships with members of the laity to attend to their affairs, with the exception of those who were entrusted by the law with looking after minors or entrusted by bishops with looking after the interests of orphans and widows.[20] This clause, which sanctioned and institutionalised the direct role of bishops in the defence of orphans, should be emphasised.

Yet if orphans were a privileged category, the role of the Church as regards abandoned children was also notable. The hagiographer of Clement of Ancyra, who was martyred under Diocletian, narrates that this saint, who had been made an orphan at a very young age, had been adopted by a rich and pious woman who did not have any children, one Sophia, who looked after him, raised him and directed him towards the faith. At the time of a famine that had afflicted Galatia, Clement took care of many children who had become orphans or had been abandoned by pagan parents who were no longer able to provide for them: he took care of them, helped them, raised them and guided them towards the Christian faith with the financial help and cooperation of their foster mothers so that these last could have the children that they had not had naturally.[21]

Of especial interest is a letter of

Augustine addressed towards the end of the year 408 to Bishop Boniface and which was concerned with the theological problems connected with the transmission of original sin and the baptism of children. St. Augustine states in particular that at times children who were exposed were found and helped by consecrated virgins who looked after them, raised them and had them baptised. He lays especial stress on the self-denial of these women who, although they had voluntarily renounced having children themselves, took loving care of those of unknown parents.[22] One should draw attention in this case as well to the emphasis placed on the parallelism of the activity engaged in by consecrated virgins, on the one hand, for the physical health of children through the care that they provided to them, and, on the other, for the spiritual health of children through concern about their baptism. This was in perfect conformity with the fundamental Christian precept of caring for both bodies and souls. For that matter, this letter also suggests the existence of a precise organisation on the basis of which it was specifically consecrated virgins, because they were women, who were asked to help those individuals who, because they were very young, needed to be looked after by women.

This testimony of Augustine as regards the West is not without equivalents in the East: Gregory of Nyssa, indeed, praised his sister Macrina because, during a famine, she rescued girls who had been abandoned by their parents and took care of them and raised them, and to such an extent that thy called her their mother and nurse.[23]

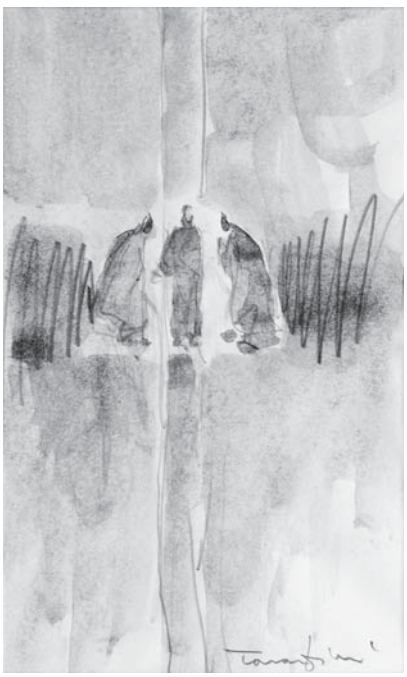
This kind of care was to be prevalent in the actions of the Church designed to help children and was to characterise the Church for a long time to come. This appears to be confirmed by the fact that in contrast with the rather early development in the Christian empire of hospitals, leper hospitals and old people's homes beginning with the rule of Constantine,[24] the first evidence that we have on orphanages and foundling hospitals comes from later on and is rather limited. In Constantinople Acacius, who in 458 was the rival of Gennadius for the post of Patriarch, which he then obtained in 472,[25] had been an 'orphan master',[26] a post which some authorities understand as being that of the rector of a specific orphanage[27] but by others as an official and unique institution.[28] The foundation of St. Paul's Orphanage is attributed to the Emperor Justin (565-578) and his wife Sofia,[29] even though some have argued that this was in fact the rebuilding of a building that had previously existed but had then been destroyed.[30] But most of the evidence refers to the reign of Justinian, under whom orphanages and foundling hospitals received a new impetus in line with the direction of the welfare policy of that Emperor, as well as a more specific legal regulation. Cyril of Scitopolis tells us that during the controversy that had arisen between the Orthodox and the monks who followed Origen in Palestine, Gelasius, a follower of Laura the Great of San Saba, went to Constantinople, but Theodorus Ascida, the Bishop of Caesarea of Cappadocia and his doctrinal adversary, managed to ensure that neither the patriarchate not the local orphanage provided him with hospitality.[31] A foundling hospital near to the monastery of the apostle Phillip in Constantinople is mentioned in a document of the Council of 536.[32]

Valuable information is contained in the legislation of Justinian. In a constitution of 528 this Emperor had already established that donations up to the sum of five hundred solids made to the Church, to orphanages and to other pious works were valid independently of their form, whereas those above this sum had to be made with the formalities of the law, with the exception, however, of imperial donations.[33] This commitment to institutes of care was then taken up in the *Novellae*. In one of these this Emperor prohibited the alienation of the property of foundling hospitals and of other charitable institutions.[34] Another attests to the existence of shops that belonged to orphanages and foundling hospitals in Constantinople and subjected them to taxation.[35] Even more interesting is a fourth constitution which establishes that the rectors of orphanages have the office of being tutors and guardians of the children in such institutions and also attests to the fact that there were similar institutions in the provinces. The Emperor, for that matter, also confirmed that the orphanage of Constantinople and the home for foreigners in Sanson had all the privileges that belonged to the Church of Constantinople.[36] The orphanage referred to here is in general identified with the orphanage that formed a part of the great complex of St. Zothic, which included a hospital and a leper hospital as well.[37] It had clearly existed beforehand but the hypothesis that its foundation went back to the epoch of this saint, that is to say to during the reign of Constance II,[38] is not confirmed by any evidence that is available to us.

This rather late and limited evidence should not, however, make us think that there was a low level of interest within the Christian empire in the health of children. On the contrary: Constantine in 315 and 322 AD has already established that there should be help in goods and money for parents who were in a state of poverty so as to prevent them from killing, selling or giving away their children.[39] This instruction, differently from the *alimenta* that had been established by the pagan emperors, sought not to obviate but to prevent the causes behind children being abandoned. In 329 and 331 Constantine issued new decrees to defend the rights of those who had taken in and raised children who had been subjected to exposure against the possible claims of their natural parents by allowing the former to keep the children, even in a condition of slavery if they so wished.[40] These last measures were motivated by the failure of the previous policy designed to impede the exposure and sale of children which, unfortunately, remained phenomena that were widespread during the subsequent epoch as well.[41] The Emperor thus adjudged that it was essential to avoid at the least the death of these children by defending those who had raised them against possible claims by those who had exposed them or sold them.[42]

This action by Constantine, which was at times seen as being near to Christian ideals,[43] was based as one can see on the commitment to encourage the action of private

individuals, whether they were the natural parents or had helped these abandoned children. Along the same lines a constitution of 369 conferred upon the Emperor the appointment of tutors and also established rules for them,[44] and in 385 Themestius praised the Emperor Theodosius for defending orphans by returning to them the goods of their fathers and compensating those who had usurped them so as to put an end to endless disputes.[45] The state, therefore, like the Church, privileged care provided by private individuals who wanted to take responsibility for orphans and abandoned children and only in the absence of such a possibility was it the state constrained to intervene with the creation of special care institutes.



This net preference for the initiative of private individuals and, at the same time, the relative scarcity of evidence on these institutes and the problem of medical care that was provided to children during the Christian epoch, can in my view be illuminated if we consider the question from the point of view of ancient medical science.[46] Beginning with the Hippocratic tradition, the physiology of children was seen as being characterised by a condition of warmth and damp, which then gradually declined with advancing age.[47] Consequently, the author of the Hippocratic *Aphorisms* listed a long series of illnesses that were characteristic of babies and children, amongst which figured in particular aptha, dental problems, violent fevers, illnesses of the respiratory system, epilepsy, and the loss of blood from the ears and nose.[48] This clinical picture is amply confirmed by the rest of the *Corpus Hippocraticum*[49] and remained substantially unaltered during subsequent epochs, as is demonstrated in particular by the testimony of Celsius,[50] Pliny the Older,[51] Soranus[52] and Galen.[53]

However, this listing of the specific character of certain illnesses that were common amongst children did not provide an impulse to the birth of a medical specialisation and paediatrics, which was unknown as a branch of medicine to the ancient Greeks and remained as such during the Roman age as well. Indeed, the first author known to us who dedicates a certain space to children's illnesses is Soranus, who lived between the second half of the first century and the first part of the second century AD. He deals with these illnesses within the context of a work on gynaecology and obstetrics; his presentation of paediatrics, like that of subsequent authors, derived from general works and does not indicate the existence of any specialist literature on the subject.[54] The treatment of new born children and babies, for that matters, was entrusted to wet nurses who had to provide for feeding, diet and the treatment of minor illnesses, whereas a medical doctor intervened only in cases of more serious illnesses.[55] The link was so close that Soranus even thought that it was advisable to treat children who were still being breastfed by changing the food regime to which the wet nurse was subjected in the belief that the treatment in this way would reach the baby.[56] His statement, for that matter, was perfectly in line with ancient medical science, beginning with the Hippocratic tracts, to the point that even illnesses like epilepsy were treated by changing the diet of the wet nurse.[57]

With respect to the treatment of older children, the ancient sources attest that this was not very different from the treatment of adults, except that an attempt was made to moderate the more energetic forms of treatment and limit the doses of drugs and medicines that were administered.[58] Thus Celsius, who on the whole was little inclined to take a person's age into account, observed that in the case of children it was necessary to moderate treatment, whether one was dealing with blood letting, baths, fasts, diets or the use of wine,[59] and various physicians, including Galen himself, expressed themselves against resorting to blood letting in the case of children.[60] The medicines used for treating children did not differ from those used on adults, except for the obvious precaution of moderating the dosages.[61]

On the basis of this well documented reality, we can understand the directions taken by the care and treatment that was provided to children. First of all, the net preference for consecrated virgins in the provision of care to children who had been subjected to exposure, as we are told by the precise testimony of Augustine, clearly derived from awareness that these women constituted the nearest that could be found to the wet nurses that these children did not have. They could thus provide, to the extent that this was possible, the medical care and the female affection that these new born children needed. From this point of view, one can well understand the late and limited role of foundling hospitals and orphanages which had to be created only when it was understood that the role of individuals was not sufficient.

For that matter, specifically the fact that the therapies for children were substantially similar to those for adults, together with the inexistence of physicians who were specialised in paediatrics, leads us to think that the help provided to orphans and abandoned children paid more attention to their maintenance than to their care; we do not even know if the foundling hospitals and the orphanages had physicians as a part of their personnel. It may, however, be interesting to recall here that according to the hagiographer of St. Zothic the Emperor Justin and his wife Sophia, when they founded the Orphanage of St. Paul in Constantinople, imposed upon it the obligation to attend to the maintenance of the patients of the Hospital of St. Zothic.[62] The orphanage of St.

Paul must have been separate from the orphanage which formed a part of the complex of St. Zothic, and there is indeed evidence for this.[63] The link, which was of a financial character as well, with the Hospital of St. Zothic seems to me, therefore, to indicate a close relationship, on the basis of which the physicians and the structures of the hospital were made available to the children of the Orphanage of St. Paul for any case that was beyond the skills of the wet nurses, thereby avoiding a useless duplication of functions and staff.

The silence of the sources on the care and treatment given to children seems, however, to a certain extent to be obviated by the information provided by the monastic Rules. The Rules of Pacolius, the founder of the coenobitic monasteries in Egypt from 320 onwards, envisaged the exemption of children, like the sick and the elderly, from the fasts that were imposed on the monks.[64] For his part, St. Benedict recommended that the buttery paid especial attention to the food given to the sick and to children[65] and prescribed that special attention had to be paid to the weakness of the elderly and the young: the rigour of the Rules as regards diet was not to be applied to them and they had to be treated in an affectionate way and fed before the usual mealtimes.[66] Lastly, the *Regula Magistri* envisaged a less rigorous regime of fasting for the sick, the elderly and children, but in this last case they had to be under the age of twelve.[67]

The monasteries, therefore, provided accommodation to children, many of whom must have been orphans or children who had been abandoned when they were born. In this they flanked the work done by private individuals and charitable institutions. For that matter, the special attention that was paid to their diets, like that paid to the diets of the sick and the elderly, seems to indicate good knowledge of the medical science of the time when diet was seen as the essential element in ensuring the health of children and recovery from their illnesses. This special attention does not surprise us when we consider that the monasteries were especially involved in medical care and conserved, as far as this was possible, what they could from the ancient science. This function of monasteries became essential above all in the West with the fall of the empire and even more so during the first part of the sixth century, the epoch when the Rules of Benedict and the Rules of the Master were drawn up – an epoch characterised by the disruptions of the Gothic war and its consequences.[68]

In the year 570 Cassiodorus wrote to the monks of *Vivarium* and exhorted them to help the sick people who came to the monastery to be treated, promising them that they would be rewarded by God[69] and inviting them to learn carefully about herbs and their use, even though they had always to remember that healing was the work of God.[70] He observed that he had left some books in the library of the monastery – if the monks did not know Greek they should use Dioscorides (indispensable for knowledge about herbs), Latin versions of some Hippocratic works, the *Method of Healing* of Galen, an anonymous compendium to which had contributed a number of authors, a work on medicine by Celius Aurelius, and not much else.[71] The library was a limited one, and to such an extent that it has been doubted whether these were the original works.[72] It was particularly concerned with knowledge about the most immediate remedies which were based on the use of medicinal herbs and dietetics. But Cassiodorus, on the one hand, confirms that the activity of the monks was not confined to their brothers but extended to those who needed them and turned to them and, on the other, observes that that the monks conserved a limited medical tradition but one that was sufficient for immediate practical needs. Of no different a character must have been the care that could be offered to children in a West that was impoverished and threatened by wars and epidemics. But such care was all that could be offered during the tragic emergencies that followed the Gothic war.

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Notes

[1] Cf. e.g. W.K. LACEY, *The Family in Classical Greece* (London, 1968), pp. 110 ss.; S. DIXON, *The Roman Mother* (London/Sydney 1988), pp.104 ss.; E. EYBEN, 'Fathers and Sons', in B. Rawson (ed.), *Marriage, Divorce, and Children in Ancient Rome* (Oxford, 1991), pp. 114 ss.; M. KLEIJWEGT, 'Kind', in *Reallexikon für Antike und Christentum,* XX (Stuttgart, 2004), coll. 866 ss.

[2] Cf. D. ENGELS, 'The Problem of Female Infanticide in the Greco-Roman World', *Class. Phil.*, 75, 1980, pp. 112-120; W.V. HARRIS, 'The Theoretical Possibility of Extensive Infanticide in the Greco-Roman World', *Class. Quart.*, 32, 1982, pp. 114-116; C.B. PATTERSON, 'Not Worth the Rearing'. The Causes of Infant Exposure in Ancient Greece', *Transact. and Proceed. of the Amer. Philol. Ass.*, 115, 1985, pp. 103-123; HARRIS, 'Child-Exposure in the Roman Empire', *Journ. Rom. Stud.* 84, 1994, pp. 1-22; P. SALMON, *La limitation des naissances dans la société romaine*, 'Collection Latomus' 250 (Brussels, 1999); J. WIESEHÖFER, s.v. 'Kindesaussetzung', in *Der Kleine Pauly,* 6, 1999, coll. 468-70; M. KLEIJWEGT, 'Kind', coll. 875-876 con bibliography.

[3] M. GOLDEN, 'Did the Ancients Care when their Children Died?', *Greece and Rome*, 35, 1988, pp. 152-163; J. WIESEHÖFER, 'Kind', in *Der Kleine Pauly,* 6, 1999, col. 465.

[4] On the *alimenta* in general cf. above all P. VEYNE, 'Les "alimenta" de Trajan', in *Les empereurs romains d'Espagne. Actes du Colloque International sur Les empereurs romains d'Espagne organisé à Madrid du 31 mars au 6 avril 1964* (par A. Piganiol et H. Terrasse, Paris, 1965), pp. 163 ss.; P. GARNSEY, 'Trajan's alimenta: Some Problems' , *Historia*, 17, 1968, pp. 367 ss.; M. MAZZA, *Lotte sociali e restaurazione autoritaria nel III secolo d.*C. (Roma-Bari 1973[2]), pp. 178 ss.; G. PUGLIESE, 'Assistenza all'infanzia nel principato e "piae causae"

nel diritto romano-cristiano', in *Sodalitas. Scritti in onore di A. Guarino,* VII (Naples 1984), pp. 3179 ss.; C. CORBO, *Paupertas. La legislazione tardoantica* (Naples, 2006), pp. 46 ss.. with a detailed bibliography.

[5] Tac. *Germ.* 19, 2: '*Numerum liberorum finire aut quemquam ex agnatis necare flagitium habetur, plusque ibi boni mores valent quam alibi bonae leges*'. On the polemic against these phenomena and the measures adepte to combat them see also Kleijwegt, *art. cit.*, coll. 878-879.

[6] *Dig.* 25, 3, 4: '*Necare videtur non tantum is qui partum praefocat, sed et is qui abicit et qui alimonia denegat et is qui publicis locis misericordiae causa exponit, quam ipse non habet*'.

[7] On the decline and disapperance of the *alimenta,* which anyway took place before Constantine cf. Corbo, *op. cit.*, pp. 56-61 with sources and bibliography.

[8] Strabus 17, 2, 5, p. 824; Diod. 40, 3, 8; Philus *spec. leg.* 3, 110-119; *virt.* 131-132; *vit. Moys.* 1, 10-11; Joseph. *C. Apion.* 2, 202; Tac. *Hist.* 5, 5; cf. in particular KLEIJWEGT, *art. cit.*, coll. 898-899.

[9] *Doctr. Apost.* 2, 2, 'Sources chrét.', n. 248, Paris, 1978, p. 148.

[10] Cf. *Epist. Barnab.* 5 d, 'Sources chrét.', n. 172, Paris, 1971, p. 202; *Const. Apost.* 7, 3, 2, 'Sources chrét.', n. 336, Paris, 1987, p. 30 ; Athenag. *Leg.* 35, 6, 'Sources chrét.', n. 379, Paris, 1992, p. 204 ; Iustin. *Apol.* I 27, 1 ; 29, 1, 'Sources chrét.', n. 507, Paris, 2006, pp. 202 and 206; *epist. ad Diogn.* 5, 6, 'Sourcres chrét.', n 33, Paris, 1951, p. 62; Clem. Alex. *Paed.* 2, 10, 96; 3, 4, 30; Tertull. *Apol.* 4, 10; 9, 6-8; *ad nat.* 1, 16, 10; Min. Fel. *Oct.* 30, 2.

[11] Cf. Tertull. *Apol.* 9, 7: '*Si quid et de necis genere differt, utique crudelius in aqua spiritum torquetis, aut frigori aut fami aut canibus exponitis; ferro enim mori aetas quoque maior optaveri'.* See also Basil. *Homil. VIII in Hexaemer.* 6, *PG* XXIX 177-180.

[12] On the polemic of Christian sources see for example KLEIJWEGT, *art. cit.*, coll. 924-928.

[13] Cf. in particular L. W. BARNARD, 'The 'Epistle of Barnabas' and its Contemporary Setting', in *Aufstieg und Niedergang der römischen Welt,* II, 27, 1 (Berlin/New York 1993), pp. 159-207 with bibliography

[14] *Epist. Barnab.* 20, 2d, 'Sources chrét.', n. 172, Paris, 1971, p. 212.

[15] *Epist. ad Smyrn.* 6, 2, 'Sources Chrét.', n. 10, Paris, 1958, p. 160.

[16] Polycarp. Smyrn. *Epist. ad Philipp.* 6, 1, *PG* V 1009.

[17] Hippol. *Trad. Apost.* 20, 'Sources Chrét.', n. 11bis, Paris, 1968, p. 78.

[18] Clem. Alex. *Quis div. salv.* 34, 2; *Paed.* 3, 40, 3, 2-3; Tert. *Apol.* 39, 6; Origen. *in Matth. Comm. Ser.* 61 (CGS, *Origenes Werke*, XI, Berlin, 1976, p. 142).

[19] Cf. above all Basil. *Reg. fus tract.* 15, 1, *PG* XXXI 952; Greg. Naz. *Or.* 43, 35, 'Sources Chrét.', n. 384, Paris, 1992, p. 204; *Carm.* 2, 1, 16, 87, *PG* XXXVII 1216.

[20] *Canon* 3, in *Acta Conciliorum Oecomenicorum,* ed. Ed. Schwartz, II 2, 1 (Berolini et Lipsiae, 1932, pp. 87-88 [179-180]; cf. C. HEFELE – LECLERCQ, *Histoire des Conciles d'après les documents originaux*, II 2 (Paris, 1908), p. 810.

[21] Sym. Met. *Vita S. Clem. Ant.* 2, *PG* CXIX 823-824.

[22] Aug. *Ep.* 98, 6: '*Aliquando etiam quos crudeliter parentes exposuerunt nutriendos a quibuslibet, nonnumquam a sacris virginibus colliguntur, et ab eis offeruntur ad baptismum; quae certe proprios filios nec habuerunt ullos, nec habere disponunt*'

[23] Greg. Nys.., *Vita S. Macr.* 26, *PG.* XLVI 988 A-B (= 'Sources chrét.', n. 178, Paris 1971, p. 232).

[24] Cf. MARASCO, 'La cura degli anziani nei Padri della Chiesa', in *Dolentium hominum*, n. 67, XXIII, No. 1, 2008, pp. 66-67 with bibliography.

[25] Cfr. M. JUGIE, 'Acace', nr. 9, in *Dictionnaire d'histroire et de géographie ecclésiastiques,* I (Paris, 1912), col. 244 ; G. Fedalto, *Hierarchia Ecclesiastica Orientalis,* I, *Patriarchatus Constantinopolitanus* (Padua, 1988), p. 4.

[26] Euagr. *Hist. Eccl.* 2, 11, p. 63 Bidez-Parmentier; Theod. Lect. *Hist. Eccl.* 1, 3, *PG* LXXXVI 172 (= p. 106, 9 ed. Hansen[2], 'GCS', N.F., Band 3, Berlin, 1995), which refers this charge to the moment of the rivalry with Gennadius.

[27] Cf. e.g. JUGIE, *loc. cit.*; Constantelos, *op. cit.*, p. 182, which refers this post to the orphanage to St. Zosimus.

[28] Cf. G. DAGRON, *Costantinopoli. Nascita di una capitale (330-451)* (Italian edition, Turin, 1991, p. 519, n. 146.

[29] *Patria Constant.* 3, 4, 7 (in*: Scriptores originum Constantinopolitanarum,* rec. Th. Preger, II, Lipsiae 1907, p. 235); *Vita Zot.* 12 (M. Aubineau, 'Zotikos de Constantinople, nourricier des pauvres et serviteur des lépreux', *Analecta Bollandiana*, 93, 1975, p. 82).

[30] Cf. Constantelos, *op. cit.*, p. 178.

[31] Cyrill. Scythop. *Vita Sabae* 87 (Schwartz, *Kyrillos von Skythopolis*, 'Texte und Untersuchungen' 49, 2, Leipzig, 1939, pp. 194-195).

[32] *Libellus monachorum ad Agapetum,* in: *Acta Conciliorum Oecomenicorum,* III, ed. (Schwartz, Berolini, 1940), p. 145, 57.

[33] *Cod. Iust.* 1, 2, 19.

[34] *Nov.* 7, *praef.* e 2.

[35] *Nov.* 43, 1.

[36] *Nov.* 131, 15.

[37] Cf. Constantelos, *op. cit.*, pp. 177-178.

[38] Cf. Costantelos, *op. cit.*, pp. 182.

[39] *Cod. Theod.* 11, 27, 1-2; cf. in particular C. CORBO, Paupertas. *La legislazione tardoantica,* Napoli 2006, 16 ss. with bibliography; Marasco, *op.cit.*, p. 69 and notes 78-79.

[40] *Cod. Theod.* 5, 10, 1; 5, 9, 1.

[41] Cf. in particular M. BIANCHI FOSSATI VANZETTI, 'Vendita ed esposizione degli infanti da Costantino a Giustiniano', *Studia et Documenta Historiae et Iuris*, 49, 1983, 190 ss.

[42] Cf. CORBO, *op. cit.*, 70-77 with bibliography.

[43] Cf. e.g. CORBO, *op. cit.*, p. 79.

[44] *Cod. Theod.* 3, 17, 3.

[45] Themist. *Or.* 34, 18.

[46] On this subject cf. above all S. GHINOPOULO, *Pädiatrie in Hellas und Rom* (Jena, 1930); J. BERTIER, *La médecine des enfants à l'époque impériale,* in: *Aufstieg und Niedergang der römischen Welt,* II 37. 3, hrsg. v. W. Haase (Berlin/New York 1996), pp. 2147-2227; M.-L. DEISSMANN, '*Kind*', in K.-H. Leven (ed.), *Antike Medizin. Ein Lexikon* (Munich, 2005), coll. 491-493; CHR. ROGGE AND E. SEIDLER, 'Kinderkrankeiten', *ibid.*, coll. 494-495 with a further bibliography.

[47] Hippocrat. *Vict.* 1, 22, Littré VI 510-511; Galen. *San. Tu.* 1, 12, Kühn VI 59 ss.; Bertier, *op. cit.*, pp. 2164-2169; Deissmann, *op. cit.*, col. 491.

[48] Hippocrat. *Aphor.* 3, 24-27, Littré IV, pp. 496-500.

[49] Cf. in particular J. BERTIER, 'Enfants malades et maladies des enfants dans le Corpus Hippocratique', in P. Potter, G. Maloney and J. Desautels (eds.), *La maladie et les maladies dans la Collection hippocratique. Actes du VI[e] Colloque International Hippocratique (Québec 1987)* (Quebec, 1990), pp. 209-220 ; Rogge and Seidler, *op. cit.*, col. 494.

[50] Cels. *Med.* 2, 1, 17-21.

[51] Cf. V. BONET, 'Les maladies des enfants et leur traitement d'après le témoignage de Pline l'Ancien', in C. Deroux (ed.), *Maladie et maladies dans les textes latins antiques et médievaux. Actes du 5. colloque international Textes medicaux latins (Bruxelles, 4-6 septembre 1995)* (Brussels, 1998), pp. 184-198.

[52] Soran. *Gyn.* 2, 20-24.

[53] Cf. S. BYL, *L'enfant chez Galien,* in: *Galeno: obra, pensamiento e influencia (Coloquio international celebrado en Madrid, 22-25 de Marzo de 1988)*, edicion preparada por J. A. López Férez (Madrid, 1991), pp. 107-117.

[54] Cf. in particular BERTIER, *La médecine*, pp. 2155 ss.

[55] Cf. BERTIER, *La médecine*, pp. 2157 ss.

[56] Soran. *Gyn.* 2, 28, 57 (*CMG* IV 93, 3-8).

[57] Cf. BERTIER, *La médecine*, pp. 2198-2200.

[58] Cf. BERTIER, *La médecine*, pp. 2198-2203.

[59] Cels. *Med.* 3, 7, 1: '*Quod si puer est qui laborat, neque tantum robur eius est, ut ei sanguis mitti possit, siti ei utendum est, ducenda alvus vel aqua vel tisanae cremore, tum denique is levibus cibis nutriendus. Et ex toto non sic pueri ut viri curari debent. Ergo, ut in alio quoque genere morborum, parcius in his agendum est: non facile sanguinem mittere, non facile ducere alvum, non cruciare vigilia fameque aut nimia siti, non vino curare satis convenit. Vomitus post febrem eliciendus est, deinde dandus cibus ex levissimis, tum is dormiat; posteroque die, si febris manet, abstineatur; ad similem cibum redeat. Dandaque opera est, quantum fieri potest, ut inter oportunam abstinentiam cibosque oportunos, omissis ceteris, nutriatur*'.

[60] Cf. BERTIER, *La médecine,* pp. 2201-2202.

[61] Cf. BERTIER, *La médecine*, pp. 2202 ss.

[62] *Vita Zot.* 12 (*Analecta Bollandiana*, 1975, p. 82).

[63] Cf. in particular CONSTANTELOS, *op. cit.*, pp. 177-178.

[64] Hieron. *Reg. Pachom., praef.* 5 (in: *Pachomiana Latina. Règle et Épitres de S. Pachome, Épitre de S. Théodore et "Liber" de S. Orsesius*, *Texte latin de S. Jérôme*, éd. par A. Boon, Louvain 1932, p. 7).

[65] Benedict. *Reg.* 31.

[66] Benedict. *Reg.* 36-37; cf. also Benedict. Anian,. *Concord. reg.* 46.

[67] *Regula Magistri* 28, 19-26 (*Regola del Maestro,* edited by M. BOZZI E A. GRILLI, II, Brescia 1995, p. 96).

[68] On the complex question of the chronology of these Rules and their precursors and origins cf. in particular BOZZI AND GRILLI, *op. cit.*, I, pp. 95 ss.; *La Regola di San Benedetto e le Regole dei Padri*, edited by S. Pricoco (Milan, 1995), pp. XI ss.

[69] Cassiodor. *Inst.* 1, 31, 1: '*Sed et vos alloquor fratres egregios, qui humani corporis salutem sedula curiositate tractatis, et confugientibus ad loca sanctorum officia beatae pietatis impenditis, tristes passionibus alienis, de periclitantibus maesti, susceptorum dolore confixi, et in alienis calamitatibus merore proprio semper attoniti; ut, sicut artis vestrae peritia docet, languentibus sincero studio serviatis, ab illo mercedem recepturi, a quo possunt pro temporalibus aeterna retribui*'.

[70] Cassiodor., *loc. cit.*: '*Et ideo discite quidem naturas herbarum commixtionesque specierum sollicita mente tractate, sed non ponatis in herbis spem, non in humanis consilis sospitatem. Nam quamvis medicina legatur a domino constituta, ipse tamen sanos efficit, qui vitam sine dubitatione concedit*'.

[71] Cassiodor. *Inst.* 1, 31, 2: '*Quod si vobis non fuerit graecarum litterarum nota facundia,in primis habetis Herbarium Dioscoridis, qui herbas agrorum mirabili proprietate disseruit atque depinxit. Post haec legite Hippocratem atque Galienum latina lingua conversos, id est, Therapeutica Galieni ad philosophum Glauconem destinata, et anonymum quendam, qui ex diversis auctoribus probatur esse collectus. Deinde Caeli Aureli de medicina et Hippocratis de morbis et curis diversosque alios medendi arte compositos, quos vobis in bibliothecae nostrae sinibus reconditos deo auxiliante dereliqui*'.

[72] Cf. e.g. V. NUTTON, *Ancient Medicine* (London , 2004), pp. 300-301.

MASSIMO ALIVERTI

3. Care for Sick Children in the History of the Church

On 21 February 787, the fifteenth year of the pontificate of Adrian I and the thirteenth year of Charlemagne's rule over northern Italy, the archpriest Dateus founded a home for abandoned children in Milan. This institution was placed by its founder under the protection and jurisdiction of the Bishop of Milan with the obligation not to modify what he had written in the deed of foundation. About a century later, on 3 February 870, the archpriest Anspertus founded in Cremona a home for abandoned children which was also for old people, poor people and pilgrims. Under the impulse of these examples offered by the Lombard clergy, during the medieval epoch many other homes to take in and care for abandoned children were founded by the church or by lay associations connected with the Church. One may cite as examples: the home created in Montpellier in 1070; that founded in Milan in the neighbourhood of Brolio in 1168; that created in Marseilles in 1188; that founded in Parma in 1200; that established in Viterbo in 1276; that founded in Florence in 1316; that created in Nuremberg in 1331; and that established in Venice in 1346. Other homes for abandoned children were created during the Middle Ages in Novara, Sienna and Treviri.

As regards Rome, abandoned children were certainly admitted to the Hospital of the Holy Spirit in Sassia in the fifteenth century as a result of a papal bull issued by Sixtus IV on 11 February 1483, which recommended that children of both sexes who had been admitted to it were to be treated and raised as though they were sons and daughters. According to a legend, the foundation of this home, which went back to 1204, was linked to the need to take in foundlings. It appears, in fact, that Innocent III in a dream had seen fishermen who, after throwing their nets into the Tiber, had dragged the waters but instead of finding fish had found the corpses of children, the victims of the shame or acute poverty of their mothers. The day after the Pope had nets thrown into the place indicated by his dream and did in fact find the corpses of new born children. He then decided to equip the city with an orphanage. In reality, the Roman home build on the side of the Tiber was referred to in the papal bull '*Inter opera pietatis*' of Innocent III as a place where '*recipiantur et reficiantur pauperes et infirmi*' and it was thus not very distant in character from many homes that had sprung up prior to that date throughout the Christian West.

Ever since the first centuries of the Christian era, indeed, a whole series of charitable initiatives had been developed with the goal of obeying the gospel precepts exemplified by the seven works of corporeal mercy reported by Matthew: 'I was hungry and you gave me food, I was thirsty and you gave me drink, I was a stranger and you welcomed me, I was naked and you clothed me, I was sick and you visited me, I was in prison and you came to me' (25:35-37). In the list of suffering people to be taken in and helped, good Christians had placed next to strangers, the poor and the sick, elderly people and children as well, these two last categories being often in a state of complete abandonment. Thus, in the main Christian communities homes of various names according to the prevalent typology of people who were admitted to them came to be created: there was the *xenodochion* for strangers; the *ptococomium* for the poor; the *nosocomium* for the sick; the *gerocomium* for the elderly; and the *brephotrophium* for children. These charitable organisations were often created by saints or by pious people who had transformed their own homes into such homes. The Church then monopolised and regulated the various activities of care that were provided, placed them under the control of bishops and entrusted their actual management to officials who were appointed by the bishops. These places of care, which were the remote ancestors of modern hospitals and generally referred to with the term '*xenodochi*' (whether they admitted people from the locality, travelling strangers, abandoned children or abandoned elderly people), were health-care structures of a very special character. They were rustic buildings where little more than a dry bed was offered for the night to those inside their walls, a blanket to cover themselves, a meal to end their hunger, and the comfort of religion offered by charitable people who sought in this way to alleviate (medicate) the corporeal and spiritual sufferings of those who had been admitted. So in the first centuries of the Christian era, as for the whole of the Middle Ages, the terms '*ospitalità*' and '*ospedalità*' were in large measure matching and to the point of being considered synonyms. Even though the accommodation role of the *xenodochi* seems at first sight to have prevailed over their health-care function, this last was probably always present. For that matter, the treatment that was most used by the art of medicine of the epoch was the regime of hygiene and alimentation and the personnel at the service of those admitted could also be figures who had the characteristics of medical doctors or nurses (or both).

What has been said about the *xenodochi* can also be applied to the

homes which were exclusively for children (the *brefotrofi*), whose foundation during the medieval epoch was stimulated above all else, as has already been observed, by the need to take in and protect abandoned children The phenomenon of the abandonment of new born children by mothers who had conceived them out of wedlock or by parents who did not have the money to support them was in fact very frequent at that time. In these cases the leaving of children outside churches could constitute a valid alternative to killing them or selling them as slaves to other families. Another way for parents to abandon children during the same epoch was what was called 'oblation', that is to say the children were offered to an ecclesiastical institution (usually monasteries but also bishoprics or mere parishes). This practice, often practiced by well-off parents in order to avoid having too many children and a consequent dispersion of the family property, also had the advantage of enabling the parents to acquire spiritual benefits as well as economic ones. Whatever the case, parents might be induced to leave a new born child in a churchyard next to a church or to engage in an oblation of a child to a monastic Order, after realising that the child had some form of illness, deformity or constitutional weakness as well. The home of a bishopric or a convent thus acquired for those who were admitted more a health-care character than care alone.

During the medieval period all the principal hospitals, which were habitually managed by religious Orders, were equipped with a ward for taking in and looking after children. These were usually foundlings who had been brought into the building through a 'wheel' which allowed new born children to be left in a completely anonymous way. In Rome, for example, there was a wheel at the Hospital of the Holy Spirit and in Milan there was one at the Hospital of Brolo. Similar wheels existed throughout the Christian West. At the Hospital of the Holy Spirit in Rome the infant was taken from the wheel and wrapped in a blue drape (the symbol of the institution). It was then taken to the prioress who looked for any signs of recognition and then handed it over to the personnel on duty. The child was then examined and washed with warm wine. It was then fed by a wet nurse and finally put in a cot. At the *Ospedale Maggiore* of Milan, which was made up of the union of various homes, the infant was first placed in the home of Brolo for as long as it was breastfed ('milk child'). It then went to the home of San Celso until it reached the age of eight ('bread child'). Lastly the child was transferred to the home of Santa Caterina if a girl, and to other homes in the city if a boy.

During the medieval period and the Renaissance the children admitted to the hospital structures for children had a very high mortality rate. This had a number of causes: a) birth often took place in a concealed place and in bad hygienic conditions; b) the new born child could have malformations or be very weak; c) during the first days of its life it was usually badly fed or subjected to bad weather conditions (snow, rain, excessive cold or heat); or d) it could reach the hospital after a very long and uncomfortable journey. In addition, in these homes for children the function of providing accommodation, which was already present to a major extent on the homes for adults, was further accentuated by the fact that in general the art of medicine of the time saw a child as a little man (*homunculus*) who was not yet worthy of attention. Childhood, in fact, tended to be put on the same level as a pathological state from which one recovered spontaneously once adulthood had been reached. Only nurses and midwives, therefore, attended to children, and this was the case with hospital structures as well.

For that matter, Western culture until the threshold of the modern age did not display much interest in childhood, and this despite the appreciation of childhood that was brought to us by Christian thinking with the cult of Baby Jesus as an intermediary between man and God. Parents, in fact, did not display real affective investment in their children, at least until adulthood, above all because of their low life expectancy at birth. The children of wealthy parents were sent away from their homes early on in order to be entrusted to nurses who raised them until, if they survived, they could, as adolescents, be readmitted to their families. A new sensitivity towards childhood appeared only at the end of the Renaissance and this increased with the passing of subsequent centuries. During this epoch there appeared the first works which dealt with the diseases of children and their treatment. For example: *De arte medica infantium* (1577) by Ognibene Ferrario, *De morbis puerorum* (1583) by Girolamo Mercuriale and *Comare o ricoglitrice* (1595) by Scipion Mercurio. In the meantime there arose in various parts of Europe other institutions for taking in abandoned children: in Naples in 1515, in Amsterdam in 1526, in Lyons in 1533 and in Paris in 1670. The art of medicine then began to be asked to provide practical help in treating sick children and there also began to be an open demonstration of suffering when they died. This was exemplified during the baroque period by the painting '*Humana fragilitas*' (1656) which was painted by Salvator Rosa shortly after he lost a young son because of the plague. Books on religious comfort for the sick and dying also began to deal with young people and children. An example of this is the little work by the Teatrine father Lorenzo Scupoli, *Exercises for the Sick*, which was published at the beginning of the seventeenth century.

From the very earliest centuries of the Christian era the Church con-

cerned itself with offering care and help to children. In this it referred to the famous passage to be found in the Gospel According to St. Mark (10:13-16): 'And they were bringing children to him, that he might touch them; and the disciples rebuked them. But when Jesus saw it he was indignant, and said to them "Let the children come to me, do not hinder them; for such belongs the kingdom of God. Truly I say to you, whoever does not receive the kingdom of God like a child shall not enter it". And he took them in his arms and blessed them, laying his hands upon them'. For that matter, the fathers of the Church concerned themselves on some occasions with studying new born children and young people. Thus, for example, Clement the Alexandrine (150-200) argued that wet nurses should feed babies with milk and that sucking on the breast helped to maintain lactation. The same author recommended that babies should sleep in hard and flat beds; he also advised temperance in eating, physical exercise as long as it was not excessive, and taking baths as long as this was done on an empty stomach. St. Augustine (354-435), for his part, argued strongly in favour of the administration to children of human milk as a food provided by God for the normal growth of a child.

During the Renaissance initiatives by ecclesiastical institutions to help abandoned, poor and sick children continued; from this epoch onwards a very large number of saints made their mark in this kind of activity.

St. Thomas da Villanova (1486-1555), the Archbishop of Valencia, fostered the creation in Spain of homes for children and young people who had no families. St. Anthony Maria Zaccaria (1502-1539), a medical doctor and priest of Cremona, provided help and health care to children in the poorest neighbourhoods of that town. In addition, he founded the Order of Bernabites which specialised in the education of young people. St. Martin de Porres (1579-1639), a Peruvian medical doctor and priest, founded hospitals and colleges for abandoned children. St. Vincent de Paul (1581-1660), a French priest, founded the 'Society of Charity', which was also open to men and women members of the laity, and this Society was particularly concerned with providing care to poor children and orphans.

Activity involving assistance and care for sick and abandoned children promoted by the Catholic Church continued during the modern epoch with a whole series of outstanding figures, nearly all of whom have been raised to the honour of the altars.

St. Giovanna Antida Thouret (1765-1826), a French sister, dedicated herself to care for the poor and sick, and was particularly concerned with the Christian and civic education of young people. The Blessed Charles Steeb (1773-1856), a German priest who was active in Verona, worked in various civilian and military hospitals; he was particularly concerned with providing care to orphans and the education of young girls. St. Magdalene di Canossa (1774-1835), a Venetian sister, founded the Congregation of the 'Daughters of Charity' which was concerned with caring for and educating children and also helped deaf and dumb children. Don Ludovico Pavoni (1784-1849), a Lombard priest, founded homes and oratories for boys, and was particularly concerned with providing care and professional training to those who were deaf and dumb. St. Vincenza Gerosa (1784-1847) and St. Bartolomea Capitanio (1807-1847), both Lombard sisters, founded the Institute of Charity which was dedicated to caring for sick people. It was also concerned with helping orphans and the animation of oratories for girls. St. Joseph Benedict Cottolengo (1786-1842), a Piedmontese priest, founded the 'Little House of Divine Providence' and was concerned in particular with helping sick children: in his institute he particularly helped children who were deaf and dumb, epileptics, the mentally retarded, those suffering from scrofula, those with rickets, and children with very heavy and repellent malformations. St. Maria Crocifissa Di Rosa (1813-1855), a Lombard sister, founded a hospital Congregation ('The Handmaidens of Charity'). She was also concerned with catechesis and providing school teaching to children, above all to the deaf and dumb. Don Luigi Palazzolo (1827-1886), a Lombard priest, founded homes, rest homes and training schools for abandoned children. The Blessed Giacomo Cusmano (1834-1888), a Sicilian doctor and priest, provided care and help to disinherited and marginalised boys. The Blessed Luigi Guanella (1842-1915), a Lombard priest, founded an institute to look after poor and sick boys and was particularly concerned with those who were mentally handicapped. St. Filippo Smaldone (1848-1923), a priest from Campana, provided care and rehabilitation for deaf and dumb young people. St. Francesca Saverio Cabrini (1850-1917), a Lombard sister, provided care to children, above all amongst European emigrants to the United States of America. She ran hospitals, orphanages, nurseries and elementary schools. St. Giovanni Calabria (1873-1954), a priest from Veneto, provided help, care and professional training to abandoned boys. The Blessed Maria Ludovica De Angelis (1880-1962), a sister from Abruzzi who settled in Argentina and provided hospital care for sick children in particular, reorganised the children's hospital in La Plata and transformed it into a modern health-care centre. She then created the Solarium di Punta Mogotes, on the Mar de La Plata, which was for very weak children or children with rickets or tuberculosis. The Blessed Luigi Monza (1898-1954), a Lombard priest, founded the association 'Our Family' which provided care to disabled young people; in particular he created institutes of a medical-psychological-pedagogic character for the rehabilitation and education of children with neurological and mental injuries. The Blessed Teresa of Teresa of Calcutta (1910-1997), a Yugoslav sister active in India, provided care to abandoned and malnourished children; she also provided care to lame children and children who were mentally retarded.

From the nineteenth century onwards, in parallel with the progressive establishment of paediatrics as an autonomous medical discipline, places of care of both a residential and clinical character which dealt exclusively with children's diseases began to be created in the principal

States of Europe (in Paris in 1802, in St. Petersburg in 1834, in Vienna in 1837, in Berlin in 1843, and in London in 1853).

In addition to public paediatric hospitals, some hospitals and hospital departments which were managed by religious for children also came into existence. As regards Italy, one may refer to the foundation in 1869 of the Hospital of the Baby Jesus by the Duchess of Salviati and other noble families of Rome. This health-care structure, which entrusted its nursing section to the Daughters of Charity of St. Vincent de Paul, continued its activity even after Rome passed from the Papal States to the Kingdom of Italy. This hospital, after being moved from its initial location on the left bank of the Tiber to the hill of Gianicolo, was placed in 1926 under the direct control of the Holy See. It developed further during the second part of the twentieth century and became a modern clinical centre that was highly specialised in the treatment of all the diseases and pathologies of childhood. One may also refer when citing Italy to the paediatric and neuro-psychiatric departments for children of university polyclinics which have arisen over recent decades – the work of Church bodies such as the Catholic University of Rome, the Biomedical Campus of Rome and the San Raffaele Institute of Milan.

With the management of these hospital structures and with the varied and diversified health-care activity of religious Congregations active in all parts of the world, the Catholic Church still upholds today her vocation which goes back millennia to care for and help with special concern the smallest representatives of suffering humanity

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ANGELO BAZZARI

4. The Witness of Saints who Consecrated their Lives to Care for Sick Children

Of the innumerable gallery of saints of charity, some have already been declared blessed, whereas others, and they are the majority, have remained 'unknown soldiers' of gospel love for children, I am here to bear witness to Don Carlo Gnocchi, the apostle of innocent pain.[1]

The Child at the Centre of Things

Don Gnocchi the 'father of mutilated children', the 'apostle of war orphans', the 'angel of children' – these are some of the appellations that have been universally bestowed on Don Carlo. And this is no matter of chance. In relation to children, indeed, he himself wrote in his testament: 'others may be able to serve them better than I have known how to and have been able to, but no one else, perhaps, will love them more than I have done'.[2] His relationship with childhood was for him always decisive and marked by a kind of fascination: 'Few things are as beautiful or more dear than a child. If the world were deprived of them, it would appear too dark to our eyes'.[3]

He met children at San Pietro in Sala as a curate and played with them as though he was one of them. He 'came across' them at Gonzaga, during his apostleship amongst the students, and he helped them to grow by taking part in their activities, above all during the summer. During the war his encounter with abandoned and forsaken children revealed to him his true vocation: 'How many children have I seen, on their sad pilgrimage of war! A tragic flower on the overturned and bloody ruins of Europe, a pale light of a smile on the dark agony of the world! Poor war children! Those, like me, who have seen them in Albania, in Greece, in Montenegro, in Croatia, in Poland, in the Ukraine, and in Russia, upset, emaciated, strays, afflicted in hunger and death, will never be able to tear from their eyes and hearts their funereal and disturbing image'.[4]

From that moment onwards service to suffering children constituted the very meaning of his life.

After returning from the war he wrote to his Archbishop: 'I have given myself and I still give myself to charity towards war victims, the mutilated, orphans and now children who have been mutilated for ever by the war because of a higher and compelling bond contracted with those who created the war, and they bear the consequences in a severe way. Because, Your Eminence, it was very easy and at times brilliant to say to the soldiers "do your duty in the name of God and divine Providence will not abandon you'. But now those promises commit me, like a credit note signed before God, and I am trying to pay it as I can in Arosio: with my invalids, with the orphans of my soldiers, and with the mutilated children of the war'.[5]

His whole work of charity began 'with' and 'for' them. 'If charity is a struggle for life how can we not look in a preferential way on children who are without affection or those who for any reason are suffering, mutilated, disabled or abandoned?'[6] *This is what he wrote and this is how his Foundation was born. Because 'every child that suffers is like a valuable little relic of Christian redemption, which is actuated and renewed in time, worthy of being honoured and almost venerated… We should see not only a little human redeemer with Christ and in Christ, but an intercession and a mediator of grace, because of the irresistible power of placation and impetration that innocent pain has in the heart of God'.*[7] *Childhood as a privileged 'place' of pacification between God and man and man with his fellows: 'In a child is reconciled and born anew life fractured by war'.*[8]

Don Gnocchi began as an educator and ended up as a rehabilitator, and this was no matter of chance. All the great saints of charity, such as Don Bosco, Don Orione, Don Guanella, the Blessed Palazzolo and very many others, were first and foremost educators who expressed their passion for education in the various fields of concrete action but always beginning with the involving and disquieting experience of the pain of children, to which they tried to provide some responses, where this was possible. And where there were no responses they took responsibility for them as though they were their own children.

The Tragic 'Event'

Still today children in the world are the martyrs of a whole range of forms of violence: 'war children', who are to be found in all the continents, the victims of hunger, of war, of famines and of stupidity and human selfishness. Child-soldiers forced to kill or abused like objects for the whims of the rich. Hopeless situations, in relation to which the 'charity of the species' and a sense of personal responsibility can respond in an incisive way and also with a certain chance of success. Then there is a pain, if one can express oneself in this way, that is even more 'innocent' than others, which directly involves the mystery of God and the creation: those with congenital infant handicaps or illness that has been acquired without

there being any human fault. Such was the tortured question posed by Don Gnocchi when he found himself faced, after mutilated children, with those with polio, and so on, and the whole rosary of those other sufferings that appear without a reason, without a fault, and without sense. This is a problem that is still very much debated today because of its perennial 'scandal' for the conscience of believers and non-believers.

Indeed, according to the World Health Organisation (WHO), 5% of children born into the world have a handicap. This means a figure of 8,000 children every day and three million every year. As regards Italy, once again according to the statistics of the WHO, 'the people who have disabilities or handicaps, many of whom are children, number millions, and thus one family in every ten experiences the tribulation of having a 'diverse' member'. This is a statistical fact that in itself makes us reflect, but which always remains a statistic that is emotionally distant from us. And it is not even much consolation for us to know that a specific adverse event happens every thousand births or once every hundred thousand births. For those who are involved, patients and family relatives, that event is always the 'event'. An event that poses deep questions to science and reason, but above all to men's hearts. Faced with a sick or handicapped child, reason halts and science, despite its claim to technological omnipotence, can tell us nothing of the underlying purposes of the appearance of this drama because science does not know the categories of purpose and meaning. It can explain at the most the causes of illness and handicap, the 'why', and hopefully it will also soon be able to tackle these causes, but it can never tell us about the meaning that pain can have. And the pain of children even less so. Dostoevsky, in 'The Brothers Karamazov', raised a cry of protest against any justification of the suffering of children with these fine words spoken by one of the protagonists of that novel, Ivan: 'If everyone has to suffer to buy eternal harmony with suffering, what have children to do with this? Answer me please. The reason why they should suffer as well and why it falls to them to buy this harmony with their suffering is totally incomprehensible'.[9]

There thus come forward the 'reasons of the heart', to quote Pascal. Reasons that are no less true and no less important than those of the intellect and which, through the gestures and the words of concrete life, 'render justice' to innocent pain by making us see how the negative as well, in the form of illness and handicap, can tell us a great deal about being men and make us glimpse something of God.

The 'Deep Problem' of Don Gnocchi

Don Carlo Gnocchi asked himself questions deeply about this mystery. Indeed, in his last work, his spiritual testament, which was written on his death bed and was entitled 'The Pedagogy of Innocent Pain' (1956), he began as follows: 'The problems that pain raises for the human mind, even when illuminated and guided by faith, are many in number and they are profound; but one that is certainly one of the most delicate and troubling is that of an apparent capriciousness in its distribution amongst men'.[10] *In these few lines is contemplated the human drama* par excellence*: the meaning of pain and its apparently unfair distribution.*

Pain, in fact, constitutes for us the problem of all problems, above all when it is innocent, and to such an extent, and specifically in order to face up to its enigma, that mankind has invented myths, elaborated philosophies, created institutions, discovered science and founded religions. To ask the question why one suffers and why one has to die, and to try to find an answer, is the most human thing in the world because it leads those who ask this question to modify the naked fact of reality and makes everyone grow in civilisation. However the mystery remains and the theodicies that have followed each other down the millennia in an attempt to defend God and explain the evil present in history have turned out to be insufficient. As was the case with Sisyphus, every attempt at an explanation that human beings have given to this great problem of pain has turned out to be a mass that has enveloped them, making the enigma even darker and the weight of silence even more unbearable.

Pain and Guilt

Many people, like the friends of Job and the Greek tragedians, believed that they had found an answer to this problem by linking pain to guilt and imputing malady to punishment. This attempt at an explanation, however, also falls into the contradiction raised by the severe observation of unfair suffering in the young and the just, as Don Carlo himself emphasised: 'Typical and more troubling than all other cases is the case of children who suffer…I believe that when one comes to understand the meaning of pain in children one has in one's hand the key to understanding all human pain and those who manage to sublimate the suffering of the innocent is able to comfort the tribulation of every man shaken and humiliated by pain'.[11] The search for another pathway by which to face up to this problem in a sensible way and by which to look for another way for it to be experienced by men certainly imposes itself.

Humanity as a Living Unity

Man is essentially a being in a relationship with others who lives in time and perpetuates himself in the continuity of the species. Without

relationships he is nailed to his loneliness which condemns him to a mortal folding in on himself and to abandonment by other people. In a few words, the fulfilment of man passes by way of the grateful gestures and good words of other men who, in 'passing through' his entire existence, make him live, hope, love and desire that this fullness of life that has been experienced will last for ever and be lived by everyone. Man thus awaits his salvation. A salvation that is not only a personal fact because, as Don Gnocchi observed, 'the whole of life is solidarity-based…mankind makes up a living unity that is solidly bound to a single and identical destiny, a participant in the good or bad of each one of its members; a mystic body that follows the same laws as the physical body, where health and illness, wellbeing and malaise, life and death, are common to all its limbs'.[12]

The Christian Proposal for a Mystery that Persists

The God of Abraham, of Isaac and of Jacob, the God of the living, took the initiative and made Himself man. As is His style, He did this without noise or theophanic apologetics. He fell into history with so much discretion that He appeared absent or distant, for many people even inexistent. He did not choose the path of power so as to tell us and reveal to us something about ourselves and our hard journey in time. He did not invade man nor did He force the creation which He had handed over (pain included) to our complete responsibility. Instead He followed, with respect and tolerance, utterly and totally, the pathway of man by making Himself flesh, blood and word. Acting in this way, He established an unbreakable covenant with mankind for all time and linked forever our destiny to His in a surprising, unexpected and dizzy nearness. As a memorial to this perennial giving of Himself and asking for nothing in return, He left us His own body. His 'response' to the evil of the world and to pain in man was as 'carnal' as one could imagine. This God did not want to explain innocent pain, but He very concretely took it upon Himself and made its redemptive potentiality be glimpsed, almost a sort of recreation of the world as He had always dreamed it from the outset: 'behold I make all things new'.[13] In the life and the death on the cross of Jesus of Nazareth, a most historical and human man who gave himself totally for love, the pain inflicted on others marked a sin and referred to a judgement, whereas innocent pain opened up new ways of understanding reality and new ways of transforming it, in line with the heart of God.

The Redemptive Concept of Pain According to Don Gnocchi

Don Gnocchi summarised the redemptive concept of pain when speaking about mutilated children: 'In every suffering child we must see not only a man called early on to take part in human solidarity in pain, according to the unhappy law of Adam, but a little lamb who purifies and redeems, in line with the loving law of Christ, a living sacrifice of innocent humanity for sinning humanity'.[14]

It is certainly the case that in this way pain, too, remains a mystery, almost as though God had reserved it for Himself. But in lived love and shared nearness, which the Incarnation tangibly expresses and completely captures, the enigma of pain, above all the pain of the innocent, becomes a 'secret that is shared'[15] with man and delivered to faith. In the human event of Jesus God speaks, to the utmost, the language of man so that man can understand something about the mystery of God.

The Pedagogy of Pain

If we locate pain and also innocent pain in this perspective, perhaps its power to arouse scandal declines and death itself loses its malignant sting which poisons life. Pain, in addition, has its pedagogy and follows its intrinsic logic which induces brotherhood.

Is it not perhaps true that proximity to the poor, the abandoned and the excluded enables us to discover what is essential in life, helping us to order things and to make choices according to precise criteria of priority? Giving food to the hungry, helping those who are sick, rehabilitating those who are disadvantaged, coming to the aid of those who are homeless and unemployed, being at the side of those who are alone – does not this educate us to use the goods of the earth to live and not contrariwise, and does it not compel us to place the person at the centre of things rather than possessions at the centre of things? Does not contact with marginalisation in its multiple forms enable us to see in a clear way a very simple truth that we often forget: that no one is sufficient unto to themselves and that the riches of the planet should be shared if we do not want to wage war against each other constantly in a way that will lead to suicide. Those who go to visit people in prison experience almost physically the anxiety of guilt and the burden of responsibility but they also discover the dimension of mercy and find reasons for forgiveness. Only those who have held a terminally ill patient by the hand and accompanied that person until their final breath know that by dying in this way one can deliver oneself up with trust at the end, as well, an end that takes on the form of a crossing over rather than an elimination – Easter, in Biblical language. Anxiety over death is thus defeated by hope and love.

If we analyse history well we always find pain at the origins of this progressive humanisation of the earth, both as a cause, because it calls for or compels the shouldering of responsibility by all people for all people, and as an effect, in order to be fought and defeated more effectively.

By an arcane mystery pain, and this is even more the case if it is innocent pain, leads us to promote life in all its forms. This is what Don Carlo Gnocchi states in lapidary fashion at the end of his work 'The Pedagogy of Innocent Pain'.

'"Rabbi", the disciples asked him, "who sinned, this man or his parents, that he was born blind?" "It was not that this man sinned, or his parents, but that the works of God may be made manifest in him" (Jn 9:1). The pain of the innocent in the mysterious Christian economy exists also for the manifestation of the

works of God and the works of man; works of science, of poetry, of love and of charity. In the mysterious economy of Christianity the pain of the innocents is thus allowed that the works of God and the works of man may be made manifest: the loving and unfinished travail of science; the multiform works of human solidarity; the wonders of supernatural charity'.[16]

Thanks to pain a continual renewal of history is achieved which draws near to its completion in that ultimate reality that we call God.

The Contemporary Relevance of Don Gnocchi

The Servant of God, Don Carlo Gnocchi, did not observe pain from without, as a neutral spectator. Instead, he 'passed through it' as a man, to the utmost. An orphan because of the death of his father when he was only six years old, he lived through the death of his two brothers when he was still very young. And then the tragic retreat in Russia in the year 1943, to which reference has already been made, with his 'vow' taken before his massacred and frozen companions to take responsibility for their children. This was a vow that was soon transformed into a 'credit note signed before God' which he honoured with the rest of his life and the institution of his Work. Over fifty years since his death that promise that was kept has become a prophecy and Don Carlo continues in the Foundation that bears his name, with branches throughout Italy and present in those parts of the world where the suffering of the least of our brethren finds neither a hearing nor a response. Because the charism of Don Gnocchi was specifically this: to fight pain by using all the means that reason, science and piety suggest, without ever stepping back and by locating suffering within the redemptive action of Christ: 'care for the sick, the arts of medicine, charity towards the suffering, and the fight against all the causes of human suffering are a true and continual material redemption which forms a part of the total redemption of Christ whose complete commitment and dignity it possesses'.[17] This is a care that acts in relation to the body and the spirit with a view to an authentic restoration of the human person directed towards 'retrieving and intensifying the life that is not there but which could be there'[18] of every man – this was a distinctive feature of his action that was handed over as a testament to the continuators of his Work.

The Fight against Pain as a New Form of Paternity

Totalitarian ideologies, violent societies, and the inhuman technologies that marked the twentieth century, which was at one and the same time both splendid and terrible, were often the outcome of a delirium of omnipotence that sought to remove pain, that attempted in Prometheus fashion to cancel limits, and tried to hide finitude in all ways possible.

The destiny of this planet which is entrusted to the responsibility of man is also suspended by the very slender thread of dialogue between the different generations, sexes and races because its conservation and the happiness of its inhabitants is today more than ever before linked to solidarity amongst men and entrusted to divine compassion.

Under every sky and at all latitudes of the planet, in every season and moment of human life, those who care for and take care of any suffering, beginning with children who are the very icon of frailty and innocence, actuate and take part in a prodigious spiritual paternity because, as Don Gnocchi wrote, 'the fight against and the victory over pain is a second generation that is no less and painful than the first and he who manages to give back to a child the health, integrity and serenity of life is no less a father than he who called that child to life in the first place'.[19]

It is the same 'look' that Jesus bestowed on the children that his disciples wanted to distance from him and whom instead Christ put at the centre of things: 'to such belongs the kingdom of heaven. Truly I say to you, whosoever does not receive the kingdom of God like a child shall not enter it'.[20] And in the Gospel of Matthew, when Jesus describes the final judgement, after listing the works of charity, he ends: 'as you did it to one of the least of these my brethren, you did it to me'.[21]

An Institutional Form of Paternity: the Don Gnocchi Foundation

Today this paternity at the service of children and the suffering contin-

ues in the Work of charity that Don Gnocchi began on the wings of a dream[22] almost sixty years ago or so and which now bears his name. The Don Gnocchi Foundation continues this unending fight against pain and every form of suffering through effective services that embrace the whole span of human life, from the cradle to the grave, that are provided by its twenty-nine centres which are to be found in nine regions of Italy and in a number of the poor countries of the planet.[23] Care and rehabilitation for all those who are afflicted by a congenital or acquired disability, for children who encounter difficulties as they grow up caused by various reasons, elderly people who are largely not self-sufficient and who do not know where they will finish their days, and patients in a persistent vegetative state or at the terminal stage of their lives who need to be accompanied. A form of paternity that has become institutional in order in a more effective way to conjoin science and charity, to share pain[24] through therapeutic acts that activate in patients all the potentialities of life,[25] in order to address in an adequate way the challenges of a globalised solidarity, of the moral reconstruction of our society, of the humanisation of science and of the correct use of technology,[26] holding in a single embrace the whole of humanity by holding its children, the memorials of the words of Don Gnocchi: 'Our internal and external attitude towards a child who is suffering because of a disability, because of deficiency, because of mutilation, because of poverty, because of illness, because of ignorance, because of abandonment or because of any other cause, must be dominated first and foremost by a profound sense of respect, of veneration; I would almost say of worship'.[27]

The commitment to continue this legacy of the founder is entrusted to the 'friends' of his 'hut',[28] that is to say to all those who, inside and outside the Don Gnocchi Foundation, hold dear the destiny of man, who is made in the image of God.

APPENDIX 1
DON CARLO GNOCCHI

Biographical Notes

Childhood

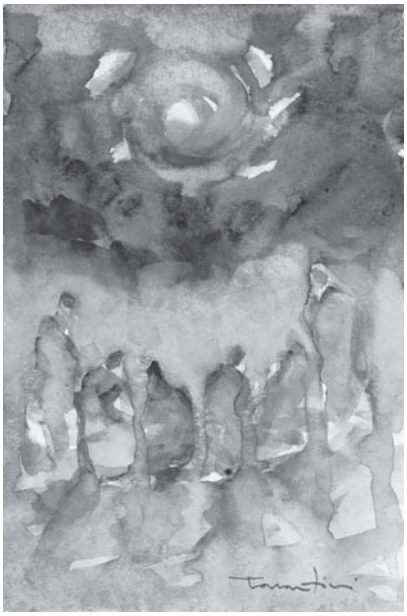
Carlo Gnocchi, the third child of Enrico Gnocchi, a marble craftsman, and Clementina Pasta, a tailor, was born in San Colombano al Lambro, near Lodi, on 25 October 1902. Made an orphan by the death of his father when he was aged five, he then moved to Milan with his brother and two brothers, Mario and Andrea, who died a little time afterwards of tuberculosis. He was then a seminarian at the school of Cardinal Andrea Ferrari and in 1925 he was ordained a priest by the Archbishop of Milan, Eugenio Tosi. He celebrated his first Holy Mass on 6 June of the same year in Montesiro, a village in Brianza where his aunt lived and where he had frequently stayed during his holidays and where ever since he was a child he had spent long periods of convalescence given that his health had been very poor.

An Assistant and Educator

The first apostolic job of the young Don Carlo was that of being an oratory assistant, first in Cernusco sul Naviglio and then after only a year at the populous parish of San Pietro in Sala in Milan. He won esteem, support and affection from the local people and to such an extent that the fame of his talents as an excellent educator even reached the archbishopric: in 1936 Cardinal Ildefonso Schuster appointed him the spiritual director of one of the most prestigious schools in Milan – the Gonzaga Institute of the Brothers of Christian Schools. During this period he studied intensely and wrote short essays on pedagogy.

The War

At the end of the 1930s, it was once again Cardinal Schuster who entrusted him with the position of spiritual assistant to the university students of the Second Legion on Milan, which included a large part of the students of the Catholic University and many ex-students of Gonzaga. In 1940 Italy entered the war and many young students were called to the front. Don Carlo, coherent with the educational drive which wanted him to be always present with his young people when in in danger, enrolled as a voluntary chaplain in the Val Tagliamento battalion of the alpine troops, and his destination was the Greek/Albanian front.



The Russian campaign

After the end of the Balkan campaign, and after a brief interval in Milan, in 1942 Don Carlo returned to the front, this time in Russia, with the alpine troops of the Tridentina, In January 1943 there began the dramatic retreat of the Italian contingent. Don Carlo, who had fallen down exhausted on the side of the road along which was walking a heavy flow of soldiers, was miraculously picked up on a sledge and saved. It was specifically this tragic experience which, after he had cared from the wounded and dying alpine troops and had listened to their last wishes, matured in him the idea of founding a great Work of charity which would indeed be realised after the war with the Pro Juventute Foundation. After returning to Italy in 1943, Don Carlo began his piteous pilgrimage in the alpine valleys looking for the family relatives of the fallen in order to provide them with moral and material comfort. During this same period he helped many partisans and politicians to flee to Switzerland and risked his life in doing so. He himself was arrested by the SS with the grave

charge of espionage and activity against the regime.

Orphans and Mutilated children

In 1945 there began to take concrete shape his project to help the suffering that had been only sketched during the war years. He was appointed director of the *Istituto Grandi Invalidi* of Arosio and welcomed the first war orphans and mutilated children. There thus began the work which would lead him to earn in the field the more meritorious title of the 'father of mutilated children'. Very soon the structure in Arosio proved to be insufficient as regards taking in young guests, whose requests for admission came from all over Italy. But when need becomes impelling, Providence enters the picture! In 1947 a large house in Cassan Magnago, in Varesotto, was handed over to him at a symbolic rent.

The Pro Infanzia Mutilata

In 1949 the work of Don Gnocchi obtained its first official recognition: the *Federazione Pro Infanzia Mutilata*, which he had founded the previous year to coordinate more effectively the works of care for the little victims of war, was officially recognised by a decree of the President of the Republic. In the same year the head of the government, Alcide De Gasperi, appointed Don Carlo a consultant of the Presidency of the Council of Ministers to advise on children who had been mutilated by the war. From this moment onwards new colleges were opened one after the other: Parma (1949), Pessano (1949), Turin (1950), Inverigo (1950), Rome (1950), Salerno (1950) and Pozzolatico (1951).

The Fondazione Pro Juventute

In 1951 the *Federazione Pro Infanzia Mutilata* was dissolved and all its property and activities were entrusted to the new juridical body created by Don Gnocchi, namely the *Fondazione Pro Juventute*, which was recognised by a decree of the President of the Republic on 11 February 1952. In 1955 Don Carlo launched his last great challenge: the building of a modern centre which would bring together his methodology for rehabilitation. In September of the same year, in the presence of the Head of State, Giovanni Gronchi, the first stone of the new structure was laid near to the stadium of San Siro in Milan.

Adieu to a 'Saint'

Don Carlo, undermined by an incurable illness, would not manage to see the work in which he had invested most of his energies completed. On 28 February 1956 death took him prematurely at the Columbus, a clinic in Milan where he had been admitted for a long period of time because of a grave form of tumour.

His funeral was on a grand scale because of the number of people who took part and the high level of emotion. Four alpine soldiers carried the coffin, and others carried on their shoulders mutilated children who were in tears. And then there was the emotion of his friends and acquaintances, a hundred thousand people to fill the Duomo with laments and the square and the entire city of Milan in mourning. Thus on 1 March 1956 Archbishop Montini, who later become Pope Paul VI, celebrated the funeral rites of Don Carlo.

All the witnesses remember that through the cathedral there ran a kind of watchword – 'he was a saint, a saint has died'. During the service a child was brought to the microphone. He said 'Before I said, ciao Don Carlo, now I say, ciao St. Carlo'. This statement was met by an ovation.

His Last Gift

His last prophetic gesture was his gift of his corneas to two blind children – Silvio Colagrande and Amabile Battistello – at a time when in Italy organ transplants were still not governed by specific legislation. The dual operation, carried out by Prof. Cesare Galeazzi, was a complete success. The generosity of Don Carlo when he was about to die and the enormous impact that this transplant had on public opinion greatly accelerated the debate. And to such an extent that within a few weeks an *ad hoc* law was passed on the question.

The Cause of Beatification

Thirty years after the death of Don Carlo, Cardinal Carlo Maria Martini began the process of his beatification. The diocesan stage, which was begun in 1987, ended in 1991. The process is now being addressed by the Congregation for the Causes of Saints in Rome. On 20 December 2002 the Pope declared him venerable.

APPENDIX 2
THE DON GNOCCHI FOUNDATION

Its history

The dream

'I dream that after the war I can dedicate myself for ever to a work of charity – whatever it may be or better what God will want to indicate to me. I wish and pray from the Lord only one thing: to serve His poor for the whole of my life. That is my 'career'… unfortunately I do not know if I am worthy of this great grace because it is a privilege'. From the dramatic experience of war, lived for the most part in the tragic retreat in Russia as a military chaplain, there matured the mission to which Don Carlo Gnocchi dedicated himself for the rest of his life with coherence and faith: beginning with the last in order to redeem their 'innocent pain' and to construct hope for the future.

The Beginnings

In 1945 there began to take concrete shape his project to help the suffering that had been only sketched during the war years. He was appointed director of the *Istituto Grandi Invalidi* of Arosio and welcomed the first war orphans and mutilated children. There thus began the work which would lead him to earn in the field the more meritorious title of the 'father of mutilated children'.

The Birth

In 1949 the work of Don Gnocchi obtained its first official recognition: the *Federazione Pro Infanzia Mutilata*, which he had founded the previous year to coordinate more effectively the works of care for the little victims of war, was officially recognised by a decree of the President of the Republic. In the same year the head of the government,

Alcide De Gasperi, appointed Don Carlo a consultant of the Presidency of the Council of Ministers to advise on children who had been mutilated by the war. In 1951 the *Federazione Pro Infanzia Mutilata* was dissolved and all its property and activities were entrusted to the new juridical body created by Don Gnocchi, the *Fondazione Pro Juventute*, which was recognised by a decree of the President of the Republic on 11 February 1952.

Against Polio

After the battle for children who had been mutilated by the war had been won (as a result, also, of mobilisations of an international character, amongst which the 'Field of the Mutilated Children of Europe'), the care complex of the Foundation was directed towards a more burdensome problem that was afflicting suffering children in Italy during that period, namely polio.

The Colleges

In the thinking of Don Carlo and in the organisation of the colleges of *Pro Juventute* the concept of rehabilitation was central. 'If we have to rebuild', he said, the first and most important reconstruction is the reconstruction of man. One must give back to men a reasonable goal in life, a strong will to achieve it and a clear rule of morality. Man must be remade. Without this, rebuilding a home for him would be a useless and ephemeral exercise in hard work. It will not be enough to give back to man the elementary possibility of thinking and willing, without which there is no truly human life – to him should also be restored dignity, sweetness and variety in living, I mean that respect for individual potentiality and that opportunity to fulfil completely the potential of his own personal riches'. In this way was born the very sozeable professional organisation, *Pro Juventute*: workshops rose up and expanded, as well as laboratories for mechanics, for radio technicians, for printers, for agricultural technicians, for paper technicians, for potters, for tailors…

The Pilot Centre

The work of Don Gnocchi grew rapidly: his project for the overall re-education of the individual, in a pathway that harmonised prevention with rehabilitation and placed man with his potentialities and peculiarities at the centre of the therapeutic process, constituted the exclusive novelty and extraordinary modernity of *Pro Juventute*. This is even more the case if one considers that it was at work at a time when the disciplines of rehabilitation were taking their first, hesitant, steps forward.

In 1955 Don Carlo launched his last great challenge: the building of a modern centre which would bring together his methodology for rehabilitation. In September of the same year, in the presence of the Head of State, Giovanni Gronchi, the first stone of the new structure was laid near to the stadium of San Siro in Milan.

Care for Every Form of Disability

The handing over when he was about to die of '*Amis, ve racumandi la mia baracca*' became for the successors of Don Carlo a watchword. Although on the death of its founder the Foundation was going through a moment of consolidation and reflection, a few years later it was already able to take off towards future achievements.

Beginning in 1963 *Pro Juventate* – which in 1957 had become the *Fondazione Pro Juventute Don Carlo Gnocchi* – extended its presence in Italy with twelve important regional centres and other hundreds of multi-purpose clinics and minor centres. In this process it expanded the range of its activities in the sphere of rehabilitation to every form of handicap, from motulesis to neurolysis and on to the congenital, phocomelic and dystrophic malformed. It dealt with pathologies of the spinal column, of the bone apparatus, scoliosis, and the most demanding forms of disability at the level of rehabilitation.

The development of scientific research

Thirty years after the death of Don Gnocchi one can say that no invalidating pathology which afflicts individuals of any age is excluded from the spectrum of action of this Foundation, which is present in many regions with incisive functions for alls form of rehabilitation entrusted to it by the relevant public body (regional governments and the national health service)

The scientific and research component has been developed through agreements with the state University of Milan, with the Catholic University and above all with the Polytechnic of Milan. These are agreements that have made the Foundation itself a model at a European and international level with a pilot structure that is complete and autonomous at the level of research and therapies of rehabilitation.

All of this led in 1991 to the recognition – specifically for the *Centro "S. Maria Nascente"* of Milan – of the status of Institute for Admissions and Treatment of a Scientific Character (IRCCS), subject to Italian private law. In August 2000 this recognition of being an IRCCS was also extended to the *Centro "S. Maria agli Ulivi"* in Pozzolatico.

The elderly and the Terminally Ill

Since 1981 the Foundation has included in its range of activities, after a suitable change to its statutes, care for elderly people, in the main those who are not self-sufficient (becoming officially in 1998 the *Fondazione Don Carlo Gnocchi Onlus*), and since 2000 cancer patients at the terminal stage of their illnesses have also been included.

Recognition as an NGO

In recent years the international dimension of the activities of the Foundation has been particular developed. This has been recognised not only by the participation of the IRCSS in joint research projects with international bodies and universities and the implementation of projects of the European Social Fund for the professional training and work placement of disabled people but, also and above all else, by the recognition which was obtained in March 2001 that it is a non-governmental organisation (NGO), something that will help in achieving greater action in developing countries.

The Don Gnocchi Foundation Today

Today the Don Gnocchi Foundation has over 5,400 people working in it, from employees to professional co-workers, for whom are pro-

duced constant programmes of training and updating.

The services are provided in a system accredited by the National Health Service in twenty-eight centres in nine regions. These structures offer a plurality of services which may be summarised as follows:

In Italy: 2 institutes for admissions and treatment of a scientific character (IRCCS); 22 units for poly-functional rehabilitation; 9 units for hospital rehabilitation; 3 units for grave acquired brain damage; 6 homes for non-self-sufficient elderly people (RSA); a hospice for terminal cancer patients; 2 rest homes; 1 centre for training, orientation and development (CeFOS); 39 local clinics for rehabilitation; 3 integrated day centres for the elderly (CDI); 5 day centres for the disabled (CDD); 3 health-care homes for the disabled (RSD); 1 holiday home for the disabled; 3,2726 long-term hospital and day hospital beds and over 9,000 people treated or cared for on average every day.

In the world. For some years the foundation has been extending its field of action beyond the borders of Italy. Recognised as a non-governmental organisation (NGO), the Don Gnocchi Foundation promotes the implementation of short-term and long-term programmes in developing countries and the on-site training of citizens. Projects and initiatives have been implemented or are currently underway in nearly all the continents of the world.

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Milan, Italy

Notes

[1] Cf. appendix n. 1.
[2] DON CARLO GNOCCHI, *Dio è tutto qui.Lettere di una vita* (Mondadori, Milan, 2005), p. 352.
[3] O. ARZUFFI AND A. BAZZARI, *Don Carlo Gnocchi. Poesia della vita. Pensieri* (Edizioni S. Paolo, Cinisello Balsamo (Mi) 2006), p. 153.
[4] C. GNOCCHI, *Cristo con gli alpini* (Fondazione Don Gnocchi –Ancora, Milan, 1999), p. 102.
[5] C. GNOCCHI, *Dio è tutto qui*, p. 59.
[6] Cfr. *Poesia della vita,* p. 155.
[7] *Ibid.*, p. 157.
[8] *Ibid.*, p. 154.
[9] F. DOSTOEVSKIJ, *I fratelli Karamazov*, I (Garzanti, Milan, 1992), p. 338.
[10] AA.VV., *Carlo Gnocchi, Il dolore innocente* (Fondazione Don Carlo Gnocchi-Ancora, Milan, 1999), p. 17.
[11] C.GNOCCHI, 'Pedagogia del dolore innocente', in *Gli Scritti* (Ancora-Fondazione Pro Juventute, Milan, 1993), p. 751.
[12] *Ibid*., p.752
[13] *Ap* 21:5.
[14] C. GNOCCHI. *Poesia della vita*, p. 157.
[15] C. MARIA MARTINI, 'Introduzione' to *Il dolore innocente* (Fondazione Don Gnocchi-Ancora, Milan, 1999).
[16] C. GNOCCHI, *Poesia della vita,* p. 101.
[17] *Ibid.*, p. 100.
[18] *Ibid.*, p. 184.
[19] *Ibid.*, p. 161.
[20] Mt19:13-15;Mk 10:13-16;Lk 18:15-17.
[21] Mt 25:35-36,40.
[22] Don Carlo Gnocchi, Dio è tutto qui, p. 91: '*I dream that after the war I can dedicate myself for ever to a work of charity – whatever it may be or better what God will want to indicate to me. I wish and pray from the Lord only one thing: to serve His poor for the whole of my life. That is my 'career'.*
[23] Cf. G. COSAMACINI, *"La mia baracca". Storia della Fondazione Don Gnocchi* (Laterza, 2004).
[24] C. GNOCCHI, *Poesia della vita*, ,p.190: 'Sharing suffering is the first therapeutic step'.
[25] *Ibid.*, p. 192: 'All rehabilitation must strive towards developing the maximum of the capacities of life'
[26] A. BAZZARI, 'Davanti al futuro', in G. Cosmacini, *La mia Baracca*, p. 120.
[27] C. GNOCCHI, *Poesia della vita*, p. 99.
[28] Cf. appendix n. 2.

friday
14
november

DARÍO CASTRILLON HOYOS

5. Faith, Charity and Sick Children

Your Eminences, Your Excellencies, distinguished participants in this international conference on pastoral care for sick children.

Who of us, with the heart of a pastor, has not felt a certain rebellion in looking at a sick child? Who of us has not thought: why must this be so? Only to then address a prayer to the Lord: 'heal him, you have the power to do that!' Why must it be so? Why must a child sick with leukaemia finish a life that has only just begun? We do not understand the reason for this.

Is it not perhaps that we are mistaken and that instead of 'why' we should ask 'to what purpose?' In these cases we must make a very great effort in order to see illness and a sick person taking faith and love as a starting point. Certainly, this is the true point of view and thus the only one that is valid.

The gospels tell us about a healing performed by Christ which leaves us astonished at the way in which the Lord acts: 'But immediately a woman, whose little daughter was possessed by an unclean spirit, heard of him, and came and fell down at his feet. Now the woman was a Greek, A Syrophoenician by birth. And she begged him to cast the demon out of her daughter. And he said to her, "Let the children first be fed, for it is not right to take the children's bread and throw it to the dogs." But she answered him, "Yes, Lord; yet even the dogs under the table east the children's crumbs." And he said to her, "For this saying you may go your way; the demon has left your daughter."'[1]

Why is Jesus so severe with a woman who is suffering because of the illness of her daughter? This Jesus is cruel, very different from the Jesus present in the rest of the gospels. Why? Here, too, the question which we should ask is not so much 'why?' as 'to what purpose?' What is the purpose of this exhibition of cruelty by Jesus, God made man?

A *girl* is ill and her *mother* goes to find help from he whom she believes will restore her daughter's health with his own power, without any medicine: the Son of God.

Why does the Lord not want to listen to her? Perhaps he is worried about more important things that command his attention? No, it is because of a simple ethnic discrimination, a humiliating ethnic-religious discrimination. The Lord? Yes, specifically him. We do not understand.

To what purpose? That is the question: what is the purpose of these humiliations inflicted on an innocent woman whose only crime was not to belong to the Chosen People? What is the intention of Jesus who troubles us with his way of treating the woman?

In the heart of Christ there is a light that illuminates us; in him there is an absolute certainty about this woman, her perseverance and her tenacity: the total certainty that only God can have. Jesus knew that the Syrophoenician woman would have gone ahead and would not have allowed herself to be discouraged by the first 'no'. And thus he grants her the gift of being able to go home knowing that her daughter had been healed thanks to her tenacity, her almost insolent insistence. Here is the faith of this woman, a faith that is a trust without any shadow of doubt in the fact that Christ would have healed her daughter and that he would have done it because she had asked him to do it. Here, too, is the love of this woman for her own child, a love that leads her to fight for her and not to concede defeat. The prize is the profound satisfaction, which for a mother has a very great value, of knowing that her daughter has been healed thanks to her insistence, thanks to her. Faith and love rewarded by God.

That woman returned happy to her own home and this was a great gift that Jesus made to her: she was convinced that her daughter had been cured thanks to her insistence. Christ granted to her two prizes with a single act: the healing of her daughter and the healthy pride of knowing that she had been an indispensable co-worker in this healing.

Faith is the virtue that leads that woman to recognise her Saviour in Jesus, he who would have been able to heal her daughter. Where others see a master, she perceives a person who has the power of God and the mercy of God to exercise this power for the good of other people.

Love is the virtue that gives that woman the strength to look for the wellbeing of her daughter above all things, even above her humiliation and her pain. For love she is prepared to do anything to heal her daughter.

We, like this Syrophoenician woman, know that God wants, as in her case, our cooperation at the cost of a great deal of pain as well in order to take care of his chosen sons, children.[2]

Faith enables us to discover Christ in a sick child, it enables us to worship Christ in that child. Charity enables us to love Christ in that child.

Faith

Faith reveals to us that human life does not belong in the least to man, although we know that it is a gift that we have received. We experience this: each one of us knows that if we live, this is not because of ourselves – faith teaches us that life is a *gift of God*. We

are stewards without any rights of ownership. Life presents itself to us more as a duty than as a right, although everyone has a right to life.

Faith gives us certain trust in the fact that God, the author of life, always wishes our wellbeing, even though this may not coincide with our concept of wellbeing.

Faced with a sick child, faith must lead us to discover that this life is a gift of God, that we must save it, care for it and protect it from its beginning, as long as there is human life and we are face to face with the first cell of this being, already with its own and never to be repeated genetic code, at the beginning of its development.

In his famous work *La peste,* Albert Camus presents with emotion the debate between the medical doctor Rieux and the priest Paneloux who fight together in the hospitals against the plague that is devastating the city. One day a young man dies amidst great suffering because of this disease. The two men are at his bedside. The doctor then turns to the priest with a burst of anger: 'This man here at least was innocent! You well know that!' The priest Paneloux answers: 'Why did you speak to me with so much anger?... For me too the episode was unbearable… It is revolting in that it exceeds our level. But perhaps we should love what we cannot understand'. Rieux reacts to this by declaring: 'No, Padre, I have another idea about love. I will refuse until I die to love this creation where children are tortured'.[3]

A few days later, in a sermon, Father Paneloux takes up and internalises the radical objection to evil that afflicts the innocent. Albert Camus summarises his preaching in the following way: 'In the field of evil the difficulties began. There was, for example, apparently necessary evil and apparently useless evil. There was Don Giovanni lost in the underworld and there was the death of a child. If, in fact, it is right that a libertine is struck down, one cannot understand the suffering of the innocent. In truth, there was nothing more important on the earth than a child and the horror that such suffering brings with it and the reasons that one has to find for it. For that matter, in life God makes everything easier… Here, instead, we have our feet up against a wall… Padre Paneloux also refused to allow himself easy advantages that would have allowed him to climb that wall. It would have been easy for him to say that the delights of eternity that awaited the child could compensate him for his suffering, but in truth he did not know anything about this. Who could state, in fact, that an eternity of joy could compensate for a moment of human pain? Certainly not a Christian, whose Master had experienced pain in his limbs and his soul. No, this Padre would have remained with his feet against the wall, faithful to the torture of which the cross is the symbol, faced with the suffering of a child'.[4]

How should we respond to the suffering of a child. In the novella by Camus, Father Paneloux says that when faced with this 'one must believe everything or deny everything'.

Without doubt medicine is obtaining increasingly spectacular victories over illness. But, although it increasingly wins battles, it always loses the war.[5]

Faith does not resolve the problem of pain in the case of a sick child because it does not eliminate pain but gives it a meaning of redemption and offering, which no philosophy offers. Faith teaches us to unite the suffering of the child to Christ and to transform into salvific what, apparently, would be useless and absurd for a human being. Faith makes suffering a sacrifice, the offering of an innocent, of a saint, for the benefit of everyone, for the wellbeing of those most in need, the less innocent.

Charity

'God created man in His own image and likeness (Jn 1:26ss): calling him to existence through love, He called him at the same time for love.

God is love (1 Jn 4:8) and in Himself He lives a mystery of personal loving communion. Creating the human race in His own image and continually keeping it in being, God inscribed in the humanity of man and woman the vocation, and thus the capacity and responsibility, of love and communion.[6] Love is therefore the fundamental and innate vocation of every human being.

As an incarnate spirit, that is a soul which expresses itself in a body and a body informed by an immortal spirit, man is called to love in his unified totality. Love includes the human body, and the

body is made a sharer in spiritual love.'[7]

Love is a concept that is very much devalued in contemporary society which is immersed in post-modern culture. Reductionisms in visions of human beings have necessarily led to a parallel reductionism in the conception of love. Thus when we speak about Christian 'love' or 'charity' we run the risk of not being understood. Love today is not understood as 'dedicating oneself' but as 'profiting by' and this is of no use in giving a meaning to human life; it does not meet the natural and spiritual aspirations of the person.

Faced with the illness of a child, love is transformed into a living necessity for the child and for us. The child needs our love and we need the love of the child, but love that is authentic, love that is donation. We give ourselves to the child and the child gives himself to us in this offering for our salvation.

I remember the letter that His Holiness John Paul II wrote to children during the International Year of the Family.[8] In this letter the Pope tells them that he expects much from their prayers and he refers constantly to love: 'People cannot live without love. They are called to love God and their neighbour, but in order to love properly they must be certain that God loves them… What joy is greater than the joy brought by love?' The loving offering of suffering is a source of grace and redemption.

Faced with the scandal of illness and the suffering of the innocent, faith reveals to us a supernatural meaning that raises our gaze towards authentic love.

We are in the year of St. Paul and that saint also guides us in this itinerary of love. He teaches us to understand love as total self-giving. Paul understands that Christ loves him because he gave himself for him: 'who loved me and gave himself for me'.[9]

I remember the image of many parents at the bedside of their sick child. How often have I heard parents say: 'Lord I will give you everything that you want, but heal my child'. These are not the words of desperate people but rather an expression of true love, of an authentic desire to give everything for their child: 'By this we know love, that he laid down his life for us: and we ought to lay down our lives for the brethren'.[10] This is the same attitude of the Syrophoenician woman of the gospel.

Love is written into human nature as a spiritual tendency. For this reason, the theological virtue of charity does nothing else but raise it to a supernatural level, but love is already there as a tendency, in that *imago Dei*, the human being. The illness of a child uncovers the frailty of this nature. But a Christian does not allow himself to fall into hopelessness and a lack of meaning. Rather, together with this weakness, he discovers the love of the always near God, and lives a friendship of correspondence with him, in whom he finds a meaning to his pain.

For a sick child, to discover the friendship of Jesus is a source of a great spiritual growth that will always help him to overcome the pains and the troubles of illness. He discovers in Jesus a friend who has suffered for him, who is near to him because he is alive. He also discovers that he is important to Jesus: 'How *important children are in the eyes of Jesus!* We could even say that *the Gospel is full of the truth about children.* The whole of the Gospel could actually be read as the "Gospel of children"… *Is not Jesus pointing to children as models* even for grown-ups? In children there is something that must never be missing in people who want to enter the kingdom of heaven. People who are destined to go to heaven are simple like children, and like children are full of trust, rich in goodness and pure. Only people of this sort can find in God a Father and, thanks to Jesus, can become in their own turn children of God'.[11]

A child knows that he is important to Jesus and for this reason he can rely upon Jesus, and he begins to build his life with him and on him. 'To build on Jesus and with Jesus means to build on a foundation that is called crucified love. It means building with someone who, knowing us better than ourselves, says to us: "You are valuable in my eyes… you are worthy of esteem and I love you".[12] It means building on someone who is always faithful, even though we lack faithfulness, because he cannot deny himself.[13] It means building with someone who constantly kneels down before the wounded heart of man and says: "I do not condemn you; go and sin no more".[14] It means building with someone who from on the cross extends his arms in order to repeat for all eternity: "I give my life for you, man, because I love you"'.[15]

And we who contemplate a sick child from the foot of his bed, at times in a passive way, without being able to do anything, we know that love also gives a meaning to everything that we can do for that child. Service to a sick person turns out to be insufficient if in this service one cannot perceive love for human beings, a love that is nourished in the meeting with Christ. Intimate personal participation in the need and suffering of the other thus becomes a *participating of myself in him*: so that the gift does not humiliate the other, I must give him not only something that is mine but myself; I must be present in the gift as a person.[16] Service to a sick child shapes us according to the ideal of Christ when it is done out of love for him.

'The more we do for others, the more we understand and can appropriate the words of Christ: "We are useless servants".[17] We recognize that we are not acting on the basis of any superiority or greater personal efficiency, but because the Lord has graciously enabled us to do so. There are times when the burden of need and our own limitations might tempt us to become discouraged. But precisely then we are helped by the knowledge that, in the end, we are only instruments in the Lord's hands; and this knowledge frees us from the presumption of thinking that we alone are personally responsible for building a better world. In all humility we will do what we can, and in all humility we will entrust the rest to the Lord. It is God who governs the world, not we. We offer him our service only to the extent that we can, and for as long as he grants us the strength. To do all we can with what strength we have, however, is the task which keeps the good servant of Jesus Christ al-

ways at work: "The love of Christ urges us on"[18]'.[19]

Experience of the limitlessness of need can, on the one hand, lead us into an ideology which seeks to do here and now what, it appears, the government of the world by God does not manage to achieve: the universal solving of all problems. On the other hand, it can become a temptation to engage in inertia when we are faced with the impression that anyway nothing can be done. In this situation, a living contact with Christ is of decisive help in remaining on the righteous path – neither falling into a pride that despises man and in reality constructs nothing but only destroys, nor abandoning oneself to resignation which would impede us from allowing ourselves to be guided by love and thus from serving man.[20]

We do not want there to be sick children in the world, but if this is inevitable, at the least let us ensure that there are no sick children without love, no sick children who are unable to give a meaning to their pain.

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Notes

[1] Cf. Mk 7:24-29.
[2] Cf. Mt 19:14; Mk 10:14; Lk 18:16.
[3] Cf. A. CAMUS, *La peste* (Gallimard, París, 1947), pp. 239-240.
[4] Cf. *Ibid*., p. 246.
[5] Cf. BERNARD SESBOÜÉ, *Creer, invitación a la fe católica para las mujeres y los hombres del siglo XXI* (San Pablo, Madrid 2000), pp. 206-207.
[6] Cf. THE SECOND VATICAN COUNCIL, Pastoral Constitution on the Church in the Modern World *Gaudium et spes*, n. 12.
[7] JOHN PAUL II, Post-Synod Exhortation *Familiaris Consortio*, n. 11.
[8] Cf. JOHN PAUL II, 'Letter to Children in the International Year of the Family', 13 December 1994.
[9] Cf. Gal 2:20.
[10] 1 Jn 3:16.
[11] JOHN PAUL II, 'Letter to Children in the International Year of the Family', 13 December 1994.
[12] Is 43:4.
[13] Cf. 2 Tim 2:13.
[14] Cf. Jn 8:11.
[15] BENEDICT XVI, 'Meeting with Young People', Cracow-Błonia, Poland, Saturday 27 May 2006.
[16] Cf. BENEDICT XVI, *Encyclical letter Deus caritas est*, n. 34.
[17] Lk 17:10.
[18] 2 Cor 5:14.
[19] BENEDICT XVI, *Encyclical letter Deus caritas est*, n. 35.
[20] Cf. BENEDICT XVI, *Encyclical letter Deus caritas est*, n. 36.

LUCIANO SANDRIN

6. Sick Children and Christian Hope

Introduction

In the encyclical *Spe Salvi facti sumus* (in hope we were saved), Benedict reminds us that 'According to the Christian faith, "redemption" – salvation – is not simply a given fact. Redemption is offered to us in the sense that we have been given hope, trustworthy hope, by virtue of which we can face our present: the present, even if it is arduous, can be lived and accepted if it leads towards a goal, if we can be sure of this goal, and if this goal is great enough to justify the effort of the journey'.[1]

But what strength is one dealing with, especially when this *present* is particularly *arduous* for a child who is undergoing the experience of illness, pain and dying and in an *arduous present* which has to be lived by those who help that child and provide him or her with care?

In this paper I will talk about Christian hope and I will interpret illness, and in particular illness suffered by a child, as an experience of loneliness, and I will interpret hope as 'consolation'. The Latin word *con-solatio* – Benedict XVI stresses in *Spe salvi* – suggests '*being with* the other in his solitude, so that it ceases to be solitude' (n. 38).

1. Illness and Loneliness

We are very afraid of being alone, of not being accepted, and of being abandoned. The first experiences that we have of our individuality derive from relationships with other people, and when we are alone we fear losing ourselves. In our childhood not only do we depend on our fathers and mothers for our lives and our safety, or on other important figures, but we acquire through these first ties our awareness of ourselves, which is the basis of our capacity to direct ourselves in our lives and is also the core of identity. We fear loneliness, isolation and silence because we experience them after a certain fashion as symbols of death, which is interpreted as an extreme separation from other people.

Solitude, the experience of being alone or of feeling lonely, accompanies our lives and at certain times makes us suffer a great deal. Different languages have different words for different kinds of solitude.[2] There is the solitude that refers to the condition of social and physical solitude, of being alone, of not having relationships with other people (aloneness) and there is a solitude that emphasises the emotional-affective component of feeling lonely, the absence of real contacts, and this can be connected with physical and social aloneness or can be completely separate from it, the outcome of a subjective perception of one's own condition (loneliness). And then there is a solitude that expresses a sense of spiritual fullness that characterises certain moments of physical solitude that is looked for, chosen or actively experienced, giving it a specific meaning (solitude)[3]. We can feel alone when we are in company, among many people, just as we can be physically alone without feeling lonely. Much depends on the cause of our solitude, on how we assess it and accept it, and on the meaning we give to it.

There are moments in life, which are marked by pain and frailty, when solitude is felt more and one is more vulnerable to the pain that accompanies it. Solitude is a significant component part of the experience of illness and disability, in which a social isolation is always experienced, when there is a greater need for affection, and greater value is given to relationships and thus one is more sensitive to their absence or their lack of substance.[4]

The solitude of a sick person can be physical, social, affective or even spiritual in character. A sick person feels betrayed by his or her body, isolated from other people, and at times abandoned by God. He or she feels alone in facing up to the worry of *his or her* illness and the decisions that he or she has to take, even when other people are at his or her side in a loving way and provide him or her with care and company. He or she feels that other people can suffer with *him or her* but not for *him or her*, and that he or she must look for the strength to face up to his or her situation and manage the suffering that it involves within himself or herself. The solitude that is present in illness cannot be totally shared and subjected to 'con-solation'.

Solitude is often aggravated by a lack of truth, by isolation as regards communication – a relational 'euthanasia' in advance. All of us have great discomfort in relation to the truth, in saying the truth and in hearing the truth, with the consequence that we are unable to communicate in an authentic way with a sick person and thus to remove his or her loneliness.[5] The result of this is affective isolation and an imposed loneliness that is difficult to accept. There are silences but also words which make the sick person feel even more alone.

Solitude is often the central theme of a grave illness. There is solitude at the moment of diagnosis, which is marked by a worry that makes the sick person feel alone in his or her world, inside a body that is suddenly extraneous, in the context of relationships that change and habits of life that have to be abandoned. There is solitude in the pathway of therapy, amidst fears, doubts and uncertainties that are difficult to share (or hurriedly silenced), aggravated by looks that do not look and by professional care that is 'dehumanising' because it is partial. There is a painful soli-

tude during the final moments of life when contact with death makes the sick person feel suddenly extraneous and foreign in his or her own world. There is the solitude of the sick elderly person which accentuates his or her previous, real or perceived, solitude. There is the solitude of a sick child who is isolated from his or her affective or social world but also from communications that concern him or her.[6] And there is the solitude of the sick person but also the solitude of his or her family relatives and those who care for him or her.

The fear of death, which is especially strong in contemporary society, leads to social isolation, to physical distance (which becomes also affective and relational distance), by which an attempt is made to 'deny any tie between us and the precariousness of life' which the patient who dies represents. Silence comes to dominate and with silence, solitude – a new and greater solitude provoked by a society which, in the health-care field as well, does not allow a dying patient to live as though he or she were a dying person who needs ties, who needs to be reassured that whatever happens he or she will not be left alone.[7] It is specifically the fear of solitude and being abandoned that is one of the most important reasons for the desperation of those that have to deal, in advance as well, with fear of death and fear of the pain that accompanies death.[8]

There is a two-way road between solitude and illness. Solitude is the consequence of illness but it is also a factor that can aggravate it. Solitude can deprive a person of important relationships, set in motion depressive processes and make him or her more vulnerable to illness. A great deal of research stresses the importance of social relationships (which channel love, membership, sharing, support and intimacy) at an emotional, cognitive and spiritual level and their influence on a person's health.[9]

In the case of a sick child all of this is experienced with an especial intensity.

2. The Solitude of a Sick Child

Special attention should be paid – both by health-care professionals and by pastoral workers – to sick children, especially when they are going through the experience of hospitalisation, a grave illness or an illnesses that lasts, with their consequent solitude.[10].

Illness is a source of suffering which, at least in part, could be alleviated, and which often leaves a mark on the future of a child, from a psychological point of view as well, in particular when the team that has responsibility for caring for and for treating that child does not understand his or her needs and does not ensure that he or she has a sufficiently welcoming place in the hospital, where the trauma of illness is joined by an interruption of normal life, separation from a known environment and a different relationship with his or her parents. A sick child can feel especially alone. Other people do not understand his or her language and this make him or her even more fragile.

A better knowledge of the experience of the child, of his or her behaviour and state of development can help in planning a correct policy towards him or her. This is so from the spiritual point of view as well. However, the idea is still very widespread that a sick child, and the paediatric ward, should not receive special attention from a spiritual point of view. The prejudice is strong that the child 'does not understand' or that it is not possible to form with him or her a meaningful relationship that is suitable to his or her age. It is also forgotten that to speak about the experience of a sick child without taking into account the 'experiential difference' between a baby that is a few months old and a boy of eleven is an 'artifice' that hinders the actuation of a suitable relationship of help.[11]

And it is often forgotten that at the side of the child there are his or her family relatives (parents, grandparents, brothers and sisters) who 'co-habit' with his or her illness, and that suitable attention to their spiritual needs and to a relational support that strengthens them can be of great help for the child as well.[12]

A child, especially between the ages of three and four – because of his or her cognitive and affective immaturity in understanding and accepting his or her experiences of pain, discomfort and privation – seems to be more defenceless than adults when faced with the trauma of illness and hospitalisation, and even weaker in controlling, through special mechanisms of strength as well, emotions and fantasies that are more anxiety-causing the younger he or she is. In addition, the borders between reality and imagination are rather labile. A sick child suffers because of what is happening to his or her body but also, and above all else, because of what is happening to his or her life, because of the pain that the illness involves and the isolation that the treatment he or she is receiving impose upon him or her. And often the sick child is left alone (even when the persons around him or her are very many in number) in addressing particularly worrying situations.[13]

Special attention must be paid to the pain that accompanies the process of dying. Adults tend to underestimate the ability of children to understand the subject of death, perhaps because they want to conserve 'a happy imaginary space for children' which defends them from their fear of dying. In reality, the ideas that a child of between the ages of three and six has about death are much more evolved that is generally believed.[14]

Awareness of death and the fear that follows from this is present in a gravely ill child much more frequently (indeed much more than is the case with healthy children) than

his family relatives and health-care workers would like to believe. At times reference is not made to it in order to conserve his or her social role and so that he or she is not abandoned. And this is done by entering into what is called 'mutual pretence' with his or her parents and with the members of the staff – everybody knows that this sick child is dying but they act as though he or she is going to go on living. In this way, each person maintains their own social role: the child continues to grow, the parents go on protecting him or her, and the members of the staff continue to treat him or her and to provide care. An anthropologist who was able to carry out a study for a period of nine months in a paediatric oncology department explains the role that children afflicted by leukaemia have in this mutual pretence. Leukaemia immediately calls into question the ability of children to fulfil the hopes of their parents and family relatives. They are no longer up to demonstrating their value through future achievements because they do not have a future, that do not have what defines children. Mutual pretence allows them to act as though they had a future, to continue to act as children. Following the rules that are needed to maintain this mutual pretence they show that they are able to meet the expectations of other people. The recognition that they receive for this behaviour is on a large scale. They gain a sense of personal fulfilment, of satisfaction and of value in their own eyes and in the eyes of those who are treating them and providing them with care. In strengthening the hopes of these adults, these children assure to themselves a presence that continues. They do not want to be left alone. But this is a fiction. 'The irony of the situation', writes this anthropologist, 'is that our feverish attempts to achieve their wellbeing at all costs creates a kind of conspiracy between the children, their parents and the hospital staff which means that in the end these children will die alone'.[15]

The child can experience many kinds of violence. The greatest form of violence that can be done to him or her is a 'non-recognition' of what he or she really is, a child, of what he or she is experiencing and how he or she lives that experience, a subject of his or her life and dreams, and not the object of our wishes and our expectations, the disappointment of which provokes in him or her feelings of guilt and shame that cause him or her, in particular, to suffer.[16] The illness, with the suffering that accompanies it and the fears that it evokes, for the child is an experience of loss and solitude. The presence of those people who love him or her or those who, in various ways, take care of him or her, can be a sign of belonging that remains, of a relationship that reconstitutes the fragments of his or her body and life, helps him or her to contain his or her worries and sustain his or her hope. There is a nearness that treats and comforts.

At times all of this does not happen. Those who should be near to the sick child draw away and those who draw near create, in their relationship with him or her, a great extraneousness and distance, even when they cover him or her with presents. 'When I awoke', relates Oscar, a gravely ill little boy, in *Oscar e la dama in rosa*, 'I saw that naturally they had brought me presents. Since I have been admitted long-term to hospital my parents have some difficulties with conversation; so they bring me presents'.[17]

At times those who are near to sick children do not know their language and thus do not manage to 'con-sole' their solitude and become their *companions on their experiential journey*. A short story, narrated by Elisabeth Kübler-Ross, can help us to reflect on the importance of interpreting the language of children, especially when they are sick and experiencing the fear of solitude and worry about dying.[18]

A girl of eight was dying. She was in an oxygen tent and during the night she called for a nurse. A young nurse came and asked her what she wanted. The girl looked at her and said to her: 'what happens if a fire breaks out while I am in this oxygen tent?' The nurse did not read behind these words the girl's fear of death and solitude. She answered: 'don't worry, nobody smokes here'. and she then left the room. However, she realised that the girl was not satisfied by her answer. She talked in private to the head nurse who went to see the girl and asked her to repeat what she had said. The girl repeated her question: 'what happens if a fire breaks out while I am in this oxygen tent?' The head nurse opened the tent, put her arm under the girl's pillow, and then asked her: 'does this help you?' The girl understood that this nurse (in speaking her own language) was really helping her and rather than drawing away from her had drawn near to her to the point of touching her. She felt understood and 'con-soled', she was no longer alone with her worries and she began to speak about her death.

In her fear of a fire the girl had expressed her fear about loneliness in the face of death and her wish for a contact that involved reassurance.

3. The Con-solation of Hope

Man has many (small and big) hopes which vary with the different periods of his life. At times it may appear that one of these hopes totally satisfies him and there is no need for other hopes. 'When these hopes are fulfilled', writes Benedict XVI in his *Spe salvi*, 'it becomes clear that they were not, in reality, the whole. It becomes evident that man has need of a hope that goes further. It becomes clear that only something infinite will suffice for him, something that will always be more than he can ever attain' (*Spe salvi*, n. 30). The various hopes that sustain him on his jour-

ney are certainly important. But without the great hope they are not enough. 'This great hope can only be God, who encompasses the whole of reality and who can bestow upon us what we, by ourselves, cannot attain'. Only God can satisfy this hope, only His kingdom can fulfil it. But 'His kingdom is not an imaginary hereafter, situated in a future that will never arrive, his kingdom is present wherever he is loved and wherever his love reaches us' (*Spe salvi,* n. 31).

'Hope does not disappoint us, because God's love has been poured into our hearts through the Holy Spirit, which has been given to us' (Rom 5:5). The great hope that is not disappointed is foreshadowed in our lives by little hopes. A relationship of care can be a place of hope. Father Roberto Zavalloni, a pedagogue, writes: 'It is not through overcoming but through and by means of little and humble human hopes…that one comes to the only hope that does not disappoint'.[19] And he is echoed by the expert on pastoral care, Henry Nowen: 'There is no reason to expect that something more important will take place in the future if the signs of hope are not visible in the present'.[20]

The human experiences of hope and the human bearers of hope can be experienced in the case of sick children as moments of passage, reliable bridges towards the hope that transcends the immediate, sensitive heartbeats of the heart of God. In his or her relationship with those who are providing him or her with care and treatment, a sick child can rediscover safety and trust and open himself or herself to hope: that his or her life has a future, that he or she will not be abandoned, that he or she will always have a place in the love and memories of his or her loved ones, that someone will take care of his or her dreams.

A 'truly Christian' therapeutic relationship is born from the fertile encounter between the questions that come from the experience of individuals and the rich history of a Word made flesh, historically experienced and handed down. As regards a sick child as well, one cannot but begin from his or her experience, from his or her questions, from his or her way of living hope as a future which finds confirmation in the present and which is lived in the present.[21]

In situations that involve waiting for a sick child to relive the tension between trust and distrust which leads him or her to the beginnings of his or her life, when, trusting in the loving response of his or her mother to his or her needs, he or she developed 'the origins' of hope: *the capacity to wait*, in safety, the actions of his or her mother, even though she is not always present in a physical sense, 'having made of her an internal certainty as well as the object of the wait'.[22] Only trust in loved ones, after experiencing their love, makes a sick child able to wait and thus to hope.

We must learn to interpret the experience of a sick child, understanding his or her language, in relation to hope as well.

In a paediatric ward, we are told by an expert in pastoral care,[23] a priest is celebrating Holy Mass and is explaining a passage from the Gospels: 'look at the birds of the sky; they do not sow or reap; you, too, should not fret'. Boris sits up. From some weeks he has not been able to take solids. His illness has not yet been diagnosed. He has had to undergo a long series of analyses and every time that they take him from his bed he feels invaded by profound worry. In response to the words of the priest, a member of that group of children who are between the ages of two and eleven, he suddenly exclaims: 'really you should not worry; but I am a bit worried that my mother will not come every day'. Silence. No words comes from the other children. With a very strong voice Boris says once again: 'you really should not worry, well, yes, a little. Who knows whether my mother will come today'. All of the children look at him tensely. All of them are familiar with this worry. Boris then says: 'and if my mother comes today, I won't have to worry about eating because she will being my meal'. I agree with Boris. Every child is familiar with the feeling of being at the mercy of others, of being alone, of being powerless in the face of events, of always waiting. All children have their worries and one of them expresses them. In this way he becomes a kind of 'shepherd of souls' of the whole group. He translates their hope. The expression of this worry is a therapy for everyone. Not feeling alone nourishes hope, gives space to the words of the Gospel and confirms them. The great hope in God who takes care of them, as he cares for the birds of the sky and the lilies of the field, is 'embodied' in trusting hope in the arrival of their mother, in the certainty that she will not allow her child not to have a meal.

A sick child can be 'con-soled' in his or her solitude by the presence of people who care for him or her, love him or her, and allow him or her to be himself or herself, that is to say a child. In the short novel that has already been quoted from, namely *Oscar e la dama in rosa*, only his grandmother allows Oscar, a child who is gravely ill, to be truly himself and to express himself in full freedom. And it is she who places him in a relationship which is not only epistolary but also existential with God.[24] It is she who 'con-soles', because she really knows 'to be with him' in his solitude, she knows how to listen to his tale and she sustains his hope.

In trusting his mother, certain of her love, a child opens up to hope. The Christian community offers itself, in this sense, as a motherly presence and a community of hope every time that in it are experienced, in meaningful relationships of the present, *anticipations of the kingdom of* love of God. And this prior experience, which gives forms to the present and to the future, is celebrated in a special way in the *sacraments*. They are *the memory of the future*, the secure pledge of its fulfilment, a place where the different forms of human fragility and solitude are defeated at their deepest roots, moments when a special tie of 'com-munion' is created with other people and with God, a 'being with the other in his solitude, so that it ceases to be solitude' (*Spe salvi*, 38).

Every time that we celebrate the Eucharist, communion with God and with each other, the divine Traveller walks with us, as he did with the disciples of Emmaus, he makes himself our travelling Companion, he makes us understand the promises contained in Holy Scripture, supports our fragile hope and

he 'con-soles' us (cf. Lk 24:13-35). If this can 'com-fort' a child, that is to say give him or her the strength to resist, it can also 'com-fort' those who take care of and treat him or her, creating a virtuous circle of mutual 'com-fort', living a communion that 'con-soles'.[25] Without forgetting that at times it is specifically children who are particularly strong (resilient) and 'con-sole' and 'com-fort' those who take care of them.[26]

In a relationship with a child who suffers *hope acts in love* and is nourished by it: 'our actions engender hope for us', observes Benedict XVI (*Spe salvi*, n. 35). From our way of 'caring' springs hope not only for the children that we care for but also for ourselves, those who take care of that child. And in this service we justify that hope that lives in us (1Pt 3:15).

If there is a great hope projected into the ultimate future, there are small specific hopes linked to the most immediate future and to the present. The ultimate hope can be 'theo-logically' narrated in finite hopes every time that their fulfilment contains the signs of the 'consolation' of the Father and keep alive our nostalgia for His Love.

Christian hope is based upon the trust of the covenant, even when the end is not in sight, but there are friendly and meaningful presences that accompany us, comfort us and reassure us. We are called to be 'ministers of hope' (*Spe* salvi, n. 34), at the side of the child who suffers through our presence, our care, our words and our relationships.

Our 'taking care' can become a true *pastoral theodicy* concerned not so much with making 'speeches' about God at the side of a child who suffers but with making him or her feel that God is near through our nearness, our tenderness, our concern and our love: a God who speaks about Himself (theo-logy) through our, albeit frail, 'con-solations'.

Conclusion

Accompanying a child who suffers means taking on, after a certain fashion, his or her suffering, so that it becomes our suffering as well. But specifically when it becomes shared suffering, in which there is the presence of the other, this suffering is penetrated by the light of love, the suffering person is no longer alone, he or she is 'consoled'.

The other, here, can be anyone of us, but the other is above all God, who made Himself man in order to 'suffer together' with us. From that moment 'in all human suffering we are joined by one who experiences and carries that suffering *with* us; hence *con-solatio* is present in all suffering, the consolation of God's compassionate love – and so the star of hope rises'(*Spe salvi*, n. 39).

With His gifts – His words, His love and His hope – God who 'comforts us in all our affliction, so that we may be able to comfort those who are in any affliction, with the comfort with which are ourselves are comforted by God' (2Cor 1:4). The consolation that God gives us, and that we are called upon to give to each other, makes us *stronger* (it com-*forts* us), it gives us the courage to resist and sustains our hope.[27]

Rev. LUCIANO SANDRIN MI
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Notes

[1] BENEDICT XVI, *Spe salvi*. Encyclical Letter on Christian hope (LEV, Vatican City, 2007, n. 1.

[2] Cf. MICELI M., *Sentirsi soli* (Il Mulino, Bologna, 2003).

[3] Cf. ROLHEISER R., *Il cuore inquieto. Alla ricerca di una casa spirituale in un tempo di solitudine* (Queriniana, Brescia. 2008) (English edition 2004).

[4] Cf. SANDRIN L., 'Solitudine e malattia: uno sguardo psicologico', in *Camillianum*, 15(2005), pp. 511-521.

[5] Cf. COLOMBERO G., *La malattia. Una stagione per il coraggio* (Paoline, Rome, 1981).

[6] Cf. BATTELLI T., 'La solitudine nel tumore', in DE MAIO D. and GUIDUCCI R. (ed.), *La solitudine sociale* (Omega, Turin, 1996), pp. 114-118.

[7] Cf. SERAVALLI E., 'Solitudine del malato morente', in MORASSO G. and INVERNIZZI G., *Di fronte all'esperienza della morte: il paziente e i suoi terapeuti* (Masson, Milan, 1989), pp. 113-117.

[8] Cf. SANDRIN L., 'Aspetti psicologici del problema dell'eutanasia' in *Camillianum* 19(2007), pp. 39-49 and 'La domanda di eutanasia provoca la nostra pastorale', in *Rassegna di Teologia* 2(2008), n. 49, pp. 227-261.

[9] Cf. SANDRIN L., 'Relazioni sociali e salute', in *Camillianum* 4(2002), pp. 137-147.

[10] Cf. GROSSOEHME D.H., *The pastoral care of children* (Haworth Pastoral Press, New York/London/Oxford 1999) e SANDRIN L., 'Per una pastorale del bambino malato', *Camillianum* 17(2006), pp. 391-411.

[11] Cf. HESCH J.B., *Clinical pastoral care for hospitalized children and their families* (Paulist, New York/Mahwah, 1987).

[12] Cf. FEUDTNER C., HANEY J., and DIMMERS M., 'Spiritual care needs of hospitalized children and their families: a national survey of pastoral care providers' perceptions', *Pediatrics*, 1(2003), pp. 67-72 and SEAGULL E.A., 'Beyond mothers and children: finding the family in pediatric psychology', in *Journal of Pediatric Psychology* 3(2000), pp. 161-169.

[13] For a summary of the psychology of sick children cf. SANDRIN L., 'Bambino malato', in CINÀ G., LOCCI E., ROCCHETTA C., AND SANDRIN L. (eds.), *Dizionario di teologia pastorale sanitaria* (Camilliane, Turin, 1997), pp. 99-106.

[14] Cf. KASTEMBAUM R.J., 'Death in the world of childhood', in KASTEMBAUM R.J., *Death, society, and human experience* (Allyn and Bacon, Boston, 1995[5]) and OPPENHEIM D., *Dialoghi con i bambini sulla morte. Le fantasie, i vissuti, le parole sul lutto e sui distacchi* (Erikson, Trento, 2004).

[15] Cf. BLUEBOND-LANGNER M., *The private worlds of dying children* (Princeton University Press, Princeton NJ, 1978), quoted in HAUERWAS S., *Naming the silences. God, medicine, and the problem of suffering* (T&T Clark, Edinburgh, 1993), p. 127.

[16] Cf. DI BLASIO P., *Psicologia del bambino maltrattato* (Il Mulino, Bologna, 2000).

[17] SCHMITT E-E., *Oscar e la dama in rosa* (BUR, Milan, 2004) (French edition 2002), p. 42.

[18] Quoted in VERSPIEREN P., *Eutanasia? Dall'accanimento terapeutico all'accompagnamento dei morenti* (Paoline, Cinisello Balsamo (MI), 1985), pp. 169-172.

[19] ZAVALLONI R., *Psicologia della speranza. Per sentirsi realizzati* (Paoline, Milan, 1991), p. 152.

[20] NOUWEN H.J.M., *Creative Ministry* (Doubleday, New York, 1971), p.14. Cf. also SANDRIN L., *Fragile vita. Lo sguardo della teologia pastorale* (Camilliane, Turin, 2005), pp. 113-124.

[21] HERTH K., 'Hope as seen through the eyes of homeless children', in *Journal of Advanced Nursing* 5(1998), 1053-1062.

[22] Cf. ERIKSON E.H., *Infanzia e società* (Armando, Rome, 1966) (English edition. 1963), p. 231.

[23] I take this story freely from ZULEHNER, P. M., *Teologia Pastorale. Vol 3. Passaggi. Pastorale delle fasi della vita* (Queriniana, Brescia, 1992), pp. 84-86. Cf. also OCCHETTA F., 'Quale speranza davanti alla sofferenza e alla morte di un bambino', *La Civiltà Cattolica* 3723-3724 (2005), pp. 251-261.

[24] SCHMITT E-E., *Oscar e la dama in rosa* (BUR, Milan, 2004) (French edition 2002).

[25] Cf. KIRPALANI *et al.*, 'Quality of life in spina bifida: importance of parental hope', in *Archives of Disease in Childhood* 83(2000), 293-297 *(www.archdischil.org)* and FEUDTNER C. *et al.*, 'Hopeful thinking and level of comfort regarding providing pediatric palliative care: a survey of hospital nurses', *Pediatrics* 1(2007), e186-e192 (*www.pediatrics.org*).

[26] On 'resiliance' see CYRULNIK B., *Il dolore meraviglioso. Diventare adulti sereni superando i traumi dell'infanzia*, (Frassinelli, 2000) (French edition 1999) and his other works

[27] Cf. WIMMER J.F., 'Consolation', in STUHLMUELLER C. (ed.), *The Collegeville pastoral dictionary of biblical theology* (The Liturgical Press, Collegeville (Minnesota), 1996), pp. 169-171.

IGNACIO CARRASCO DE PAULA

7. Christian Responsibility and Sick Children

It appears that for adults, and in particular for parents, but not only for parents, responsibility constitutes a suitable approach to children. Indeed, every individual is seen as being responsible – must answer for, must render account for – what has been given to him and entrusted to him, and if the gift or act of entrusting concerns not a thing but a person then that responsibility increases in proportion to the extent to which the person involved needs care and protection. Every young person, therefore, and this is even more the case if he or she is sick, must always provoke in adults – whether they are relatives, teachers, health-care workers or anybody else that one may imagine – awareness of a precise duty which could be defined by the phrase 'taking care of', that is to say being ready to identify and to meet, with solicitude and as far as possible, the physical and spiritual needs of the person that has been entrusted to them.

1. The Specific Christian Dimension of Responsibility in Health-Care Professionals

As a moral approach, responsibility is a human phenomenon and not one that is specifically Christian. It is based upon the rationality of human nature and its capacity to be responsible for one's own decisions and choices. However, a vision of man that is exaggeratedly individualistic, with its consequent ethical relativism, has strongly called into question this assumption, placing the sphere of responsibility in a merely procedural context which only draws upon the so-called minimal 'procedures' which are of a nature that is more ritual than substantial, for example supplying information, obtaining consent, respecting privacy, etc. Given that this approach tends to exclude any 'rule' that comes from reality itself, in particular from human nature, it is inevitable – as we will see below – that serious difficulties emerge as regards practical action when the substantial goods of the human being are touched upon – for example life and moral lordship.

For that matter, we must bear in mind that a moral perspective is not something that is static and defined once and for all at the level of its smallest details. It is, instead, a project on a journey with man, at least as regards specific decisions which are located in human contexts that are constantly new. It is specifically the moral action of a medical doctor that is an example as regards the need for a continual refinement of professional ethics, in close connection with the scientific development of medicine and with a cultural sensibility that is in constant evolution. The answer to the ethical dilemmas raised by contemporary medical practice requires an assiduous search for what is authentically human and thus morally correct, since many problems that are raised today are at times completely new and constitute authentic moral 'challenges', above all when they are addressed in a secularised context that does not facilitate agreement about truth and good.

To ask oneself about Christian responsibility in a clinical context means asking oneself how the message of the Gospel can reach contemporary health-care contexts and how the message of salvation can be announced to those who suffer because of illness and those who work to alleviate the suffering of sick people. In other words, it means asking oneself about how suffering and service to suffering can be evangelised, so that, through the moral action of a believer, every suffering man manages to make his illness not an insuperable and senseless slope downwards but a place of encounter with Christ and his salvation. Faith in Jesus Christ, in fact, by investing every person also founds, together with human nature, the true identity of the Christian person and, on a par with human nature, is a source of rules for concrete action.

For the Christian, therefore, the first source of rules comes from 'humanity', that is to say that *primordial duty to act in a human way* which is natural law: it is, in fact, the wise gift of the Creator. The criteria for discerning good, for identifying values and rules that support a sense of responsibility are, for Christians as well, 'human' criteria, those values that are able to discover and apply practical reason. However, a moral heritage exists which is 'exclusive' to Christianity, in the sense that it becomes recognisable and concretely realisable only in the light of faith and grace. And this without a shadow of contradiction in relation to what is specifically human. The source of both, in fact, is the same: He who created man as a person who is free to choose and is responsible for what he has chosen, is He who calls man to faith. Faith in Christ expands and completes the horizon of the human. Indeed, its offers a single word for human action, which is always a word of salvation who those who practise it. The unconditional value of the life of a 'little one' afflicted by a congenital deficit or by a crippling illness constitutes an extreme example that a man who is not touched by grace might not be able to perceive, but which for a believer in Christ becomes a very precise responsibility and a privileged place of witness to his or her faith. The Christian identity, like human identity, becomes recognisable specifically through action. Moral action is therefore the ultimate test of faith itself.

Christianity has a specific moral-

ity because it possess its own specific anthropology, that of seeing in every man, on the one hand, the image of God and, on the other, a creature in a state of precariousness and in need of salvation, salvation that he or she can never reach on his own. Before being an inherent ethical specific, the Christian specific is an anthropological specific which offers contents on which Christian ethics are called to reflect, providing in this way a higher understanding of what makes human life worthy of being lived.

2. The Spheres of Christian Responsibility in Paediatric Medicine

We thus come to the heart of our subject: where does the Christian specific of responsibility in caring for sick children emerge? It should be said at the outset that in secularised society, as well, today a praiseworthy concern about the many needs of children has developed. An outstanding example of this is the Convention on the Rights of the Child[1] which was proclaimed by the United Nations in 1989. In this it is stated that on the basis of the dignity that is inherent in all the members of the human family, and of the equality and inalienable character of their rights, children have to receive the protection and the care that they need in order to integrally perform their role within society, and that because of a lack of physical and intellectual maturity they need special protection and care, both before and after birth. This Convention also states that pre-eminent attention must be paid to the welfare of children and that children must be assured the help and care that is required for that welfare (art. 3), as well as the right to have access to the best state of health possible and to benefit from medical services and rehabilitation services (art. 24). These rights of the child, which are universally recognised, have been widely applied in the sphere of health-care services that are offered to patients who are children, at least in industrialised countries.

For believers, in every hospital and care reality the Christian responsibility to engage in solidarity is present, that ethical and existential value that underlies taking care of the other, based upon the new commandment of love and on a recognition of the mutual dependence of individuals as constituting an intrinsic dimension of man which leads him to feel responsible for other people, coming to the help of his weakest and most needy neighbour. Solidarity is, first of all, a profoundly human and evangelical reality. However, it also becomes a professional duty for those engaged in social services, for example health-care workers. Professionalism in this case is not limited to the provision of a service at a technical and humanitarian level but also implies a personalised form of service which through an overall welcoming of the other constructs an authentically human relationship. In this sense, the value of Christian solidarity is distant from a contemporary interpretation that is rather widespread which identifies it with merely pietistic forms, moved for the most part by emotional impulses or by proclamations of principle that are rather abstract. Indeed, it requires a serious and not fleeting commitment designed to address concrete situations of need in a realistic way.

For Christians, solidarity has its foundations and model in God Himself, in His Trinitarian mystery and in His placing Himself in a relationship of solidarity with man to the point of leading him to communion with Himself. In this perspective, Christian professionalism, because it is rooted in communion with God, finds its highest form in *charitas*, in *agape*, in that love which is characterised by free-giving and self-giving.[2] *Charitas* rises above the requirements of justice[3] and commiseration in order to open up to a sharing that in itself can be limitless and reach the point of total self-giving. *Charitas*, therefore, is the fullness of any human relationship and the specific form of Christian solidarity. At a practical level, it takes concrete form in the overall welcoming of the other as expression of care for the human person and his unconditional dignity. In this case, a believer cannot but perceive a clash with the contemporary individualistic dynamics of the culture of the 'single' which increasingly tends to subjectivise needs, to close itself up in privatistic forms of behaviour.

An immediate conclusion derived from what has been said hitherto should be the following: responsibility both at a human and Christian level towards sick children 1) should be expressed in the defence of their lives specifically because they are threatened or disabled by illness, and in the actual recognition of the unconditional dignity of sick children even when they are gravely afflicted by deformity, by congenital handicap or by immaturity before or after birth; and 2) such responsibility should prevail over other duties such as those that derive from burdens for the family, for society, for the health system, etc.

The primacy of the person, whether he is healthy or sick, and thus of a child, whether healthy or sick, should be agreed upon by everyone, without hesitation and not only at the level of words; however this is encountering increasing difficulties in being recognised not only in the political economic and productive worlds etc. but also in the health-care professions. Here I would like to have a brief look at two situations which today seem to reflect an unexpected disappearance in terms of the perception of priorities in the world of health as regards childhood. I am referring, on the one hand, to the debates about the treatment of neonates born with spina bifida and the re-

suscitation of babies of very premature births, and, on the other, to the prevention of sterility in young people who have to undergo cancer treatment. Although in the first case it appears that responsibility is absent because of omission, in the second it appears that it wants to be extended in a not very reasonable way. In these alternatives it is always the child who runs the risk of suffering the consequences.

3. The Responsibility Deficit

When, unfortunately, a child is born with a grave lack of development or with a serious congenital defect, a medical doctor finds himself or herself faced with the unpleasant dilemma of deciding which action is clinically possible and reasonably suggested in order to the save the life of the child. Medical science is not all powerful and the neonatologist and the paediatrician find themselves much more often than they would lie to be in the situation of being unable to anything that is really useful. However, it is one thing to forgo attempts which in science and in conscience are held to be ineffective for a specific patient but it is another to impose limits on bases which are not clinical but utilitarian, excluding difficult or overly burdensome patients from access to forms of treatment provided by the health service.

In 2005 the Dutch Association of Paediatrics adopted the well-known Groningen Protocol which introduced into medical practice the deliberate termination of the lives of neonates who have spina bifida or other comparable anomalies. This protocol may be seen as the synthesis of a series of approaches which today are rather widespread as regards neonates who are affected by congenital anomalies and who have foreseeable future disabilities. According to this protocol, the decision to end the life of a neonate is a hypothesis which should be considered in relation to three categories of patients: 1) those who have no chance of surviving;[4] 2) neonates subject to a regime of intensive therapy who have an extremely pessimistic prognosis, above all as regards quality of life;[5] and 3) children who, even though they are not dependent on intensive care, have, in the view of their doctors and parents, a very much reduced quality of life, in addition to intense suffering. In these cases, indeed, doctors and parents could legitimately come to an agreed judgement that death would be a more human solution than going on living, with an authorisation of the termination of the life of the neonate.

The objections raised to this protocol are many in number and scientifically based. However, I will not here dwell upon them but will, instead, direct the reader to the specialised literature in the field.[6] But I would like to make one observation which might appear banal but it is clearly not so if it is the case that documents of this kind are produced.

The authors[7] of this protocol use an extremely direct terminology in referring to practices involving the termination of life. They have no reservation in recommending the active interruption of a human life, that is to say procured death. Nor is there any attempt to mask this policy by trying, for example, to locate it within the categories of no exaggerated treatment or the proportionality of treatment. This document thus reveal how even a moral awareness of doing wrong has disappeared, as a result of which there is not even a need to mask this wrong or attenuate it. It is simply declared because it is no longer seen as something that is bad.

A position that is not distant in terms of mentality from that of the Groningen Protocol is that which envisages the non-resuscitation of neonates who are gravely premature or who are of very low body weight. This is a position that was proposed in Italy in the Florence Charter but then rejected by the Italian Society of Neonatology. The recommendation not to engage in resuscitation in this case is motivated not so much by the low likelihood of the success of the resuscitation techniques but by the fear that the consequences of the premature birth will impede the child (and at times his or her family) from achieving a quality of life that is held to be satisfactory. In addition, there is no idea that offering a life expectancy constitutes precisely that act of doing good that makes up the first foundation of the ethical legitimacy of all forms of medical treatment. The offering of life expectancy should not be seen as a benefit of little importance and even less as an injury to the patient, and this leaving aside possible considerations about the future quality of life of that patient. Health is certainly an important value and a pre-condition for the carrying out of many human activities but it is not a pre-condition for the full achievement of the humanity of an individual, of what is commonly called 'happiness'. Happiness in a full sense is also possible in the presence of precarious health. It is clear, instead, that emphasising the untreatable pain or the possible future suffering of these neonates seems to constitute a mask behind which are concealed decisions that come from assessments of quality of life and which lead to new ideologies of discrimination.

In September 2006 the Chair of Neonatology of the Catholic University, together with the Institute of Bioethics, drew up and published guidelines to avoid possible exaggerated treatment in neonatology.[8] However, these recommendations explicitly exclude that the quality of life that is foreseeable for a neonate may constitute a criterion for the decision not to resuscitate the little patient.

4. An Excess of Responsibility

There is a responsibility in relation to child to introduce him or her to reality and to help him or her to construct his or personality and autonomy. This very delicate educational process involves both psychological and moral components and requires constant accompanying so that the child's temperament and character are forged in line with truth and in a way that is psychologically balanced. Illness and the dynamics of treatment can gravely threaten both these elements, above all in adolescents, who are in a crucial stage of their lives as regards the development of their moral conscience, their ability to move independently towards good, and to see good as binding. The need for a moral upbringing is today often ne-

glected or ignored, although it is rarely denied. In particular, one touches here upon the sphere of sexuality where adults, in front of an adolescent, often adopt an approach that oscillates between confidence and embarrassment, but which anyway is a kind of flight from responsibility. This is not the moment to dwell upon the forms or causes of this. I would here like to dwell only on a question that is rather specific to paediatrics and cancer.

It is well known that the unwanted effects of anti-blastic agents and of the radiation treatment which are used to combat many forms of tumour include, among other things, a temporary or permanent reduction in fertility. Some regimes of therapy are associated with a high risk of sperm dysfunction, even though the new systems of treatment, although the results have still to be tested, seem to be less toxic.[9] Whatever the case, a quota of patients (which varies according to the system of treatment that is employed), even though spermatogenesis returns, have even after many years a sperm quality that is at times severely compromised.

For this reason, the routine proposal of the obtaining of sperm is recommended, both in adults and in boys who have reached puberty. The protocol for the taking of sperm proposes the production of three to six ejaculations, each one about 48-96 hours after abstinence.[10] One study carried out in Germany[11] is said to demonstrate that adolescents of the age of fourteen are able to discuss the decision as to whether to conserve sperm and, except in the case of a few exceptions, they are able to masturbate in order to produce sperm samples. It has also been suggested in the case of boys who do not want or cannot engage in this practice that machines should be employed that are used in individuals who have spinal injuries – the strong vibrator or the rectal electric probe, instruments which, among other things, have to be used under anaesthetics in order to avoid pain to the patient

Well, in most of the scientific literature in the field, the only ethical questions and issues raised in relation to the obtaining of sperm relate to securing clear informed consent from the patient and his family and the limiting of the costs that the patient will have to meet for the procedures of sperm collection and cryopreservation. Some articles argue in favour of the inclusion in this informed consent of prior directives about the parents of the patient, in the case of the death of the patient himself, obtaining a grandchild through resort to surrogate motherhood.

The creation of a policy and the involvement of an ethical consultant to help families are also recommended, bearing in mind the important emotional aspects that are implied and the complexity of consent, above all as regards the future. However, as regards ethical questions connected with the modality of the obtaining of sperm, the real possibilities of it being used, the difficult problems raised by the procedures of assisted procreation, the banalisation of fatherhood, etc., the silence is devastating. At the most the possibility, which is not very rare, is observed that the parents may be more interested than the patient himself in obtaining the possibility of producing grandchildren, whereas the boy may still encounter difficulties in understanding if he really wishes to become a father.

It is rather evident that the adoption of such a 'procedure', which is strongly technical and deliberately amoral, can only with difficulty be in the interests of a child who is fighting between life and death. The responsibility of those who provide treatment and care should not be to place heavy responsibilities on those who receive such treatment and care. Indeed, the responsibility of the health-care worker is neither confined to an ethically adequate use of medical treatment nor extended beyond realistic, proportionate and already consolidated forms of treatment. It must attentively take into consideration the fundamental needs of the child as a person, in the peculiarity of his or her process of growth and development, and not least as a child of God, who is very loved, in his 'littleness', by our Heavenly Father.

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Notes

[1] This text continues on from many Charters and Declaration on the rights of children.

[2] Cf. BENEDICT XVI, *Deus caritas est,* 25-XII-2005.

[3] Justice and with it fairness require that there is first of all a recognition of the fundamental and inalienable rights of the individual which spring from his very human dignity.

[4] It is assumed that they will die shortly after birth despite the application of the systems that are available.

[5] For example, neonates with grave cerebral anomalies or extensive organ damage connected with extreme hypoxemia.

[6] In particular the following work deserves to receive a great deal of attention: DE JONG H.T., 'Deliberate termination of life of newborns with spina bifida, a critical reappraisal', *Childs Nerv. Syst.* 2008 Jan; 24 (1): 13-28.

[7] VERHAGEN E. AND SAUER P.J.J., 'The Groningen Protocol - euthanasia in severely ill newborns', *New Engl. J. Med.* 2005; 352: 959-962.

[8] The title of this document is 'Proposta di Linee-guida per l'astensione dall'accanimento terapeutico nella pratica neonatologica' ('Proposed Guidelines for Abstaining from Exaggerated Therapy in Neonatalogical Practice'.

[9] TROTTMANN M., BECKER A.J., AND STADLER T.H., *ET AL.*, 'Semen quality in men with malignant diseases before and after therapy and the role of cryopreservation', *European Urology* 2007; 52: 355-67.

[10] SCHOVER L.R., AGARWAL A., AND THOMAS A.J., 'Cryopreservation of gametes in young patients with cancer', *J. Pediatric Hematology/Oncology* 1998; 20 (5): 426-28.

[11] KLIESCH S., BEHERE H.M., JURGENS H., *et al.*, 'Cryopreservation of semen from adolescents with malignancies', *Med. Pediatr Oncol* 1996: 26: 20-7.

8. Inter-Religious Dialogue

ABRAMO ALBERTO PIATTELLI

8.1 Judaism

During the reciting of passages from the *Shema*, the profession of faith that takes place twice a day for a Jew who is faithful to his or her tradition, a phrase from the Pentateuch is repeated: 'and you shall teach them diligently to your children, and shall talk of them when you sit in your house, and when you walk by the way, and when you lie down, and when you rise' (Deut 6:7). It is undoubted that that this text refers to young children, those, that is to say, who have not yet reached the age of thirteen and who, as a result, are subject to the defence and protection of their own families. These families have the obligation to bring up their children in, and to transmit to them, the values of tradition.

This text refers to the special care and concern that should be shown towards minors, to their physical and moral health. According to the Talmud, amongst the duties of parents, in addition to that of upbringing, there are those of inserting them into the world of the professions and leading them to marriage. There is even the obligation to teach them to swim. By this rather picturesque image, the intention is to emphasise the need to provide minors not only with the instruments that will guarantee their survival but also to assure that they have the means by which to defend their lives and their physical health.

One thing is anyway clear: the relationship between an adult and a minor must not be taken lightly or in a not very responsible way. All of this also comes from another consideration. In the Jewish tradition, and the Jewish Biblical tradition in particular, sons and daughters, and children in particular, represent something that is dear and valuable because they are deeply wanted in that they are an evident sign of the blessing and intervention of divine Providence. Biblical Scripture, through the words *vachai baem* (Ex 18:5), that is to say 'so that He may live in them' (through observance of the precepts and laws of the Torah) or 'so that He may live amongst them' (amongst the society of individuals) draws attention to a very important principle. Life is a supreme value that must be defended above all other objectives. But this instruction applies both to individual adults and to minors who are not yet under the obligation of respect and observe the Torah. I would like to give an example of this. Jewish tradition envisages that a male child on the eighth day after his birth should be subjected to the circumcision of his foreskin as a sign of his entrance into the covenant of Abraham. In this case a slight illness in the child is sufficient for this ceremony to be put off until his complete recovery. All of this is because the Eternal God of life wants individuals to have life and the Torah is an instrument for the life and the moral progress of men.

In Rabbinic literature expressed in the Talmud a principle is repeated according to which a minor is not responsible to the law because he or she does not possess intellectual maturity. At the same time it is established that if someone causes injury to a minor that person must answer to the law because Scripture lays down 'He who kills a man shall be put to death' (lit. *Nefesh*, soul) (Lev 24:17), whatever the age of the person involved. It is possible to read these words from the point of view of medical intervention: every intervention must be careful and precise.

When we engage in a brief historical survey through Biblical sources and those of the Talmud, we realise how there are relatively few cases concerning illnesses and accidents where children are involved. Of interest is the case of the grandson of King Saul. The Biblical text informs us that Gionata, the son of Saul, had a son called Mephibosheth who at the age of five limped with both legs after his nurse, who was fleeing after the defeat of the king, had dropped him from a wall. Mephibosheth did not have a particular political role during the reign of David. However, Scripture teaches us how a handicap should not be kept quiet about or hidden and also that it should not become a reason for marginalisation and segregation. On the contrary: it should be the subject of care and concern on the part of society.

Another two cases relate to the action of the Prophet Elijah and his disciple Elisha. In both episodes

children are involved who no longer breathe and are even lifeless but are then brought back to life by these two famous figures. According to Rabbinical exegesis, this is a case of *haskarà*, an illness of children which involves the inflammation of the throat and the risk of suffocation. According to others, it is a form of measles which involves a high temperature. It should be observed that during the rites against drought described by the *Mishnà*, people implore 'that the *hashkarà* may not fall upon children'. Prayer, in this case for the health of children, is an important element in the Jewish tradition.

Care for children is a pre-eminent task of the family. But society, too, must play its part through the development of paediatric medicine and the care that is due to the special needs of minors in terms of their development, nutrition and infectious diseases. This applies above all to today when unfortunately the tendency is to marginalise the weak, the defenceless, that is to say those whose contribution is held to be insufficient as regards the economic and social requirements of the population.

Another consideration leads me to observe how the physical, emotional and spiritual needs of children are different from those of adults. On need only think here of how the simple nutrition of children changes according to their various levels of age, development, education and conditions of health. This applies even more to any medical/health-care approach that one has towards minors.

The ethical-medical problems concerning children relate above all to the fact that any decision that concerns them is taken by others people, whether one is dealing with parents, tutors or even tribunals. The pre-supposition of this is that minors are not able to take decisions for themselves and thus a paternalistic replacement has to take decisions for them. In my view the foundation of this power to take decisions must be nothing else but the best interests of the minor, a principal that must guide any medical approach. In this field there are inevitably ethical situations of extreme delicacy. For example the point to which it is allowed to conceal the truth from a patient or the consent of the sick person, the privacy of the patient, the terminally-ill patient, the donation of organs, and so forth. It is obvious that in some cases the action of a paediatrician must be accompanied by the opinion of special health-care workers such as psychologists or by the opinion of a rabbi as a man of religion.

Experimentation on minors requires a separate analysis. We all realise how it is not possible to obtain positive results in the field of paediatrics in general, in the case of a new medicine or a new pharmaceutical, without engaging in experimentation on children. The physical and mental damage that can be caused to a minor in this can be enormous and irreversible. However, we cannot have their assent or consent. We thus realise how great is the responsibility of both medical doctors and those who carry out such experimentations. It is said that who he who saves a life of an individual saves the life of the whole world. But how much more does this principle apply to the life of a child, to his or her life in *fieri* which contains who knows how many positive prospects!

In recent times within the Jewish community, and above all in its health-care institutions, there has emerged an orientation to involve minors as much as possible in a conscious decision, where, that is, their age and maturity allow this. No difference must exist between a minor and an adult as regards the protection of health and the right to health. The same applies to the right to accede to health-care agencies and to care, the right to the alleviation of pain and suffering, and the allocation for them of economic resources and instruments for action.

I have tried briefly to sum up the approach of the Jewish tradition as regards illness in children and their sacrosanct rights. I will end this paper by calling to mind that the term used by the Jewish language to refer to a minor is *ben* which literally means 'son', just as I recalled at the beginning of my paper the Biblical words 'and you shall teach them diligently to your children'. Well, the word *ben* is connected with the verb *banà* which means 'to build'. Children, minors, are a synonym for builders, those, that is to say, those in whom we repose our hopes and our future, and thus those who deserve our protection, our care, and our attention.

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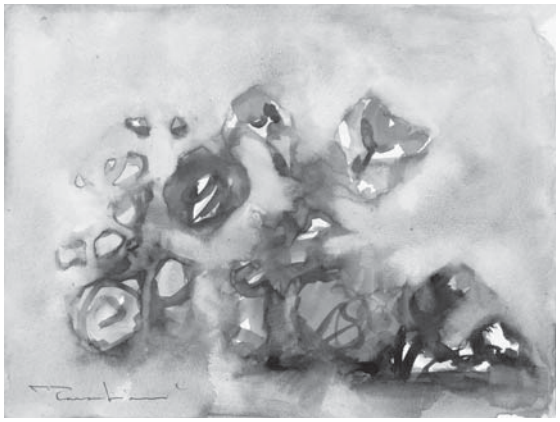

REDWAN ABDALLAH

8.2. The Islamic Point of View

In the name of God the Merciful.

May God Bless the Prophet Mohammed and the Prophets Moses and Jesus and all His Prophets and Messengers, and may Peace be upon you!

Your Eminences, Excellencies, Ladies and Gentlemen, I greet you with the greeting of Islam, *as-salam alaykum*, may peace be upon you!

I am especially honoured to take part, as a representative of the Islamic Cultural Centre of Italy, which has the largest mosque in Europe, in this twenty-first international conference organised by this Pontificium Consilium Pro Pastoralis Valetudinis Cura. The subject of this conference, chosen by His Holiness Pope Benedict XVI, is 'pastoral care in the treatment of sick children', and it is a subject of great importance and great emotional impact, and the choice of the Holy Father is a choice of great wisdom. Children in general, and in an especial way sick children, deserve our care, our affection and our love.

Today, at this august assembly, representatives of the academic and scientific world, medical doctors and distinguished clinicians, exponents of politics, representatives of civil society, religious, families and volunteers have come together. All of those who have gathered here have only one concern – to reflect together, each according to their expertise and their beliefs, in order to help sick children.

Islam, like all other religions, is called to make its own contribution to alleviating the suffering of sick children. The action and contribution of religions should not be interpreted as being alternative to medical treatment or to the role of the family. Every action and every role complements every other action and role. Cooperation between medical doctor, families and volunteers, together with the support of religion, can have extraordinary results. You will certainly have noticed that I spoke about the support of religion and not of religious. In the hospital tradition of Muslim countries one can not find religious, whether volunteers or employees at a place of work, who work by accompanying patients on their journey of suffering. This absolutely does not mean that religion is absent; indeed the contrary is the case. Faith is constantly present because it is spread throughout the whole social fabric. It has a way of expressing itself through medical doctors, family relatives and the sick themselves.

Such a permanent presence of faith is expressed in the very words of the people that we meet in hospitals and we see gather around the sick. I am thinking here of phrases such as 'we are in the hands of God', 'this is the will of God', or 'let us call upon the mercy of God'. I remember the words used in private to me by a Moroccan surgeon as he was going out of his ward: 'I have done what I had to do. The rest will be done by God'.

In common parlance, the permanent presence of God in the face of illnesses in a striking way translates the role of faith and its value into the dual role of refuge and protection in the face of the devastating and destructive effects of illness. We invoke the mercy of God so that He may come to the aid of all His creatures, and in a special way of those who are in situations of extreme frailty. This frailty has an even more sensitive cloak when one is dealing with an innocent child who has been attacked by malady. Suffering is a human trauma and laceration which upsets existence but it can at the same time become a profound human experience which helps us to understand the meaning of life and its value, and above all it can become an opportunity to draw near to God, or to draw near to Him once again. Learning to 'suffer with dignity', seeing illness as an expression of

the will of God, is the basis of this drawing near to God because pain and illness, like life and death, are a part of human existence, which is sustained and governed by divine laws. Suffering must be combated and faith in God, to whom life belongs, helps us to bear its effects. The help that comes from medicine and the world of health care is an obligation: it is necessary and incumbent upon us to have resort to all licit meansand to take advantage from medical science and the techniques which are available to us today to combat illness, praying to God to alleviate the suffering of

our children, enabling them and allowing them to rediscover smiling and the joy of living.

Coming from the south shores of the Mediterranean, that is to say from Africa, I cannot but end my paper by turning my thoughts to the million of children who suffer not only because of illness but also because of hunger and thirst, because they are the victims of illiteracy and the lack of all forms of health care. Children who suffer because they undergo the most horrible forms of exploitation. Only a true chain of solidarity, at a planetary level, can save them. This will not be an impossible mission if each one of us feels humanly involved and shoulders responsibilities. And it is above all the powerful of the world who must play their part. If within the space of a few days the powerful of the world disbursed more than a thousand milliard euros to save the banks, could not a similar gesture be carried out to save that part of the world that suffers.

Dr. REDWAN ABDALLAH,
General Secretary,
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Rome.

KEZEVINO ARAM

8.3 Care of the Sick Child: a Practitioner's Perspective from the Field

Respected moderator and fellow health practitioners, thank you for inviting me to be part of the inter-religious panel that is collectively looking at the burden of the sick child. Experiences of mortality and morbidity still affect disproportionate numbers of children worldwide. In the present global (social, economic and political) scenario, such a situation puts us all to shame. The resources we have today can surely make a healthy life for all children a possibility. Glimpses of such models are present, few in number and skewed in their concentration in developed countries.

The leadership of the Pontifical Council for health is therefore, significant in this context, because the Council along with its constituents serves a significant section of the global community, particularly the most vulnerable. As a child health practitioner myself, I value this space for constructive debate and cooperation, and, as a person of faith, this opportunity to live faith through collective action!

Children's Day in India

However, let me first bring to you special greetings for children's day in India today. I begin my presentation with an anecdote and one that I have incorporated in my writings before: "It's Children's Day again", said 11-year-old Asha to me. Seeing her enthusiasm, I asked her what she would like to do on a day that is dedicated to her…to millions like her! She smiled and without hesitation replied, "I want to do something that will make me happy!" Walking away from this conversation I told myself what a privilege it is to serve these amazing children through the many child health initiatives we have a chance to be part of.[1]

Living this privilege with hope is however a continuous struggle for most health workers: societal practices, hospital centered-medical education, structural gaps in programming, misallocated resources, ill-informed policy, frustrated colleagues and most of all uncounted, invisible, and vulnerable children, challenge us everyday and in many ways.

It is for these very reasons and others that I feel we need to think together and explore the possibility of working together!

Why the Need to Focus on Care for Sick Children?

The continuing burden of poverty, deprivation and ill health amongst children is a shared concern. Childhood is rightly described as a unique experience, influenced by two important processes – growth and development.[2] A sound body and mind is what every child aspires for, so does his family, and indeed every individual who values the 'gift of a child'.[3] It is therefore, not only logical but also ethical to collaborate beyond our traditional and comfortable spaces for a cause and a challenge that is universal in its presentation.

Children also provide a sensitive viewing of societal functioning. It is in this context that I take statistics and experience from my own country regarding mortality and morbidity. Of a billion people in India, children constitute about one-third of the population. The start to life for the majority of our children is compromised with only 30% of the children having an adequate birth weight. Morbidity resulting from disease and deprivation is reflected in many ways. For example, only 64% of children have been covered

with vitamin A supplementation, 33% with adequate sanitation facilities and 59% with immunization against measles. Each of these data reflects the gaps in health services – preventive, promotional and curative.

The sick child is not only vulnerable because of his/her illness, but is also risks being tapped in the vicious cycle of malnutrition, disease and poverty. My Professor of Pediatrics often says: "A child cannot wait. Her needs of today are as urgent as the needs experienced in an emergency. Delayed health interventions are deprived rights for children!" Morbidity and mortality still take away the precious lives of children.

India reported a maternal mortality ratio of 300 and a lifetime risk of maternal death as one in 70[4]. The mortality experience of the mother is a proxy of the mortality experience of the child, both interconnected and unique at the same time. Care for the sick child can be built on the three pillars that affect health-promoting initiatives, which have been identified, namely, knowledge enhancement, attitudinal change and informed practice. This, however simple it may seem at first glance, is an essential requirement, both for health care providers as well as for the millions of children, men and women who access and utilize health-care services.

The GNI (Gross National Income) per capita for India in 2006 stood at $US 820. If one disaggregates the use of this per capita income, the pie is very poorly divided demographically for children and as a sector for health. While the sick child has immediate needs as regards restoration of health, the complex interplay of situations and needs must also be understood. Restoring rights, responsibilities, dignity and quality of life (and every child deserves this!) is an essential part of promoting children's health. Listening to and working with children is something we must strive to incorporate into our thinking and practice as we wish to make a difference in the lives of our children. Child participation is to be actively sought if we want to help enhance children's innate ability to make positive contributions to society.[5]

Life expectancy in India doubled over six decades from 32 to 64 between 1947 and 2007. Yet, in this day of modern technology and connectivity, only 41% of births are registered.

A majority goes unregistered…..unrecognized…invisible and often very sick.

Arokiyam or Wellbeing: the Hindu Perspective[6]

Margas: Paths to the divine

Innumerable paths to the divine have been developed by Hindu sages and yogis, but they are generally divided into four major paths:

Raja yoga – the royal path of meditation

Karma yoga, the path of selfless service,

Bhakti yoga, the path of devotion,

Gnana yoga – the path inquiring reflection.

The acknowledgement of diversity in paths in the pursuit of the divine as well as the intrinsic worth of each one of them can be expanded to understand the concept of empowerment and care for the sick child. If one considers the above yoga's as *margas* (paths) then empowerment in its very essence is composite: knowledge, commitment, action and reflection all finding their place.

The promotion of children's health also requires the dynamic coming together of people and institutions who have expertise in pursuing any one of the above margas. Because of the compositeness of the pursuit for human self-realization, an argument can also be made for the broadening of conversations and partnerships beyond the immediate sphere of religion and spirituality to civil society and ethical obligations in caring for the sick child.

Religion, Spirituality and Social Causes

'The hallmark of spirituality', says Swami Agnivesh, 'is responsiveness to the given context'. He goes on to say 'This is what distinguishes spirituality from religion in its common practice. In fact, religion in itself is meant to be a source of empowerment for human beings in their effect to make sense of and cope with their worldly life'.

The relationship between the individual and the divine is discussed extensively by Swami Agnivesh. He says, first, that every individual needs to relate to the divine and live by the discipline that goes with it. Secondly, there is a need to understand oneself, where questions such as who are we, what is the meaning and purpose of life, what is the scope of human destiny and what are the means for human fulfillment? etc., become important. Thirdly, we need to relate wholesomely to the given social context where the dynamics of living together with others assumes profound spiritual significance. It is in this context that the dynamism of our spirituality finds practical expressions.

The spiritually enlightened person cannot remain indifferent to the problems and suffering of others. Justice becomes the most authentic expression of spirituality in the social context. This entails a sense of responsibility for the kind of society we create and the human predicament that prevails in it. Fourthly, every human being needs to maintain a healthy relationship with the material world, the order of creation all around him. He needs to practice justice in the way he relates

to the total order of creation, taking care of the world around him, respecting the integrity of creation as an important aspect of our human vocation. When this is forgotten and creation is exploited in violation of its sanctity and sustainability, we precipitate crisis.

Hindu leaders, including Swami Vivekananda and Mahatma Gandhi, while representing humanity also led their own communities to introspect on the situation of their marginalized brothers and sisters. Mahatma Gandhi's call for *Poorna Swaraj* or total freedom included both internal and external dimensions. Freedom from prejudice and discrimination was as much discussed as political and economic freedom. Thus, powerful interpreters of the tradition have influenced Hindu thinking. These leaders have also led their own communities to transformation and integration.

Interfaith Dialogue as a Building Block to the Promotion of Health

We must not however, forget that we have come a long way in the promotion of children's health…we need to celebrate our *shramadan* (the gift of our labour!), our scientific discoveries, our achievements in children's health and most importantly the individuals and institutions we have created in health promotion especially for the sick child….who are present in many homes, communities and nations. This to me is the privilege we have in being child health practitioners.

We can continue to take action together: Religious beliefs differ. Nevertheless, in every village and in every continent in the world, most religious believers share some very basic moral convictions... the dignity of human life, the right to live free from oppression, poverty and disease, and the importance of caring for our earth. These shared moral beliefs provide a foundation for action. No time has ever been more urgent for multi-religious cooperation. Principled cooperation can respectfully align the deep reservoirs of faith inspired common action.[7] As Vice Moderator of Religions for Peace, I appeal to you to explore this valuable instrument of inter-religious dialogue and cooperation. Building healthy communities can also be a valuable way of ensuring peace and justice.

At home for us it has been a meaningful opportunity to work with the Health Commission of the Catholic Bishops' Conference of India (CBCI). It is estimated that nearly 10 per cent of India's health care services is provided by CBCI. It is not just the share of work that is recognized by all but also the commitment, quality and reach that accompanies it. While continuing to serve the vulnerable communities across the country, they have also been pioneers in addressing newer challenges like HIV/AIDS and mental health problems. I consider this collaboration in my country a concrete expression of inter-religious dialogue and a partnership which is bound to grow over the years.

The search for self-realization, the struggle for progress and inclusive growth of a society based on values is a valuable part of the Hindu perspective on human development. Mahatma Gandhi said: 'Faith does not admit of telling. It has to be lived... May we continue to live this blessing together!'

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Notes

[1] Children's Day: A Reminder / Reflections / Kezevino Aram

[2] **Growth** in Pediatrics refers to physical growth and **developmen**t to the maturation process

[3] '**India's Children :** Is reversing the vicious cycle of Deprivation, Stigmatization and Disengagement a Possibility?'

Paper contributed by Dr.Kezevino Aram to the special NCRI Commemorative Volume to mark the Birth Anniversary of Mahatma Gandhi

[4] Unicef Country statistics: INDIA

[5] Excerpts from the South Asia Interfaith Ethics Education Workshop report

[6] Excerpts from Legal Empowerment to Societal Transformation: The Hindu Perspective/ Swami Agnivesh and Dr.Kezevino Aram

[7] *We Can Cooperate For Peace / Religions for Peace*

CHEN, KAI-YU

8.4 Spiritual Care of Sick Children from the Buddhist Perspective

1. The Fundamental Faith of Buddhism

According to the *Avatamsaka Sutra,* immediately after he had attained Great Enlightenment under the bodhi tree, the Buddha exclaimed that all sentient beings are endowed with Buddha Nature, i.e., the potentiality, inherent in all living beings, to achieve Buddhahood. However, owing to their ignorance, attachment, delusion and defilement, sentient beings are entangled in *samsara,* the cycle of life-and-death. Once they awake and realize this ultimate truth, they can be disentangled and liberated from *samsara.*

2. The Essence of Buddha's Teachings

The essence of Buddha's teachings lies in the Four Noble Truths which he expounded in his very first sermon after attaining Great Enlightenment. As a matter of fact, the doctrine of the Four Noble Truths is tantamount to the diagnosis and cure of sufferings and illness in human life. This is why Sakyamuni Buddha has also been known as the Great Physician (or the Great King of Medicine), and Buddhism can be regarded as a religion of medical care: Buddha as the physician, the *Dharma* (teachings) as medicine, and the *Sangha* (order) as nurses, which amount to the Three Gems in Buddhism. In contrast to ordinary medical science, Buddhism is mainly concerned with the cure of mental or psychological illness, which is responsible for many physical diseases.

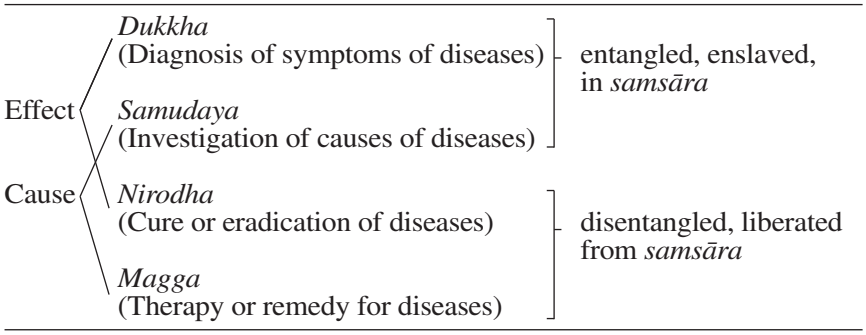
The Four Noble Truths can concisely be formulated as follows:

1. All existence is suffering (*dukka).*
2. The true causes and origination of sufferings have been discovered (*samudaya).*
3. The cessation and eradication of all sufferings is possible (*nirodha).*
4. The Way leading to the cessation and eradication of all sufferings is eightfold[1] *(magga).*

Regarded in the light of the metaphor of the Great Physician, the Four Noble Truths can be further elucidated thus:

1. The first truth of suffering specifies the disease and it admonishes us to face the situation of human suffering as the ultimate concern.
2. The second truth of the origination shows the cause of the disease and it guides us to explore the cause of suffering as ultimate truth or reality.
3. The third truth of cessation encourages us to aim at the eradication of suffering as the ultimate goal.
4. The fourth truth of the Way is the medicine that cures, and it inspires us to practise the Way leading to the eradication of suffering as the ultimate commitment.

There is an intra-relationship within the Four Noble Truths, illustrated as follows:



3. The Causes and Therapies of Diseases

According to Buddhist scriptures, the causes or origins of human illnesses are generally placed into six diagnostic categories: (1) disorder of the four physical elements (i.e., earth, water, fire, and air) triggered by overworking or over-action; (2) insalubrious or poisoned foods or drinks; (3) improper sitting meditation; (4) caused by spirits or ghosts; (5) caused by Mara or devils; and (6) previous karma.

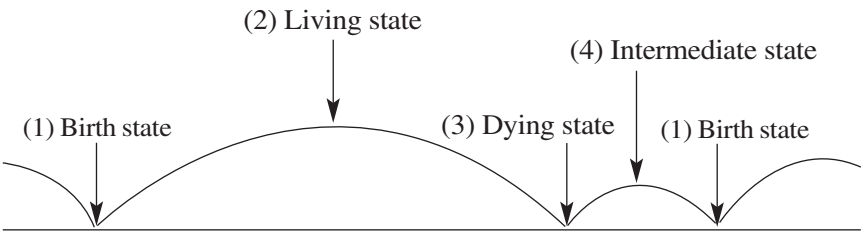
If the illness is caused by overly physical action or work, insalubrious foods or drinks, it can be cured by taking medication. If the disease is caused by improper sitting meditation, taking medication will not be helpful. Instead, one has to correct one's posture and breathing during sitting meditation. If the illness is caused by spirits, ghosts or devils, it can be cured only by the power of deep contemplation and great mantra. If the illness is the result of one's previous karma, its cure can only rely on the power of inward contemplation and outward repentance. Because of the variety of illnesses, there are different therapies and cures. We should pay close attention to their distinction. Otherwise, it would be like holding a knife and hurting oneself.

From the Buddhist perspective, human illnesses can be divided into two main categories: physical and mental disorders. The former is easier to cure whereas the latter is more difficult to deal with. As with the physical illnesses, food and drink are regarded as effective medicine. Herbal medicine is applied only when food and drink are consumed improperly. Very often, the discontinuation of unhealthy behaviour or habits and the cultivation of good ones may cure the illness without any application of medicine. As with mental illnesses, the prescription of medicine is not enough and may not be helpful; the practices of regulating breathing, concentration, insight meditation, contemplation, and so on are essential and much more effective. In Buddhist medical science, an imbalanced or unwholesome mind is considered as the main cause of all illnesses. A wholesome mind is the recipe for physical and mental health. The practice of Buddha dharma is as important as health insurance and medical care.

4. Life-and-Death Views from the Buddhist Perspective

Among human sufferings, fatal diseases, terminal illnesses and death may be the most horrible ending of life for most people. Nevertheless, all religions believe in life after death, i.e., rebirth, Buddhism and Hinduism explicitly, Christianity and Islam implicitly. Without the idea of rebirth, all religious striving, moral restraint, mental purification, responsibility, justice, and so on would be meaningless. This life is considered by all religions as a preparation for a future life – as a school of learning in which to quality for higher understanding and celestial bliss. However varied the many concepts of rebirth may be, it can be thought of only in terms of continuity. Whatever the shades of opinion in this regard may be, it contains essentially a preoccupation with death as a portal to a new life. While still living in the present, the mind is thus preoccupied with a life yet to come.

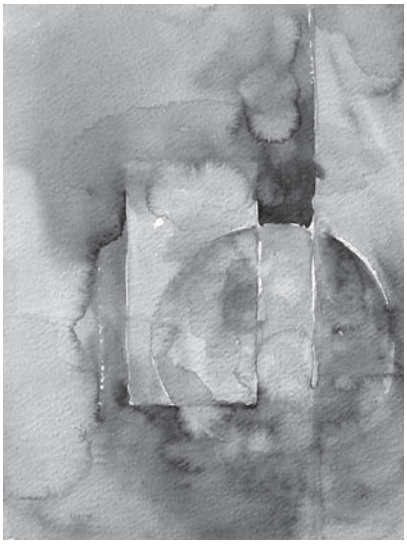
From Buddhist point of view, the existence of all sentient beings in the *samsara* world is an ongoing process of the life-and-death cycle, and can be subdivided into an endless flow of four states of existence as follows: (1) Birth state of existence; (2) Living state of existence; (3) Dying state of existence; (4) Intermediate state of existence.



5. The Spiritual Care of Sick and Terminally ill Children

As discussed above, while our body and mind may be the cause and origin of many illnesses, they also possess the power to cure. It is like the two sides of a coin. We even have the potential to attain Buddhahood, even to lead a healthy life and cure illnesses if we follow the right Way. In contrast to adults, children are more vulnerable to many childhood maladies and certain diseases or infections, but are more revivable at the same time.

The essence of the spiritual care for sick children lies not only in the therapeutic aspect of medical care, but in the awakening of the patient's healing power within. Even when an illness is incurable, if we can help the patients to get a deep understanding of the true reality of life and death, to realize the meaning of their own life, be it long or short, they will certainly feel that it is worthwhile to live with gratitude. They will feel more confident about loving without hatred, experiencing the vicissitude of life, fulfilling their own task in life, and lastly to dying with peace, dignity and no regret or sorrow.



If a illness is curable, besides proper medical care we can help and guide sick children to realize their potential Buddha nature, to practice regulating their breathing, concentration, and insight meditation, to cultivate compassion and wisdom, and therefore enhance the self power of self-healing.

If the illness is incurable, in addition to the above mentioned, we can share the sick child's experience, sad or happy, sorrow and fear, dream and hope. We can help terminally-ill children to understand that the quality of life is much more important than the quantity of life and to realize that dying is a birth into a brand new life ahead. We can accompany these children in accomplishing their last journey, in finishing their 'unfinished business', and prepare them to welcome the forthcoming life. They can choose to return to this world to continuously practise the Way of Bodhisattva, or to go the Pureland of Amitabha Buddha to pursue the higher learning of the Dharma.

From the Buddhist view of life-and-death, 'death' does not really exist, it is only a turning point of transition to the next life. In this light, 'death' itself is not the real problem. Instead, 'how to die with dignity', 'where do we choose to be reborn' and 'how to prepare for the next life' are the real issues of human life.

Generally speaking, children are

more self-aware of and acceptable to life-and-death issues than adults, especially terminally-ill children. Adults may often doubt: Are children with incurable illnesses precocious? Or they just do not understand what death is and thus they can easily face it. Suffering is the identical twin of growth. Death is a kind of 'experience' rather than 'knowledge'. Children may not understand less about death, adults may not understand more about death. However, adults may not have more life-and-death experience than children; on the other hand, adults and the aged are preoccupied with too many taboos, superstitions and misunderstanding about death: they can not even truly understand death. Therefore, the opinion that 'children just do not understand death' is a blind spot and a prejudice of adults. As a mater of fact, many terminally-ill children, out of their personal experience with life-and-death issues, have a direct indescribable realization about death; therefore, they can face it calmly.

We should not underestimate the ability and potential of sick children to understand and cope with illnesses and even death. Terminally-ill children are more in tune with their 'total' life, and have awareness of their existence after death and full awareness of a continuation of life. They have a special kind of inner knowledge about death and use a special kind of symbolic language to express it. We have to understand that this is a kind of pre-conscious awareness and not conscious, intellectual knowledge. It comes from their inner, spiritual, intuitive dimension of existence and naturally prepares children to face the forthcoming journey of transition, which is very often denied or escaped by adults.

To end, the belief in life after death, or more precisely life after life, provides more than answers – it offers endless hope for all terminally-ill patients.

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Note

[1] The Buddha specified the Eightfold Noble Ways: Right View, Right Thought, Right Speech, Right Livelihood, Right Action, Right Effort, Right Mindfulness, and Right Concentration.

JÁN ĎAČOK

8.5 Pastoral Care in the Treatment of Sick Children: the Point of View of Post-modernity

Introduction

At the international conferences organised by the pontifical Council for Health Care Workers in the years 2004, 2005, 2006 and 2007 I had an opportunity to refer to the principal characteristics of post-modernity. Here I will confine myself only to certain complementary aspects of this phenomenon which will help us to have a better understanding of the relationship between post-modernity and care for sick children.

As I have emphasised elsewhere, post-modern man feels fear when faced with unknown situations, and in particolar suffering, pain, old age and death. Faced with pressures of this kind, he tries to flee towards 'better solutions' – suicide, assisted suicide and euthanasia. I will attempt to present the post-modern stance in relation to care for sick children in particular through the vision of Peter singer (1946) an Australian philosopher, and in part also through the work of Hugo Tristram Engelhardt, Jr. (1941), an American philosopher of German origins. These two authors are seen as the principal representatives of post-modern bioethics.

Singer emphasises the need for 'new ethics' with his 'five new commandments' or 'radical five commandments' because Christian ethics cannot meet his requirements as regards daily life. He formulates 'new ethics' in 'his' own way – radical, autonomous, different at any price, provocative, cynical and inhuman. In his moral approach to human life and death Singer proposes 'new commandments' which are clearly opposed to the 'ancient' commandments.(1) This approach is said to express his 'rethinking' of Christian ethics and his 'rewriting' of a new ethical perspective.

1.

'The First Ancient Commandment: Treat All Human Lives as Being of Equal Value'

In Singer's view medical practice and daily experience create difficulties as regards the belief in the equality of human lives. Singer accuses ethicists, some medical doctors and the official representatives of traditional morality of 'rhetoric' and recommends a new solution for

certain situations (gravely malformed children adults and old people in a permanent vegetative state or people in an advanced state of Alzheimer's disease) where sick people have lost awareness and with great likelihood will not be able to reaquire that awareness.

'The first new commandment: recognize that the value of human life varies'

At the centre of this commandment is consciousness because 'a life without consciousness does not have any value'. In addition to consciousness there are also other characteristics that have to be assessed: ability to engage in mental, physical and social interaction with other individuals, the probability of consciousness in the future, membership of a family or group, behaviour by the members of a family or group, etc. The ideological and radical position of Singer is expressed in the justification for the first new commandment: 'without consciousness none of these characteristics can exist'. Moral behaviour and decisions in relation to these sick people are addressed only from a utilitarian position: the opinion of families, the wishes of individuals expressed in the past, the limitations of medical resources, the opportunities for an organ transplant, etc.

2.

'*The Second Ancient Commandment: Never Intentionally Suppress an Innocent Human life'*

Singer recommends a rejection of this commandment because it does allow solutions to various and complicated situations. He employs a dual argument: 1. in the past many women died during childbirth when the head of the baby became stuck. In his opinion, the only way by which one could save the woman was by what was called *craniotomy* or the crushing of the head of the baby and its consequent death. This policy was understood as the ultimate step but without it both the mother and the baby died. 2. The decisions of some judicial institutions have approved the intentional ending of innocent lives (for example the cases of Tony Bland and Lillian Boyes in Great Britain). Both these sick people had arrived at a stage when 'life can be of no benefit to those of live it' and thus 'it is better to resort to active means to suppress an innocent human life'. The principle of the sacrednesss of life, therefore, is no longer respected and with this the 'second ancient commandment' also deserves to be rejected.

'The second new commandment: accept responsibility for the consequences of your actions'

This commandment invites us to reflect more on the correctness of the decision to end the life of a sick person than on how to do this, both through the suspension of alimentation and through a lethal injection. In other words, it does not matter how a life is ended but whether the decision to do this is just. The future of a society can be connected only to prohibition on murder. But it is not necessary fpr individuals to save their fellows who are in a state of urgency. And from this Singer comes to the following statement: 'people who are ready to kill are normally more frightening than those who are ready to allow people to die. In daily life, therefore, there are good reasons for forbidding murder more rigorously than the act of allowing to die'.

3.

'The Third Ancient Commandment: Never Take Away Life and Always Try to Avoid Others Doing This'

Throughout the history of Christianity suicide has been rejected as an attack on one's own life and attempted suicide has been seen as a crime and thus prohibited. The promotion of the morality and defence of life was a public requirement of individual States. Under the influence of John Stuart Mill, however, the position spread that a State can act against the will of a citizen only in order to prohibit him or her from doing injury to other people. The State cannot intervene when one is dealing with the both moral and physical wellbeing of a citizen. If this principle is applied to people who are gravely ill and want to be helped to die, they do not cause injury to anybody and the State has no sufficient justification for intervening.

'The third new commandment: respect the wish of people to live or die'

At the centre of this commandment is the definition of the person by John Locke which Singer adopts as his own. Only a person can express the will to live, project his or her future, and understand its meaning. And here once again we encounter the radical apporoach of the author of the 'five new commandments': 'it is one thing to take away the life of a person against his or her will and another to take away life from an individual who is not a person…For all these reasons, to kill a person against his or her will is much more grave than killing an individual who is not a person. If we want to express this in terms of rights, it is reasonable to say that a right to life exists only for persons'.

4.

'The Fourth Ancient Commandment: Grow and Multiply'

For the ancient Jews and Christians a large number of children and numerous families were understood as signs of the blessing of God. But down the centuries the world population has undergone an extraordinary increase. According to this author, we have arrived at such a point that 'it is immoral to encourage an increase in births. This, indeed, could reduce both the possibility of the development of poor countries and cause grave harm to our planet. And this requires a reformulation of the 'fourth commandment'.

'The fourth new commandment: bring children into the world only if they are wanted'

For Singer, to destroy an embryo in a laboratory is morally mistaken because it could potentially become a person. The potentiality of the embryo appears to foster the existence other new human beings. But on the other hand, argues Singer, our planet is already enormously overpopulated. And this situation induces him to adopt a position that is in opposition to the previous one: 'if it is not morally

deplorable to kill an embryo because this does not cause injury to an existent being it is also not deplorable given that fact that in doing this one less person comes into the world'. As one can see, both of these conceptions reflect a utilitarian approach.

5.

'The Fifth Ancient Commandment: Treat Every Human Life as Invariably More Valuable than Every Non-human Life'

This 'commandment' essentially belongs to the ethics of the sacredness of life. Singer, however, reduces the while of humanity to an 'animal species'. According to his position, a dog, a pig or another animal possesses greater current and potential capacites, as regards self-awareness and communication, than a gravely handicapped child.

'The fifth new commandment: do not engage in discrimination on the basis of species'

This commandment aims at the 'rejection of speciesism'. In the past an inadequate morality was created which did not take into consideration beings that are very similar to ourselves. Some animals (dogs, chimpanzees or gorillas) resemble normal humans more than some members of our own species do. These last, however, are gravely handicapped. These animals are capable of relationships, of enjoying many things, of feeling pain and of being more aware than gravely disabled people. This position is applied to the relationship between a handicapped person and a monkey: according to the legislation in force, a monkey can be killed for the purposes of a heart transplant for a human being whereas killing a handicapped human being for the same reason would be assessed as constituting murder. Singer sees this as 'mistaken' and justifies this in the following way: 'The right to life is not the exclusive inheritance of the species *Homo sapiens*; it is…a right that specifically belongs to persons. Not all members of the species *Homo sapiens* are persons and not all persons are members of the species *Homo sapiens*'.

Engelhardt goes in the same direction and this thinker does not recognize all humans as having the status of oersons. In his view, 'foetuses, infants, the gravely mentally retarded or wounded people in irreversible comas are human but they are not persons. They are members of the human species but in themselves they do not have the status of being members of the secular moral community'.[2] This position opens the door to the justification of tolerance of authentic infanticide. It is not surprising that Engelhardt proposes and justifies secular morality, which 'is not able to provide any criteria for choice'.[3] This is confirmed by his subsequent position: 'resort to euthanasia… will appear to be a responsible and correct individual choice. Economic concerns and fear of pain, suffering and diabilities will exercise such strong pressures as to make suicide, assisted suicide and euthanasia options that are no less acceptable than prenatal diagnosis and abortion'.[4]

Conclusion

As we have seen, Singer develops his bioethics as a dramatising or revolutionary series of cases. This last individual case wrongly draws general conclusions that go against human dignity and against Catholic morality, which is already labelled as being 'old' and 'no longer useful'. He invites us to 'rewrite the commandments' and is convinced that in the future his new ethics will act as a guide for decisions concerning life and death.

Engelhardt develops a secular morality and cosmopolitan secular bioethics. In the context of his morality and bioethics, he accepts suicide, assisted suicide, euthanasia, voluntary abortion and infanticide at a legislative level. The bioethics of Singer and Engelhardt come to disturbing conclusions that facilitate pressure being put on the weakest (and amongst these children as well), official social selfishness, and a loss of a sense of limits as regards murder. In an extreme synthesis, post-modernity in relation to sick children offers only its selfish, cold, cynical, inhuman and non-Christian logic.[5]

The Christian position is in opposition to this logic. According to this position, our God who was revealed in Jesus Christ wanted to be the God of the weak and children. Jesus Christ invited adults to become children and he invited children to come to him: 'Let the children come to me…'(Lk 18:16). Pope Benedict XVI in his encyclical *Spe salvi* writes that 'life…is a relationship. And life in its totality is a relationship with he who is the source of life'.[6] This is the hope for sick children as well.

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Notes

[1] For the summary of both these 'new' and 'ancient' commandments I follow P. SINGER, *Ripensare la vita. La vecchia morale non serve più* (Milan, 1996), pp. 193-208. For the complex phenomenon of post-modernity in relation to the final stage of human life see J. A OK, *La postmodernità nel dibattito bioetico. Il caso delle questioni di fine vita* (Trnava, 2007).

[2] H. T. ENGELHARDT, *Manuale di bioetica* (Milan, 1999), p. 159; see also H. T. ENGELHARDT, *The Foundations of Christian Bioethics* (Lisse – Abingdon – Exton (PA) – Tokyo, 2000).

[3] H. T. ENGELHARDT, *Manuale di bioetica*, p.108.

[4] H. T. ENGELHARDT, *Manuale di bioetica*, pp. 382-383.

[5] Cf. J.-R. FLECHA, *Moral de la persona. Amor y sexualidad* (Madrid, 2002); CH. W. COLSON – N. M. DE S. CAMERON (eds.), *Human Dignity in the Biotech Century* (Illinois, 2004).

[6] BENEDICT XVI, *Spe Salvi* (Vatican City, 2007), n. 27.

Third Session

What Should Be Done?

SERGIO PINTOR

1. Sick Children: Catechesis and Formation in the Faith

It is my intention in this paper only to emphasise certain fundamental aspects of this subject. Indeed, this subject refers to a specific age in development which is characterised by various stages and various cultural visions, to a condition of illness, which is very diversified as regards typology and contexts, and to education and formation in the faith with its specificities and its related questions and issues.

The apostolic exhortation *Catechesi tradendae* can suggest to us a unifying and challenging perspective: how can we reveal to a large number of children, young people and teenagers, including those who are in a condition of illness and disability, the face of God who is love, which is manifested to us through His Son Jesus Christ – the Lord of life who took upon himself our infirmities in order to heal them and save us?

How can we help them to encounter the person and the mystery of Jesus in order to accept his invitation to follow him and become a part of his Kingdom which has been begun but which will be completed only in eternity? (see *CT*, n. 35).

1. Some Beliefs and Concerns

At the base of the education in the faith of children and young people who are in a condition of illness there must be certain fundamental beliefs and concerns.

a). First of all, the belief that overall care for sick children and young people requires respect for their right to education in the faith. One cannot forget that education in the faith and education in the catechesis have their specificities connected with childhood or boyhood or girlhood, not least because 'every age of man has its own meaning in itself and its own function in the achievement of maturity' (CEI, *Rinnovamento della catechesi*, n. 134).

The meaning of this age is not subordinated to adulthood and has its own dignity and specific needs as an age in life which, when there is a condition of illness, encounters the mystery of God with its own specific character. The *General Directory for Catechesis* rightly declares: 'For various reasons today, rather more than in the past, the child demands full respect and help in its spiritual and human growth. This is also true in catechesis which must always be made available to Christian children. Those who have given life to children and have enriched them with the gift of Baptism have the duty continually to nourish it' (Congregation for the Clergy, *General Directory for Catechesis*, n. 177).

b). The belief that the involvement of various educating individuals and institutions as well as a connection between them is necessary so that education in faith can appear significant and vital in the special condition of illness that children and young people are experiencing.

c). The need to see sick children and young people as the real subjects of medical care and of education in the faith and not as mere 'objects'. This requires not beginning always and exclusively from our vision as adults but, rather, beginning with the singularity of the person of sick children or young people, bearing in mind the psychological and existential condition of each one of them and the understanding of their illness that each one of them may have. Indeed, the way that each one of them lives out and interprets their illness, the feelings that they experience, the way they address the experience of pain and the very idea of death itself – all these are aspects to be taken into consideration in order to illuminate through education in the faith the reality that each of these sick children or young people is experiencing.

d). There derives from this the need for a series of concerns which are connected with each other: the need for attention to be paid to the centrality of the person of the child or young man or woman with his or her singularity, moment or stage of development; the various kinds of illness that is being experienced (whether it is grave or not, chronic

or temporary, makes the patient an invalid or not…); the need for attention to be paid to the various cultural, social or faith contexts of the child or young person; the need to pay attention to the diversity of the educating individuals that have to be involved: parents and family relatives, health-care workers and pastoral workers, hospital chaplains and parish priests of the Christian communities, voluntary workers…; the need for attention to be paid to the various kinds of places that are providing care – the family, hospitals, other care-providing structures…; the need to be careful never to isolate education in the faith and a catechesis from the broader and involving context of the community, within which it is helpful to promote through ordinary catechesis itself – with its pathways involving initiation into Christianity – an education in the faith that illuminates the problems and questions that arise in the condition of illness that very many children and young people experience, and where parents, teachers of catechesis and adults can be formed in the faith so as to be able to accompany children and young people to live situations of illness and suffering in Christian light and hope.

2. Essential Criteria and Indications for Education in the Faith

Education in the faith and catechesis during childhood and boyhood or girlhood is characterised from within by a gradual process of initiation into the Christian mystery and the Christian life, with attention being paid to the various stages of development that are specific to this age and the practical condition or situation of illness that accompany them.

Beginning with the indications offered by the various reflections that have been developed as regards catechesis and education in the faith for children and young people, and above all by the most recent documents of the Magisterium, one can point out certain general criteria and principles to be borne in mind for education in the faith for children and young people who are in a condition of illness, disability or suffering.

a). A first criterion is that of promoting and forming around sick children and young people a small but authentic 'educating community' which in various ways and with various tasks which are always based on great love, with various languages and signs, help them to open themselves to the light and hope of the Gospel.

b). To promote education in the faith that is rooted in the sacrament of baptism and located within an essential vision of the design of love, communion and salvation that is already actuated and at work in the concrete reality of our lives so as to achieve complete fulfilment in eternity, in a design of God who today takes care of each one of His children, when they are in a condition of illness as well, in order to support them until they are given full health and definitive salvation.

c). The method and contents of education in the faith can be suggested by the pathway of faith celebrated in the liturgical year: Advent, Christmas, Lent, Easter and Pentecost, some Marian feats, All Saints Day, All Souls…

A catechesis can be developed in relation to the liturgical year that helps in knowing the person of Jesus and his mystery through the facts of his life, his teachings, his miracles, his death and resurrection, and his remaining with us in the Church and the sacraments.

In this context it will be easier to help children and young people – according to their age and concrete condition – to discover and live the sacraments of Christian initiation as participation in the life itself of Jesus and as actions that Jesus is himself engaging in today in their lives – the Eucharist in particular as his presence amongst us, as his nearness and care in a condition of illness as well.

d) Education in the faith of children during the various stages of childhood should be conceived of and implemented as a 'magisterium of life' connected with concrete situations. It should also involve the individuals and environment that surround the child in order to transmit almost by 'osmosis' and with a communicative language the values and the attitudes specific to an inseparable human education and education in the faith: openness to mystery and the transcendent, the meaning of trust and entrusting oneself, of giving and selfless giving, of invocation and prayer…

e) Education in the faith for young people (of the ages between six and ten) could have as its objective that of illuminating the various moments and aspects connected with the various stages of their age in life and the concrete condition of their illness, in an approach involving initiation into the Christian faith and life. The characteristics of this catechesis, according to the apostolic exhortation *Catechesi tradendae*, are: a gradual introduction into the Christian mystery in the life of faith and the Church, and in this context preparation for, and the celebration of, the sacraments 'in a lively way' (cf. *CT*, n. 37). It is clear that in taking into account the various conditions of illness or disability one should begin from an occasional catechesis in order to move towards an approach and a catechesis that are essentially of an overall character.

f). Special attention should be paid to education in the faith in the case of children and young people who find themselves in conditions of grave disability, above all mental disability. They, too, have the right to know and live the mystery of Christ as a light and support in the realities that they experience. This is a catechesis that requires specific

training for pastoral workers and the teachers of catechesis, approaches involving welcome and authentic affection, and an appreciation of symbolic language and signs beginning with listening and an interpretation of their language.

g). Lastly, we should ask ourselves and be concerned about being able to support through education in the faith all those children and young people who are gravely disadvantaged, that is to say when, for example, the support of a family and a family environment is absent in part or completely, or when they live in conditions of cultural and social degradation, marginalisation and acute poverty. This is an appeal to our Christian communities who are called upon to bear witness to the care and fatherhood/motherhood of God, His predilection for the young and the weak.

Conclusion

Before ending this paper I would like to emphasise the importance of the training and capacities of pastoral workers. As witnesses to hope and educators in the faith, they must be companions and friends to sick children and young people so as to listen to them, to understand them and share their language, to communicate the light of the Gospel with symbols and signs, and to narrate the action of the God of life and of love.

All of this should be done with the family and the other people who are involved in caring for the sick child or young person, promoting an educating community and a climate of Christian hope. And with a great certainty – the Holy Spirit lives in the hearts of children and young people and makes them capable in their simplicity of understanding and bearing witness to the mystery of God in a condition of illness as well, as was taught to me by Daniela, a girl aged six, whose testimony I would like to employ to end this paper.

Daniela is a girl who suffers from a rather grave and rare form of Mediterranean anaemia and she is compelled to have constant blood transfusions. She is aware of everything. I met her for the first time almost two years ago when I visited a small parish of the diocese during the novena of Christmas. Amongst the prayers that the children are invited to recite, I heard the voice of a girl who prayed as follows: "Baby Jesus I ask you to enable to find a bone marrow that is compatible with mine". I went to see her immediately after the novena and, looking me in the eyes, she said to me: "you know if Jesus wants to, he can cure me, but if he wants to take me to be with him, I would be equally happy".

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EUGENIO SAPORI

2. Sick Children and Sacramental Pastoral Care

At this international conference of the Pontifical Council for Health Care Workers, which is examining the large numbers of problems of sick children, I believe that a pastoral look at the celebration of the sacraments with such individuals, who are indeed so important in the lives of families and Christian communities, is not something that can be absent.

The presence of so many people here today also demonstrates the notable interest in this subject which remains of special contemporary relevance for those who are in contact with suffering innocence and with families who often have to bear this burden without understanding the reason for such events.

I feel that it is my duty now to extend my sincere and affectionate thanks to all those mothers whom I have encountered in my ministry because they have enabled me to understand the meaning of what St. Camillus wanted: 'First of all, everyone should ask for the grace of the Lord that they may have maternal affection for their neighbour, so that they can serve their neighbour with all charity, in the soul and the body, because we wish with the grace of God to care for all sick people with that affection that a loving mother has for her sick only child'.[1]

I believe that this lesson is not of little import, and for this reason it is worthwhile addressing this supplication to the Holy Spirit.

Premise

The literature on this subject is not abundant and for this reason I must of necessity resort both to certain generalities and to my own personal experience and that of my pastoral co-workers at the Hospital of Padua (Italy).

After a look at the historical-liturgical development of the sacraments of Christian initiation (baptism, confirmation and the Eucharist), I will then examine in detail certain features of sacramental pastoral care with sick children, without forgetting that a primary objective of a pastoral worker (whether a priest or a member of the laity) is that of entering into the mentality of children, perhaps 'on tip toes', that is to say delicately, with respect, without taking anything for granted and without believing that one knows everything already. It is not enough to know theology (this is only a premise, albeit an important one), it is necessary to know how to know our interlocutors; hence the need for a relationship that reaches optimal levels.

This is a premise that was taught to me indirectly by a child (Nicola) during a visit. His grandmother who was at his side and was worried about the health of her grandson at the end of the conversation asked me for a prayer and a blessing for Nicola so that he could achieve a swift recovery and return to his home. Once the prayer had begun, the child remained silent, and this despite the repeated requests of his grandmother. In the end, this woman, tired of repeating the same things without obtaining any result, rebuked Nicola, who, in a rather serious way, answered her in the following way: 'But Granny, we are in a hospital. We are not in a church to pray!' This tells us how much seeing and experiencing reality (including the reality of prayer) is different in the case of a child, who lives in his or her own world.

A Look Backwards

During the first centuries of the Christian era[2] baptism was received in adulthood and this only after a serious pathway of preparation (the catecumenate) in order to avoid someone embracing the faith only out of enthusiasm who would then not have the strength to resist its trials, In the catechesis importance was given to the description of the Easter vigil when the neophytes were introduced after the moment of baptism to the moment of 'confirmation' and then to the celebration of the Eucharist.

The different mentality of the seventh and eighth centuries involved the matching of religious belonging and civil belonging – baptism, in fact, meant not only membership of the Church but also membership of a Christian nation.

The spread of the baptism of children spread during that period. All of this took place not only because of the phenomenon of infant mortality but also because of a fear that children who died without baptism would be damned. Later, the legislation of the Church upheld that baptism had to be administered as early as possible.

Subsequently, bishops were responsible for the rite of confirmation which was placed between baptism and the Eucharist; this took place when bishops could not be present at the celebration of baptism – something that took place above all in country districts. In this case, a priest baptised the candidate and gave him or her holy communion, and this took place in the case of children as well.

With the Fourth Lateran Council (1215) it was prescribed that beginning with the age of discretion every believer had to confess his or her sins once a year to his or her priest and draw near to holy communion at least at Easter. In this way there immediately took place the detachment of the Eucharist from baptism, which was received during the first days of a person's

life. It was also in this period that the faithful drew near increasingly less frequently to holy communion, and there was an increasing desire to see the consecrated host.

After the Council of Trent the Ritual of baptism (1614) paid especial attention to children who were in danger of dying and thus the following was prescribed: 'the minister can be any person; certain special cases (babies born to dead mothers, children born dead, monsters…) are examined and receive suitable treatment; some doubts are taken into consideration; general baptism is envisaged for more than one person at the same time; there is, lastly, a sole prohibition: nobody is to be baptised while they are still in their mother's womb'.[3]

In the same Ritual it is laid down that a priest can omit all the previous prayers and baptise the child immediately when that child is gravely ill or its life is endangered; however, there remains the obligation to engage in the ceremonies that have been omitted later on.

Increasing discussion about the age of discretion increasingly accompanied the celebration of confirmation and first communion. The question was only resolved in 1910 when Pius X, by his decree *Quam singulari,* asked that throughout the Church the practice of celebrating first communion roundabout the age of seven was restored. The Pope was thus reacting to the vision of communion as a 'prize' to be deserved through major efforts involving ascesis and moral commitment. Although in order to draw near to holy communion due initiatives are necessary, it was argued that one should not forget that the Eucharist is also a support for the weakness of man, bread that nourishes him on his pathway of Christian life.

This thinking of the Pope has been remembered recently. The Prefect of the Vatican Congregation for the Clergy, Cardinal Card. Darío Castrillón Hoyos, in a letter disseminated by that body and addressed to priests on the occasion of the Year of the Eucharist, observed: 'Allowing children to be able to receive the Eucharistic Jesus as soon as possible was for many centuries one of the fixed points of pastoral care for the youngest of the Church, a custom that was restored by Pius X in his time and which was praised by his successors, as has been done on a number of occasions by our Holy Father John Paul II…We priests called by God to steward, in union with our bishops, the Most Holy Sacrament of the Altar, can and must look first of all at children as the first recipients of this immense gift: the Eucharist, which God has placed in our fragile pots of clay, on our consecrated hands'.[4]

Confirmation

The celebration of confirmation seems to be a little more complex[5] given that according to shared rules in the West the bishop is the ordinary minister, even though there are exceptions, for example the case of the dying. Pope Sylvester († 335), indeed, on his own authority, allowed priests to bestow confirmation (but with that confirmation blessed by the bishop) on people who were in grave conditions of health.

Amalario di Metz in his *Liber officialis* (of the ninth century) developed the idea of a greater fullness of grace because he attributes to a person who has received confirmation, after his death, a higher level of celestial glory than a person who has only been baptised. The analogy of the different levels of brightness of the stars in the night sky is used as a comparison. This idea in the Scholastics acquired particular importance because in this way the confirmation of children was justified, as was the possibility that a priest could administer confirmation to them when their lives were in danger.

Emphasis should be laid as regards sick people on the measure adopted by Benedict XIV († 1758) who in his *Institutiones ecclesiasticae* invited parish priests to supply the names of those who had not yet received confirmation even though their lives were in danger so that they would not die without this sacrament. This was also laid down by St. Charles in his 'Pastoral Instructions of the Ambrosian Ritual'. Subsequently, the Code of Canon law of 1917 (can. 788) established that in the Latin Church young people could receive confirmation even before the age of seven when there was a real danger of death. In some declarations of the Church's Magisterium during the nineteenth century we can observe that confirmation was seen as a communication of the Holy Spirit for the soul in order to grant it constancy and strength during grave dangers and during the Christian life.

The decree *Spiritus Sancti munera* of 14 September 1946, which was issued by the Congregation for the Sacraments, basing itself upon tradition and the teaching of St. Thomas, allowed an ordinary priest, in specific conditions, to administer confirmation to the gravely ill, including children who had not yet reached the age of reason. It proposed a very simple rite that was also introduced into the official edition of the Roman Ritual of 1952. A German theologian, D. Koster, directly referring to this decree on the confirmation of the sick, believed that he could speak of a new interpretation of confirmation which for him became Christian witness to, and imitation of, the passion and death of Christ. In this way, he said that it became the sacrament of Christian formation for suffering and death.

The Liturgical Reform of the Second Vatican Council

In the liturgical books that sprang from the last ecclesial reform we can find some specific rites for children whose lives are in danger. This applies to baptism and confirmation, whereas the ritual of the anointing of the sick and pastoral care for the sick contains only the rite for the celebration of confirmation where there is the laying on of hands on the sick person with a prayer invoking the Spirit through his gifts and the minister by confirmation makes the sign of the cross on the child and pronounces the formula: 'receive the seal of the Holy Spirit which has been given to you as a gift'; the person who is receiving confirmation, or someone in his or her stead, replies:' Amen'.[6] If this can be done, it is advisable to add, for example, the renewal of the promises

of baptism, the profession of faith, and the Lord's Prayer.

The Code of Canon Law of 1983, with reference to conditions where there is a danger of death, states that in this case the age of the candidate should not be taken into consideration (Can 889 § 2), the minister can be a parish priest but also a priest of any kind (Can. 883) who should, however, use the confirmation consecrated by the bishop (Can. 880 § 2).

The *Catechism of the Catholic Church* (1992) emphasises that the presbyter must confer confirmation on such a person because 'the Church desires that none of her children, even the youngest, should depart this world without having been perfected by the Holy Spirit with the gift of Christ's fullness'.[7]

A general look at the liturgical books reveals that little attention is paid to sick children as regards pastoral care involving the sacraments. In general, the translations of the texts of the individual bishops' conferences follow the official edition issued by the Holy See, and thus only the essential parts of the rite, which should be performed in cases of extreme need, are indicated.

However, an exception can be found in the English edition of the rite of the visit – stress is laid upon the importance of prayer at the bedside of the sick child, with the adaptation of everything to his or her age and his or her level of understanding. The same attention is paid to his or her family relatives.[8] As regards the sacraments, this text stresses that the important sacraments are those of initiation (baptism, confirmation, the Eucharist) and thus there is no reason, especially in grave cases, to delay for too long the moment of first communion and this is in line with the tradition of the Church.[9] In addition, the child, this Ritual continues, can receive the sacrament of the anointing of the sick if he or she has sufficient use reason to understand the meaning of this sacrament.[10] With respect to all the rites of the sacraments with children, it observes that there are special adaptations for their celebration.

Which Sacraments are most Requested?

It is certainly the case that for some departments – for example neonatology, general or special paediatric surgery – the sacrament that is most requested is baptism and this is because of the real danger to life that is perceived in these situations.

This is a very special and intense moment for the family and especially for the mothers involved. The person who celebrates emergency baptism must take into account the situation of the child but he cannot ignore the suffering of his or her family relatives. Baptism is a sacramental celebration that refers to our reality of being children of God, reminding us that we are and we entrust ourselves to His hands. This belief is expressed even better in communal prayer, involving not only the family relatives but also the health-care workers (nurses, medical doctors).

I have witnessed moments of strong emotion on the part of parents when they realised that together with them there was the whole of the personnel praying for their child with a single heart and a single soul, almost as though they were invoking from the Lord supplementary help in their professions. But, on the other hand, it is necessary to avoid baptism becoming almost a 'magic moment' that can solve all the problems of the body and the spirit.

Who Requests the Sacraments?

In the majority of cases the request comes from parents who are always near to their children during their admission to hospital. Generally all of this takes place in a situation of faith experienced in the drama of the illness or, in other cases, when there is the possibility that the child will die. For the older children the request is for Sunday communion or communion when there are special days in the year of the child or special solemn occasions.

Baptism is requested more often when there are operations or actions that could be dangerous because they take place during the first days of a child's life and in very precarious situations. In this case it is often the people who surround the child (family relatives and health-care workers) who press for the sacrament, for the further reason that the mother is not always aware of the real situation of her child and the father is involved in mediating between the medical doctors and his wife.

The requests for confirmation for children who have only received baptism are not as frequent as they once were. Perhaps this has been encouraged by the fact that the certainty that the child has already been baptised does not create questions about what should be done from a sacramental or spiritual point of view. In addition, nowadays, within the field of pastoral practice, the sacrament of confirmation lies between two well defined limits – either it is ignored because it is held not to be necessary to salvation or it is bestowed *in extremis* on sick children who have only received baptism, thereby meeting the need to offer a further sacrament to a person who cannot receive the anointing of the sick.

What are the Priorities of the Sacraments?

The Eucharist certainly represents the centre of the whole of the liturgy and of the Christian life and for this reason it constitutes the point of arrival of Christian initiation. Various experiences involv-

ing celebration of Holy Mass with children in our hospital suggest that they should be involved in the liturgy through an animation that takes into account their lives and their opportunity to participate. I remember that one day a child in a very direct way confided to me that he did not like Holy Mass because, he said, 'the priest always speaks and he does everything'.

The holidays of Christmas and Easter are particularly indicated because they create a certain expectation in this sector, above all if there is also cooperation between the teachers of the hospital school. The children prepare a number of drawings that are suitable for the circumstance (at Christmas: sheep, stars…; at Easter: swallows, flowers, eggs etc.) which enrich the environment where the Eucharist is celebrated. Everything is accompanied by their prayers which are very simple but concrete because they express deep wishes for themselves and for all the children in the world, invoking peace, love and health for everyone.

The celebrations that take place – perhaps it is useful to observe this once again – must always be communal, involving not only the children and their parents but also the family relatives who are present, as well as the health-care workers who in this way declare not only their faith but also their affection and their commitment to the overall health of the sick child.

One obstacle that has to be overcome is the mentality, which is often present, that sees the sacraments as being 'magical', that is to say as a lucky talisman which solves all problems and heals immediately in a miraculous way.

And Confession?

Someone at this point could ask: what meaning does the sacrament of penance or of the confession of sins have for children? This sacrament is requested for the most part by older children who have acquired a certain sense of sin, at least as an offence against Jesus. At times the parents or family relatives invite the child to engage in confession in order to ask forgiveness from Jesus before they receive the Eucharist. The sacramental encounter – in this case – becomes a suitable occasion for a face to face dialogue with the child, giving him or her an opportunity to express his or her feelings and discomforts in relation to his or her illness without the 'filter' of the presence of other people. Often it is very positive encounters of this nature that have brought out unthinkable problems and questions because they have enabled me to discover how much sick children are more sensitive and more mature than one might otherwise have thought.

It seems to me useful when discussing this subject to return to St. Peter's Square and to the meeting which took place on 15 October between the Holy Father Benedict XVI and children receiving their first communion. Livia addressed the following question to him: 'Holy Father, before the day of my first communion I went to confession…But I would like to ask you: should I go to confession every time that I take holy communion? Even when I have committed the same sins? Because I realise they are always the same'.[11] The Holy Father answered as follows: 'I would say two things: the first, naturally, is that you should not always go to confession before communion unless you have committed sins that are so grave that you should go to confession…The second is this: it is very useful to go to confession with a certain regularity. It is true that usually our sins are always the same but we clean our homes, we clean our rooms, at least once a week, even though the dirt is always the same…The same thing applies to my soul, to myself; if I never go to confession my soul remains neglected and in the end I am always pleased with myself and I no longer understand that I must strive to be better. This cleaning of the soul, which Jesus gives to us through confession, helps us to have a more lively conscience, one that is more open, and thus it also helps us to mature spiritually and as a human person'.[12]

Towards a Conclusion

I believe that the words of the Holy Father that have just been quoted can be applied to all those sacraments that involve sick children. The sacraments are as useful for interior beauty and maturing in a spiritual sense in moments of suffering and illness as well as they are in other moments. The theology and the practice of the Church have developed a sensitivity towards sick people above all when their lives are in danger – the Church has never neglected to infuse the gift of the Spirit and the fullness of grace into them.

Lastly, one should notice that pastoral care in these cases should not only be concerned with essential and necessary things, but, rather, it should go beyond this and cultivate a special interest for the family relatives of the child who are present through prayer which for everyone involves comfort and hope, being helped by the invocation of the Comforting Holy Spirit and of the Virgin Mary, Mother of Church, who at the foot of the cross was an active presence of comfort and peace for Jesus himself and for his disciples.

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Notes

[1] Cf. M. VANTI, *Scritti di san Camillo de Lellis (*Il Pio Samaritano, Milan/ Rome, 1965), p. 73.

[2] For a summarising idea on Christian initiation in history, cf. P. CASPANI AND P. SARTOR, *Iniziazione cristiana. L'itinerario e i sacramenti*, preface by W. Ruspi, (EDB, Bologna, 2008), pp. 23-33.

[3] Cfr. *Rituale Romanum*, Romae 1614, pp. 6-9.

[4] Letter of the Cardinal (8 January 2005) printed in *30Giorni*, January-February 2005, p. 9.

[5] Cf. SAPORI E., 'Cresima', in *Dizionario di teologia pastorale sanitaria*, ed. by G. CINÀ *ET AL.*, (Camilliane, Turin, 1997), pp. 297-302.

[6] In the Ritual of the Italian Bishops' Conference we find this description in chapter VI (nn. 205-206); this rite is present in all the translations of the various bishops' conferences.

[7] *Catechism of the Catholic Church*, n. 1314.

[8] 'What has already been said about visiting the sick and praying with them (see no. 46) applies also in visits to a sick child. Every effort should be made to know the child and to accommodate the care in keeping with the age and comprehension of the child. In these circumstances the minister should also be particularly concerned to help the child's family': Ritual, *Pastoral Care of the Sick*, .n. 47.

[9] If it is appropriate, the priest may discuss with the parents the possibility of preparing and celebrating with the child the sacraments of initiation (baptism, confirmation, Eucharist). The priest may baptize and confirm the child (see Rite of Confirmation, no. 7b). To complete the process of initiation, the child should also receive first communion. (If the child is a proper subject for confirmation, then he or she may receive first communion in accordance with the practice of the Church.) There is no reason to delay this, especially if the illness is likely to be a long one': Ritual, *Pastoral Care of the Sick*, n. 48.

[10] The child maybe anointed if he or she has sufficient use of reason to be strengthened by the sacrament of anointing. The rites provided (Chapter IV) are to be used and adapted': Ritual, *Pastoral Care of the Sick*, n. 50.

[11] 'Incontro di catechesi e di preghiera del Santo Padre Benedetto XVI con i bambini della Prima comunione (Piazza San Pietro, 15 ottobre 2005)', supplement to the edition of October 2005 of *30Giorni*, Rome, 2005, p. 7.

[12] 'Incontro di catechesi e di preghiera del Santo Padre', pp. 8-10

TONY ANATRELLA

3. The Psychology of a Sick Child in the Pastoral Approach

'Let the children come to me,
and do not hinder them; for to such
belongs the Kingdom of God'
(Lk 18 :16)

Introduction

Pastoral life requires one to be able to take into account the experience of people in order to develop a pedagogy directed towards allowing them to live their own situations in the mercy of God and the hope given by Jesus Christ. Beginning with baptism, a child is immersed in the life of Christ and it is with him that the child learns to live, from that very moment, as a risen person. The Christian life begins in the today of the history of each individual and of other people, and not only at the end of time. In the inter-religious debate ideas are attributed to the Church that do not belong to the Gospel.

I propose that you observe and analyse the experience of a sick child, what his or her illness represents for him or her and the questions that he or she poses himself or herself. My paper will be illuminated by that of H.E. Msgr. Sergio Pintor on 'The Catechesis and Formation in Faith of Sick Children' and by that of Rev. Eugenio Sapori MI who will address 'Sacramental Pastoral Care for Sick Children'. In order to avoid repetitions, I will place my words in an existential approach in order to understand how the Christian life allows a spiritual understanding of certain events. In addition, I would like to point out that on Internet I have not found any reference to pastoral care for sick children – a fact that should make us reflect.

We must respect the specificity of a sick child and not project onto him or her the characteristics of a sick adult. A child does not yet possess the same psychological organisation and the same emotional maturity of adults to be able to consider events in the right objectivity. He or she often tends to centre around himself or herself the problems of health that are being experienced and to want to manifest them in the relationship that is developed with his or her parents or try to ignore his or her illness.

1. Children and Illness

Very probably a child who suffers is aware that he or she is sick and has to be treated. But in the majority of cases, when a grave illness has been diagnosed, for example cancer, and the child is not yet suffering because of it, he or she encounters difficulty in accepting that he or she has to undergo various tests, be treated and admitted to hospital. He or she does not understand this situation because he or she does not see anything tangible in his or her own body. Some parents, so as not to worry their child, prefer not to say anything to him or her and keep him or her in the dark as regards the illness, even though he or she is being treated. This is mistaken behaviour because the child can perceive the emotional change and change in attitude of towards him or her of his parents and family relatives. He or she does not know that his or her parents are worried about him or her, but he or she can perceive the feeling of insecurity that they experience. The cloudy climate in which he or she finds himself or herself can be for that child a source of insecurity and the 'unsaid' that surrounds him or her is a factor that generates anxiety. The child feels that something is being plotted but he or she does not know what it is.

It is not necessary to reveal the diagnosis in the medical sense of the term to the child – this is not necessary in the case of a child – but it should be explained to the child that he or she has been struck by an illness and how he or she will be treated so that he or she can develop a relevant mental representation of it. One should also take into account what the parents would like to tell or not to tell their child and what the child is able to understand and what he or she wants to understand. At times, the children who do not want to know anything allow their parents to deal with their illness together with the hospital staff. This reaction is understandable when one knows that for the child his or her parents and adults are mediators between him or her and the problems of existence. The child can, therefore, continue to live his or her own life as a child through playing and centres of interest that are connected with a certain age.

In the best of cases, information about his or her illness will allow him or her to become familiar with the treatment and install a climate of trust between himself or herself, his or her parents and the medical doctors who are treating him or her, thereby coming to control more effectively his or her own fears and worries. In medical and hospital centres, we have pedagogic material made up of dolls and figurines, beginning with which we explain to children their illnesses and the related forms of treatment. Fun is had giving injections to furry dolls or engaging in a surgical operation on a little doll, showing that everything is done to avoid suffering and to be cured. In pre-adolescents or in adolescents it is possible to show analyses of biological products under a microscope or through the study of medical x-rays. In this way children know on what object they should

focus their attention in order to fight against their illness.

A child who feels well does not understand that unknown constrictions must be placed on him or her. When he or she is admitted to hospital and begins to feel bad, one should be prudent because he or she could feel bad because he or she has been admitted to hospital or because the fear of being distanced from his or her family could be troubling him or her.

In the pastoral approach we start from the fact that the child needs to know and to learn to this end he or she should trust other people and other places, he or she should accept, that is to say, that he or she is out of place. In the catechism he or she will discover the things of God that he or she will not hear elsewhere. The episode of the child Jesus who disappears from the sight of his parents to talk with the doctors of the law is an example on which we should reflect and work in order to understand the spiritual questions that a child asks himself or herself.

2. The Child and His or Her Sufferings

There is often a difference between the representation of the illness by the parents and medical doctors and the representation engaged in by the child. If the family relatives are rightly troubled about what is at stake in terms of life in the illness, about the way in which the child will respond to the treatment, and about his or her possible sufferings, he or she, instead, is elsewhere and develops other worries.

2.1 The fear of separation and of being abandoned

The first and most recurrent worry is that of being separated from his or her parents and, principally, from his or her mother. The clinical and theoretical studies on the psychology of attachment in childhood and adolescence tell us that some children who have been separated from their parents can develop grave mental disturbances that can prejudice the later development of their personalities.

Children left alone in hospital because their parents work experience depressive periods. They feel abandoned and their stay in hospital is seen as involving anxiety-inducing separation. Indeed, they fear that they will never see their parents again. Their apprehension forms a part of the original spectre that we encounter in numerous tales and legends, namely that of being abandoned. The hospital appears as that place of definitive separation that all children fear. The child is more worried about separation than he or she is about the illness. Advances have been made and others till have to be made to allow parents to be near to their children by allowing them to stay in the hospital for the time required for the treatment.

2.2 The fear of not being loved and of being dispossessed of their bodies

The second worry of the child concerns his or her body. For a long time he or she experiences his or her body as an extension of the bodies of his parents. He or she knows that the treatment that is provided is supplied by his or her parents, by one of his or her siblings or, possibly, by a nanny or by grandparents. Within a few days, however, he or she comes to experience a destabilising upheaval when he or she sees acting on him or her another hand which, in some technical actions, will make him or her suffer: a small and painful injection, an irritating manipulation of sensitive areas, or washing that will render his or her corporeal intimacy naked. A child, including one who is well, who sees, for example, a student doctor examine his or her sexual organs will quickly say to his or her parents: "he touched me!". At the moment of personal washing in hospitals we often see children ask their parents or another member of their family who is present to themselves engage in care for their personal hygiene rather than entrusting themselves to extraneous hands.

A child who, following a physical contact, feels pain because he or she has an organ that is sick or because the surgical operation has not yet healed over, or because a new pain has appeared, associates it with the act of the person who accedes at that moment to his or her body. This outsider wants to do him or her harm and in fact harm has been done. His or her suffering will be even more accentuated because up to that moment he or she felt that his or her parents protected him or her and protected him or her against all harm. In the past he or she could have turned to his or her mother or father in order to be comforted and relieved in his or her pain. Their absence in this kind of situation is incomprehensible for him or her and he or she does not understand why his or her parents are not present to protect him or her and to support him or her. He or she thus thinks that he or she has been forgotten about and not loved and also runs the risk that he or she will feel dispossessed of his or her own body.

In order to avoid this kind of sense of being lost it is advisable for parents to bring their child the clothes that he or she likes, the games that he or she prefers or the photographs of the members of the family that he or she likes and of the domestic pets to which he or she is especially attached. These are aspects that reassure the child and maintain keen his or her habitual points of reference. The relationship with his or her family relatives is thus maintained and lightens his or her sense of fracture, of abandonment and self-spoliation.

One of the first topics that is logically developed in the catechesis is emphasis on the presence of God who wants to come to us, who thinks of us and calls us to enter in-

to a relationship with Him. He does not forget us, even though our eyes cannot see him directly. The presence of God in his invisibility is rich in meaning in Scripture. A child who finds himself or herself faced with his or her own loneliness can be sensitive to this presence of God which he or she can rediscover in the Biblical text and thereby then nourish his or her spiritual life.

2.3 Fear of being attacked at a physical level

A child can be afraid of the specialists who intervene on him or her and on his or her body. The medical treatment that is administered to the child can provoke reactions and can involve secondary effects as physical modifications: loss of hair in the case of chemotherapy, nausea, vomit, great tiredness, and weight loss. Chemotherapy based on corticoids set in motion an irresistible need to eat and this involves an increase in weight and changes in mood (the individual becomes aggressive or depressed).

The child constantly worries that the secondary effects of the treatment are stronger than the illness itself. He or she fears that this will get worse with the complicity of his or her parents who have given their consent to the treatment. They tell their child that they want his or her recovery but he or she can interpret their attitude as being favourable to the illness or even a the origin of the pathology. 'It was my parents who did this to me', a child said to the medical staff who then had to explain to him that they were not the cause of his illness. Despite these objective facts, some children with a narcissistic psychology do not stop stating that it was their parents and not they themselves who had recourse to medical doctors. To ensure that the family and the medical staff are seen as being at the side of the child and not viewed as aggressors, it is important to explain to the little patient that his or her parents need medical doctors to treat him or her and cure him or her.

A child always fears the intrusion of extraneous individuals into the intimate sphere that constitutes his or her psychology or body. A child accepts their intervention more easily when the parents are next to him or her, even though he or she may complain and weep, or when he or she knows that they trust the doctors and have given their consent.

Behind this tendency of the child there is another product of the imagination – fear of being attacked or having to deal with someone who will treat him or her badly. Fear of the scissors of a barber/hairdresser, the syringe of a nurse or the various instruments of a medical doctor go back to the primordial fear of being attacked in his or her body and intimacy.

It is for this reason that all the gestures that are carried out in relation to the child must be explained, if not also the subjects of play with him or her in relation to certain objects. They will thus be located in the real and not in the imagination of the child who feels attacked and needs to be surrounded with kindness and affection in order to understand that it is his or her wellbeing and health that are being sought after.

All of these observations mean that the child needs to be surrounded by the knowledge that it is his or her illness that is being dealt with.

There are numerous encounters between Christ and people who ask him to be protected and reassured by God. Despite their difficulties and sufferings, he gives them the strength and the grace of God, in whom they continue to have trust and hope. There is no fatality in God; life remains open and the future is always with Him.

3. Communicating with a Sick Child

When parents discover that their child is afflicted by a grave illness, they try to find the origins of this misfortune. They often look for them in the outside world and attribute the illness to various causes: pharmaceuticals taken during pregnancy, alimentation, pollution, even a possible jinx cast upon them. The illness is experienced as a punishment because the parents are said to have committed a sin, which is not without connection to the Oedipus complex which is reactivated in this way. But their moral suffering is accentuated when their sick child makes his or her parents responsible for his or her illness. We are immersed here in the heart of the question of obligation and desire through the child; but because this is not the subject of my paper I will simply point out the challenge.

Future mothers are often worried about giving birth to a deformed child or a child with problems. When reality is joined to imagination soon some of them are troubled and feel blameworthy, but here it is necessary to introduce a sense of reality so that they do not remain the prisoners of their protective interpretations. Parents need to be reassured so that they face up in the best ways possible to the situation of having a sick child.

3.1 The child holds himself or herself responsible for his or her illness

A child whose thinking still depends on the processes of his or her imagination often launches himself or herself into narcissistic interpretations of what happens to him or her, given that he or she has not yet acquired the sophistication of the various logics of cause and effect. He places himself or herself at the centre of various unhappy and unfortunate events in his or her life, he or she thinks that he or she is at the origin of what happens to him or her, whether it is good or bad. He or she thus thinks that the illness is a punishment because he or she has disobeyed or been bad. Because at times he or she is asked to adopt a

certain form of behaviour, 'don't eat too much chocolate or you will fall ill', and he or she has not always obeyed, he or she imagines that the illness is a consequence of his or her behaviour. He or she will even come to think that he or she cannot get better because he or she deserves this punishment because, for example, he or she is jealous of a sibling. The child, however, does not fall ill with leukaemia, cancer or hepatitis because he or she has not controlled his or her greed or because he or she has been bad towards a sibling.

The taking of drugs and medicines can also be seen as a punishment by the child, especially those that have a bad taste given that in his or her family he or she is used to receiving only good things to eat. The bad taste of drugs and medicines can also evoke in him or her both poisons and dangerous foods of tales and legends.

At every stage of the treatment and the medical requirements it is important to explain to the child what is happening so as to avoid that he or she does not turn the situation against himself or herself. In this way we should open up to the child other sources of pleasure, which he or she often encounters in food. The use of family objects in the company of people who are interested in him or her and that the child loves are indispensable steps in maintaining communication and a relationship, of a playful character as well, with him or her. Playing is one of the principal activities of children and to the extent that this is possible they should not be deprived of it.

Here it is important to demonstrate the originality of God who enables us to know Christ. He is not a God who wants to prostrate us and punish us, but, on the contrary, He wants our happiness. He is the God of the Beatitudes, those pathways that open up in his or her life where the child may think that God wants to punish him or her through his or her illness. The reality is the opposite: He is at the side of those who suffer, the sick and the poor.

3.2 The feeling of impotence

According to the nature of the illness, the child may be relatively isolated in hospital or in his or her own home, without the right of having contacts except with his or her parents and at times with his or her siblings. The treatment, the tiredness that this provokes and the increased surveillance that is engaged in to ensure that the child does not get harmed in the case of risks of haemorrhages all restrict human relationships and at times limit certain forms of physical activity. Physical contacts are circumscribed and all the child's favourite sporting activities are forbidden. The child may experience and associate these prohibitions as and with punishments, given that he or she does not have the right to go out, to meet friends of his or her age and to play with them. Once again, the child feels impotent in the face of all these restrictions which exclude him or her from a group of children of his or her same age.

The physical sufferings connected with illness and treatment run the risk of being experienced unconsciously by the child as a physical punishment and a deliberate wickedness committed against him or her. For a long time suffering and pain were associated by the child with wrongdoing carried out by someone and wellbeing and the pleasurable things of things were connected with the goodness of somebody else. From the outset he or she thinks that he or she deserves the punishment of suffering because he or she has not been sufficiently sensible and in this way he or she may direct all of his or her aggressive charge against his or her own parents or siblings.

Faced with all the prohibitions that limit the activities in which children usually engage, he or she feels subjected to a medical authority where the medical staff and his or her parents implement the orders that are given. The child is precluded, for example, from having access to sports and control over his or her body and is thereby deprived of doing what he or she usually does in his or her development in order to affirm his or her independence and autonomy. The child is led back to a passive stage in his or her development when he or she completely depended on his or her family relatives to live. A feeling of regression and self-spoliation impedes him or her from choosing people and centres of interest that are different from his or her parents. The child runs the risk of remaining in a mere relationship of fusion with his or her mother, something that is extended to all the people that he or she encounters to meet his or her need for maternalism.

The child is thus confused in an unpleasant situation of impotence and it is not enough for him or her to be wise to recover and leave the hospital, something that he or she had been taught in other matters. The working injunction 'if you are good Father Christmas will bring you presents' is no longer effective. His or her magic thoughts will no longer those produce positive results that were previously taken for granted: the illness continues on its course and the moment when he or she will leave the hospital is no longer foreseeable. The child runs the risk of developing a loss of self-esteem, which is all the more accentuated because the medical doctors are interested more in only a part of his or her body that is to be treated than in his or her person and the centres of interest of his or her age.

We must pay especial attention to this reducing effect which can modify the image that a child, a pre-adolescent and an adolescent can have of themselves. They run the risk of interpreting certain medical prescriptions and limitations as prohibitions on being and on being like others of their age. Some adolescents who have lived in these conditions encounter serious difficulties once they have become adults in freeing themselves from them, in socialising and in valuing themselves through professional activity.

It is important for the child to be seen by adults as a being going forward into the future, called to grow and to improve with the support of his or her parents and the other adults that have responsibilities towards him or her. The encounter with Christ through the Gospel will help the child spiritually to find this support and to learn to esteem himself or herself because he or she is loved and willed by God. The feeling of impotence experienced by the child finds a solution in spiritual terms in the fact that he or she can be himself or herself only through another, that is to say Christ. And in

speaking to God in prayer, the *confessio*, the child will free himself or herself from an omnipotent and chimerical imagination and enter all the possible facets of the real. Christ is the guide, the initiator of the real, He through whom we can become. The child can become himself or herself only through Christ.

3.3 At the margins of the family

It often happens that family life is upset when the grave illness of a child is announced. The members of the family will then live according to the rhythms of the treatment, the medical tests and the development of the illness, making other concerns become of secondary importance. The family develops a new dynamic by placing the sick child at the centre of things and adopting a protective and indulgent approach to him or her.

The benevolent approach of the family relatives towards the sick child will give him or her the impression that most of the educational principles that inspired the behaviour of his or her parents have disappeared. This situation creates in the child a morbose worry. He or she thinks that he or she has a new power over his or her parents but he or she soon realises that this is not due to knew skills that have been acquired thanks to his or her aptitudes but is simply the result of his or her frailty and weakness, This liberality reveals to him or her how difficult it is to establish relationships with him or her. He or she no longer appears as a child like other children who depends on the authority of their parents – he is seen as a sick child. Suddenly he or she finds himself or herself isolated in relation to other people. Paradoxically, the delicate and permanent attention paid to him or her by those who are near to him or her put him or her to one side and marginalise him or her.

The child can be afflicted by the dizziness of the image that is sent back to him or her whereby he or she could be free to do what he or she wants, to 'do anything', and not to have limits. Such an attitude confines the child in worry and the guilt at the idea that he or she can manipulate his or he family relatives at will. The image of the tyrannical child or adolescent runs the risk of frightening him or her, given that he or she does not find in front of him or her any requirements or any opposition to his or her desires, deprived as he or she is of reliable and solid adults at an age when a child needs and respects authority and the strength of his or her parents. Suddenly, he or she can feel weakened given that he or she has to rule without restraint over his or her entourage.

A sick child often rebukes himself or herself with having caused pain to his or her parents and with increasing through his or her needs the worry that burdens them because of the tribulation that his or her illness represents. He or she is afraid that he or she will be loved less because he or she feels responsible for their suffering. For this reason, it is of determining importance for the parents to conserve all of the educational requirements as regards their sick child and to see that child in his or her role as a child who still needs to learn the codes of life. The educational context and its needs have to be maintained. It is evident that the situation is not always easy to control, above all when the child, in accepting the medical treatment, suffers because of it as well and feels the need to take vengeance for the wrong that has been done to him or her. Usually, the child directs his or her aggression against his or her parents and makes them pay for what they have not managed to impede, namely the illness, the medical treatment and the admission to hospital.

He or she is often invaded by ambivalent and paradoxical feelings towards himself or herself and towards those who surround him or her. He or she wants to protect them from his or her illness and suffering, at the same time making them responsible for what has happened.

He or she does not yet have the cognitive instruments and the emotional maturity that will enable him or her to express his or experience in words. His or her parents have the tendency to see their sick child and to deal with him or her beginning with their own experiences, which are extraneous to him or her. Misunderstandings, irritations and aggression come to complicate the relationship and at times provoke dramatic forms of incomprehension, in particular when the child or the adolescent, in becoming aggressive, refuses to see his or her parents, and closes up in himself or herself to the point of refusing any relationship with other people.

The parents thus need to understand the various psychological reactions of their own child so as not to be destabilising and add a feeling of guilt to a feeling of impotence. We must concern ourselves with communication with the child in order to explain to him or her simply what is happening, and at the same time remain in our position as adult educators in order to find the pedagogic instruments that take into account his or her classic interests as a child and an adolescent and find a solution to the difficult situations that may be experienced. He or she must be seen at every moment as belonging to the family and his or her age band. A visit by friends or the sending of messages by a mobile phone or Internet constitute valuable help.

Faith in Christ involves moral consequences and enjoins conduct that is consistent with the words of the Gospel. A child perceives this and is ready to understand this. He or she will have to discover that faithlessness to the words of God can be forgiven. He or she is sensitive to the fact that whatever the situations in which he or she finds himself or herself the requirements are maintained. But they will be presented in gospel sweetness and in divine mercy so that he or she realises that he or she will always be loved by God. In the name of this love we can invite him or her to have a realistic outlook so that he or she becomes freed from the idea that he or she is responsible for his or her illness, the cause of the suffering of his or her parents and their inability to heal him or her. It is the task of the catechesis to stress the fact that God opens us to the sphere of what is possible in life.

Conclusion

The pastoral relationship with sick children is developed in this singular context. Most of the time it

is possible to treat them with the pedagogic help of the family relatives. At times we are struck by the maturity, given their age, that some children acquire when faced with illness. They know how to speak about their illness, how to fight, how to help other children, how to console their loved ones and how to pose essential questions.

'What does God accept me being ill?' 'What have I done to be ill?' 'Will God protect my parents when I am dead?' Some children, both those who have attended catechesis and those who have not, often express these questions which we have to accompany. We should also enrich their relationship with Christ and with Christ the sacrament, drawing inspiration from the numerous episodes in the gospels that tell us about the healing of sick children. The daughter of Jairus (Mk 5:40) whom Christ invites to rise up as a pre-announcement of his resurrection. The daughter of the royal functionary (Jn 4:43-47) whom Christ heals from far away. The daughter of the widow of Nairn (Lk 7:11-17) when Christ shows that he is stronger than the strength of death.

Healing here has a meaning and a spiritual importance that does not leave children indifferent. God does not abandon His children, He is near to them and He loves them for what they are, where a child often experiences a jealous love and excludes all the others before opening himself or herself up to goodness and otherness.

The faith of a sick person is essential. 'Take heart, daughter; your faith has made you well' (Mt 9:22). But faith borne by others is an equally valuable support when a person or a parent implore healing for their own child or another child. Faith in Christ is equally a pathway that has to be followed in order to begin to understand that he wants life for us and eternal life with the Father. Faith can be an opportunity to discover or rediscover God who speaks to us and whose words are salvific. Healing in the gospels is a sign of the forgiveness of sins and of distancing from evil.

These are all spiritual perspectives that illuminate the fear of the child that he or she will be abandoned, of being responsible for his or her own illness or of being the source of the suffering of his or her parents, and even of being placed at the margins of his or her family and of other people. The words of Christ reveal to him that he or she counts in the eyes of God and that with Him he or she can discover his or her own parents, siblings, friends and all those who attend to him or her in order to restore life to him or her.

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JACQUES SIMPORÉ

4. Research and Medicines, Nutrition and Lifestyle

Nowadays, deficiency, infectious, genetic and metabolic pathologies are strictly correlated with lifestyles because of the mutations and fluctuations that have taken place in our modern societies. In order to achieve a defence against the various illnesses that afflict first and foremost children under the age of five and expectant women, all over the world numerous scientific studies are carried out in the spheres of pharmacology, pharmacogenetics, nutrigenetics and genetic categories in order to identify medicines, foods and food supplements that are effective in restoring at a nutritional level, strengthening, and treating people who have been the victims of the consequences of their own inopportune activities.

Indeed, through his behaviour and his irresponsible activities, man provokes nature which rebels and launches numerous challenges in his direction. In its rebellion, nature brings about: 1) the proliferation of infectious pathogenic microbes which cause epidemics, if not indeed great endemics or pandemics; 2) an increase in genetic diseases and tumours provoked by various mutagens which are often toxic products that have been produced by human activity; and 3) droughts and floods that involve, here and there, families and imbalances which every year kill a large number of people in developing countries and the first victims are children under the age of five.

For us, this International conference of the Pontifical Council for Health-Care Workers on this subject comes at the right moment because the lifestyle of each individual influences the physical health of everyone. Like adults, children, too, need pastoral and spiritual accompanying.

The subject of this paper, which is formulated in the following way 'research and medicines, nutrition and lifestyle', fits well into the general subject of this international conference, namely 'pastoral care in the treatment of sick children'. It is my intention to address the subject that has been entrusted to me in three parts: the current lifestyles of people and the principal causes of infant mortality; research and medicines; and a presentation of examples of the recovery of malnourished children through the use of spiruline and misola at the St. Camillus Medical Centre of Ouagadougou in Burkina Faso.

1. The Current Lifestyles of People and the Principal Causes of Infant Mortality

A large number of the pathologies of adults such as diabetes, hypercholesterolemia, obesity and cardiovascular diseases are closely linked to lifestyles. These last can often bring about, directly or indirectly, a large number of illnesses in children. Some examples explain this:

1.1 At the level of genetic diseases and tumours

We know that 10% of tumours are hereditary and that at least two mutational events are needed for the process of cancer formation to begin.[1] Parents who have gene mutations of specific alleles due to ionising factors can transmit very specific genetic diseases and tumours to their children. In addition, because of the duration of their education and the pursuit of a professional career, many young people marry late. It is very evident that a woman who marries after the age of thirty and wishes to have a child at the age of thirty-five, for example, has a strong likelihood of generating a child with triosomy 21! We know how much children with Down's syndrome suffer and how much they need psychological and spiritual accompanying.

1.2 At the level of infectious diseases

When certain infectious diseases are contracted (measles, toxoplasmosis, HIV/AIDS, hepatitis B…), which can be transmitted from mother to child, we understand that the lifestyle of parents can directly influence the health of their children. Measles and toxoplasmosis in a pregnant woman often involves a co-infection[2], a malformation of the foetus, whereas HIV and the virus of hepatitis B provoke respectively in the child AIDS[3] and cancer of the liver. In addition, endemic illnesses such as malaria, cholera, meningitis, polio, dehydrating diarrhoea, etc., which are widely present in tropical areas and every year kill millions of children, arrive because of a lack of hygiene, a lack of education in adults, and a lack of suitable health-care organisation.

1.3 At the level of malnutrition

Because of drought, floods and climatic changes caused by out lifestyles, today two billion people suffer from malnutrition and eighteen million people die every year from hunger.[4] In developing countries, 146 million children under the age of five are under weight, beneath the average weight, that is to say one child in every four.[5] Sixty million children under the age of five suffer from emaciation (about one in every ten). In Africa and Asia anaemia is factor in 20-23% of all post-birth deaths.[6] As a consequence, every year malnutrition is at the origin of a half of the deaths of children under the age of five.

This situation is characterised, on the one hand, by over-alimentation (in the West) which provokes obesity and by hypercholesterolemia which induces diabetes and cardiovascular pathologies, and, on the other, by under-alimentation (in developing countries) which leads, above all in children, to various forms of deficiency, to kwashiorkpor, to marasmus, and, finally, to death. Table I describes infant mortality in the world in 2005.

Table 1. Infant mortality in the world in 2005

Infant mortality by region in the world 2005			
Region	Deaths of children under one		Percentage of dead new born children (in thousands)
	Number (in millions)	Distribution (%)	
Asia	4,08	54	46
Africa	3,06	40	90
Europe	0,05	1	8
Latin America	0,34	4	23
North America	0,03	0	6
Oceania	0,02	0	27
World	**7,57**	**100**	**49**

Source: Nations Unies 2007, *World Population Prospects, the 2008 Revision,* Fiche pédagogique, INED, www.ined.fr

2. Research and Medicines

Eighty years after the discovery by Sir Alexander Fleming of penicillin B (3 September 1928), and over a hundred years since the research carried out by Louis Pasteur, antibiotics and vaccines allow us to fight in an effective way against a large number of infectious diseases. Taking advantage of advances on genetics and biotechnology, researchers are still working today on the creation of new pharmacological products against malaria, meningitis, cholera, Ebola, Alzheimer's disease, cancer, AIDS, etc. The future of medicine lies in the new treatments that modern industry will make available to human society. The years to come promise numerous discoveries in the field of biotherapy (gene therapy) thanks to the use of the techniques of pharmacogentics, nutrigenetics, microarray and thanks to greater knowledge about the human genome.

2.1 In the field of genetics

So far in the whole world over five thousand hereditary diseases have been identified. Thanks to predictive medicine, in children a large number of genetic or metabolic diseases such as phenylketonuria, lactose intolerance, gluten intolerance, etc., can be avoided. Indeed, every year various research articles are published on these subjects.

As regards chromosome disorders such as trisomy, numerous studies try to understand, in the case of children who are afflicted by Down's syndrome, the mechanisms of co-morbidity in order to reduce their suffering through treatment.

It is estimated that in the world about 242,000,000 people suffer from various types of anaemia linked to genetic changes. In Africa and America, drepanocytosis kills about 100,000 back children every year. In this field a great deal of pharmacological research carried out both in Africa and in the West exists. In Burkina Faso we have FACA created by Professor Pierre Innocent Guissou; in Benin VK 500, discovered by Dr. Jérôme Fagla Médégan; NICOSAN, whose use against drepanocytosis is the subject of controversy in Nigeria; without forgetting about the benefits of the new anti-drepanocytosis product, HYDROXYURÉE (Hydrea®).

In addition, through pharmacogenetics or pharmacogenics, using the revolutionary techniques of microarray, doctors no longer waste time in finding the right pharmaceuticals for their patients because each sick individual, thanks to molecular hybridisations, receives a pharmaceutical that corresponds to the identity of his or her own genetic inheritance (genome).

2.2 In the field of infectious diseases

In the field of infectious pathologies, various scientific teams in the world are working on research into pharmaceuticals or vaccines against pathogenic germs such as *Plasmodium falciparum*, the measles virus; the cholera vibrion; the meningococcus; HIV, Koch's bacillus, the hepatitis viruses, etc., which each year infect and kill millions of people and above all a very large number of children.

2.3 In the field of malnutrition

In this field, throughout the world various non-governmental organisations (NGOs), non-profit-making humanitarian associations, research structures and small industries for the transformation of food are working to create complexes of nutritive enriched flours and food supplements to achieve the nutritional recovery of malnourished children. And thus we have; XEWEUL FLOUR (enriched with spiruline) in the Niger; PRÉMIX (dry flour mixed with oil) in France, GARIN KWAMUSO (flour for the malnourished) in Nigeria, manioc flour in the Ivory Coast; NIGUE-FARINE, enriched flour in Chad; FAMEX (a mixture of maize and soya flour) in Ethiopia; MISOLA (millet, soya, peanuts) in Burkina Faso; and SPIRULINE in Latin America, Europe and Africa…

At the dawn of the era of personalised medicine, nutritional genomics or 'nutrigenomics', which studies the interactions between genes and alimentation, will cer-

tainly contribute to a better adaptation of the alimentation of individuals (children, adults and the elderly) not only to their genotype but also, and above all, to their phenotype. This new knowledge will allow the prevention of the outbreak, or the slowing down, of the advance of pathologies in individuals who are made vulnerable because they have specific genetic polymorphisms. Nutrigenomics corresponds, therefore, to the study of the genes involved in the absorption, the transport, the metabolism and the elimination of nutriments, and in the mechanisms of the action of nutriments and their metabolites.

3. Description of an Example of the Recovery of Malnourished Children Using Spiruline and Misola at the St. Camillus Medical Centre of Ouagadougou, in Burkina Faso.[7]

Burkina Faso is one of the sub-Saharan countries most afflicted by malnutrition and this constitutes a grave problem of public health. In this country 50% of all deaths of children under the age of five are linked to (grave or moderate) malnutrition and 38% of children under the age of five have an insufficient body weight.[8] The protein-energy malnutrition (PEM) of children under the age of five constitutes a problem of public health which, together a high incidence of infection by HIV/AIDS, accentuates the problems of nutrition in the case of children. The fight against poverty in Africa, begins, therefore, with the recovery of malnourished children who are the hope for tomorrow.

The aim of this study is assess the impact of food supplements made up of spiruline (*Spirulina platensis*) and misola (millet, soya, peanuts), produced at the St. Camillus Medical Centre (SCMC) of Ouagadougou, Burkina Faso, on the nutritional state of malnourished children.

Material and method

This study was carried out on 550 malnourished children under the age of five, 455 of whom had cases of grave marasmus, of whom had marasmus of average gravity and of whom 38 had kwashiorkor, which is associated with marasmus. We divided the children on a random basis into four groups: the first group – 170 children took misola (731 ± 7 kcal a day); the second group – 170 children received spirulina in addition to usual means (748 ± 6 kcal a day); third group: 170 children received spirulina with misola (767 ± 5 kcal a day); the fourth group was the control group: 40 children received only usual meals (722 ± 8 kcal a day).

The weight of the children was measured once a week until they were admitted to the Centre for Nutritional Recovery and Education (CNRE) with scales sensitive to units of ten grams. Their height was measured by placing them on their sides whereas children over the age of two had their height taken when they were standing up. Their nutritional status, assessed with brachial perimeters, was compared to the Jellife classification,[9] taking into account the fact that this varies little in children under the age of four. The study lasted eight weeks.

Results

Table 2 shows the anthropometric parameters of the children at the beginning of our study. The anthropometric measurements to which they refer were comparable except for the HAZ of group C. In addition, according to VIH serology, no significant difference was observed in these parameters: HAZ, WHZ, WAZ and BP.

We may observe that there was a physical improvement in all the children after the eighth week of nutritional recovery. We find in a more significant way this increase in weight in the group that received misola and spirulina. These changes in status between the treatment groups are described in Table 3.

Table 2. Anthropometric parameters of the children examined in the study[a]

	A 170 children with Misola	B 170 children with Spiruline as well as usual meals	C 170 children with Misola and Spiruline	D 40 children with usual meals	Analysis of variation
Age (months)	15,39±8,3	14,96±5,9	13,86±8,5	15,19±4,35	P = 0,269
Height (cm)	67,00±8,3	69,84±5,8	69,06±8,5	68,24±4,5	P = 0,005
B.P.	11,17±1,2	10,40±1,0	11,20±1,2	10,37±1,0	P = 0,0001
Weight (kg)	6,12±1,4	5,98±1,1	5,99±1,5	6,10±1,2	P = 0,741
HAZ	-3,93±5,3	-2,64±2,1	-3,35±5,3	-3,23±1,5	P = 0,057
WHZ	-1,73±2,5	-2,88±0,9	-3,05±0,75	-2,32±1,02	P = 0,0001
WAZ	-4,01±1,0	-3,88±1,0	-4,38±0,9	-3,99±0,9	P = 0,0001

[a]HAZ = Height for age z-score; WHZ = Weight for height z-score; WAZ = Weight for age z-score, B.P = Brachial Perimeter.

Table 3. Nutritional status at the beginning (1) and at the end of the study (2).[a]

	A 170 children with Misola	B 170 children with Spiruline as well as usual meals	C 170 children with Misola and Spiruline	D 40 children with usual meals
WHZ1 1→ 2	-1,73±2,51 P=0,035*	-2,88±0,95 P=0,000	-3,05±0,75 P=0,000*	-2,42±1,02 P=0,065*
WHZ2	-1,14±2,64	-1,80±1,53	-1,18±1,63	-2,00±0,99
WHZ2/ WHZ1+WHZ2	34,14%	37,50%	62,90%	17,35%
WAZ1 1→ 2	-4,01±0,98 P=0000**	-3,88±0,90 P=0,000**	-4,38±0,91 P=0,000**	-3,99±0,9 P=0,013**
WAZ2	-2,95±1,12	-3,10±1,14	-2,71±1,17	-3,45±1,0
WAZ2/ WAZ1+WAZ2	26%	20%	38%	14%

[a]WHZ1 = Weight for height z-score at beginning of the study; WHZ2 = Weight for height z-score at the end of the study; WAZ1 = Weight for age z-score at the beginning of study; WAZ2 = Weight for age z-score at the end of the study. Student T test *WHZ1àWHZ2; **WAZ1àWAZ2 ;

Table 4 shows the biochemical composition of every 100 grams of misola used at the CNRE and the lipid composition of this product in which the acid content is made up of palmitic acid, linoleic acid, oleic acid, linolenic acid and palmitholeic acid.

The composition of the culture of CNRE spiruline is presented in Table 5.

The lipid composition of Spirulina in Burkina Faso is taken from Table VI. The acid contents are: palmetic acid, linoleic acid, oleic acid, γ-linoleic acid, stearic acid and plamitholeic acids.

Figure 1.
Creating spiruline in tanks

Table 4. Nutritional composition of 100 grams of misola used at the CNRE

Biochemical composition	Principal concentration
Lipids	12%
Proteins	16%
Glucides	61%
Calories (kcal/g)	410

Table 5. Nutritional composition of every 100 grams of spiruline cultured at the St. Camillus Medical Centre compared to levels in the data of international literature (Green Flamant, 1998)

	Our results	Green Flamant levels
Water content	4.87%	3-7%
Ashes	10.38%	7-13%
Vegetable fibres	7.81%	8-10%
Lipids	6.00%	6-8%
Proteins	57.10%	55-70%
Glucides	13.84%	15-25%

Table 6. The composition of fatty acids of Spirulina in Burkina Faso

Fatty acids	Wt % of total fatty acids
Palmitic acid, 16:0	28.04
Palmitholeic acid, 16:1 (9)	2.69
Stearic acid, 18:0	13.44
Oleic acid, 18:1 (9)	18.88
Linoleic acid, 18:2 (9, 12)	21.87
γ-linoleic acid, 18:3 (6, 9, 12)	15.08

Misola, which has a 61% rate of glucides with 410 kcal/100g, has an energy content that is higher than spiruline which has only a 13.84% rate of glucides with 338 kcal/100g. In contrary fashion, spiruline, which in addition is an anti-oxidising substance, has a 57.1% rate of proteins, whereas misola has only a 16% level. In addition, spiruline with its component of -6 of lipids contributes to an effective recovery of the immunity system of children.[1] These results confirm how through the administeration of misola with spiruline (this association provides an energy input of 767 ± 5 kcal/a day with a hypothesis of proteins of 33.3 ± 1,2 g a day), one obtains an efficient food for the recovery of malnourished children who are afflicted by the HIV/AIDS infection.[11]

In this way, through this project, the acute malnutrition of children has been corrected. However, it remains high at a global level. It emerges, therefore, from this research, that in countries with limited resources the nutritional recovery of malnourished children is possible by using spiruline and misola as food supplements and complements.

Conclusion

Yesterday's scientific research constitutes the medical treatment of today, and the studies carried out at the present will shape the medicine of tomorrow. Together we support scientific research with the aim of opening up new pathways of treatment for the medicine of the future. Certainly, as we have seen, through their behaviour and their lifestyles parents can foster the development of specific pathologies in their children. But as Scripture says: 'In those days they shall no longer say: 'The Fathers have eaten sour grapes, and the children's teeth are set on edge. But every man shall die for his own sin; every man who eats sour grapes, his teeth shall be set on edge''[12]

But today, faced with the numerous diseases that afflict innocent children, such as the vertical transmission of HIV which produces AIDS in children who are breast fed, teratogenesis, malformations produced by *Toxoplasma gondii* and measles in unborn children, or the forms of trisomy that blindly attack foetuses, scientific research does not appear to be able to eradicate these pathologies in the short term. What should be done for these sick children? How should these children who die without reaching the age of reason be accompanied at a pastoral level? In the face of these paediatric sufferings, faced with the powerlessness of medicine in offering healing, we are disorientated. But for believers, as we are, our help lies in the Name of the Lord!

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Note

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[12] Jer. 31:29-30

MARIA JOSEP PLANAS, MAGDA BOLTÀ, GUILLEM PUCHE

5. How to Adapt the Hospital Environment to the Social Context of Children

THE 'HOSPITAL FRIEND' PROJECT. THE ST. JOHN OF GOD HOSPITAL, BARCELONA

1. Introduction

A hospital for the most part is a place where children interact with pain and fear. Numerous studies maintain that the psycho-social characteristics of paediatric patients mean that their perception of the environment and the emotional experiences associated with the process of hospitalisation need special attention in order to avoid negative consequences during the period of childhood. For families as well, the admission of a child to hospital generates special emotions, which at times are difficult to work through.

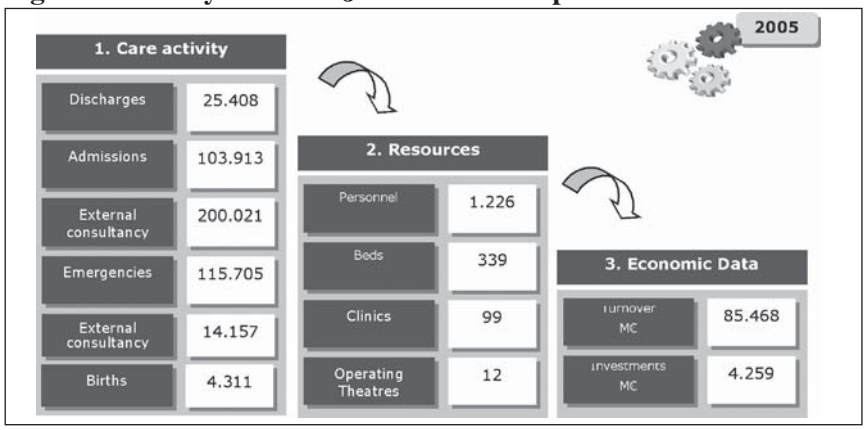
And it is obvious that given its nature and the way it works the hospital environment has a great capacity to produce stressful environmental conditions. In the case of children, this process is even more accentuated, specifically because of the special features of a child's cognitive interpretation of the environment that surrounds him or her. It is also true, however, that these same special features of children who are patients allow, with relative ease, the obtaining of positive stimuli that have a contrary effect and act as environmental conditions that involve ease of mind for children.

Strong in this belief, the Hospital Friend project seeks to have an influence in a positive way on the hospital experience through a significant institutional policy in order to obtain the best environmental conditions which can then generate ease of mind for patients. It works with a broad fan of possibilities that go from the smallest daily detail to a total change in the image of the hospital and through a general plan of reforms and direct intervention upon the model of care and treatment.

2. Precursors

The St. John of God Hospital is a mother-child monographic centre in Barcelona and is owned by the Hospital Order of St. John of God. The most relevant statistics regarding this hospital are as follows:

Figure 1. Activity of the St. John of God Hospital



In order to offer care that is directed towards the person in his or her entirety, the St. John of God Hospital initiated some years ago an initiative that seeks above all else to reduce to the utmost the negative impact of admission to hospital for children. The actions taken in this direction have been placed under the heading 'area of hospitality', employing the etymological meaning of the term. It aims to ensure, that is to say, that a person who is admitted to hospital feels at his or her 'own home', with the allocation of resources and services beyond the mere level of health care which will help children and their families to live out the hospital experience in the least traumatic way possible.

Subject to the coordination of this area, various services have been grouped together that are particularly aimed at securing this objective: a school, a playroom, the work of volunteers…In addition, with the passing of time and animated by an observation of the benefits that are really obtained for children, the workers begun in a spontaneous way to contribute in a spontaneous way with their own ideas and projects, all of which have the same goal.

In the year 2004 and within the context of the drawing up of the strategic plan of the hospital for the following years, it was decided to go beyond this as regards the aims of the hospitality area and to consider a minimisation of the emotional impact of the hospitalisation of children as an authentic *institutional policy* which, in a transversal way, will have an impact on all the areas of the organisation of the hospital.

Two fundamental strategies were the cutting edge of this policy: the first was to strengthen and to increase the services of the hospitality area (the field of services) and the second was to 'paediatrise', so to speak, the hospital (the field of structures) with the idea of transforming it into a place that is truly for children.

The development of work in both these initiatives led with the passing of time to us understanding that both

the services and the structures formed a part of the same objective, and this is why they were placed together in a common programme. Thus was born the Hospital Friend programme.

The first action (which was a constituent part of the programme) was the adoption by the hospital of a decalogue of commitments, beyond simple intentions, which was to form a part of the culture of care within the centre and which at the same time was to guide the actions of the programme, thereby creating an authentic institutional policy for the whole of the organisation of the hospital.

This decalogue was the following:

1. The hospital chooses a model of care centred around the family and thus will fully incorporate parents into the care process.
2. The *internal rules and regulations* of the hospital will be adapted in order to meet and uphold the rights of hospitalised children.
3. The hospital will have professionals who are especially trained in *techniques to address situations of stress* or with an emotional charge and/or high level of anxiety.
4. The *intimacy* of children will be respected at all times, with their privacy in relation to all procedures and/or research guaranteed.
5. The hospital will have human and structural means that will allow the continuation of *school studies* in a way that is suited to the clinical status of the children.
6. The children will have the *right to play and engage in recreational activity* and the hospital will thus have the necessary amenities for this.
7. The *information technology supports* will have goals and contents that assure an understanding of them by children, with linguistic and cultural diversities also taken into consideration.
8. The hospital will facilitate *mutual support between families* beginning with movements of associations, with their full incorporation into the dynamics of the centre.
9. The *structures* will be conceived in relation to the accompanying of the family.
10. The *interior design* of the hospital will maintain the philosophy of a hospital for children both at the level of decoration and as regards elements that stimulate a visual interest.

3. The 'Hospital Friend' programme

The Hospital Friend programme concentrates its efforts in three spheres, embracing at the level of principle the whole of the organisation of the hospital, both from the point of view of its internal culture and as regards how it functions and its physical structure. These spheres are:

3.1 The model of care centred around the family

The family for the child is not only his or her source of care and provision as regards his or her material requirements and basic psycho-affective needs but is also the point of contact between him or her and the outside world. To separate the child from his or her parents means to deprive him or her of his or her fundamental reference point, and this is even more the case if the child finds himself or herself in conditions of vulnerability and confrontation as regards what he or she does not know, as happens when he or she enters into contact with the health-care environment.

Redirecting health-care services in order to meet the needs of families raises many difficulties. To pass from a service centred around the child to a service centred around the family requires a new model of care that makes the family an inherent and inseparable part of the object of our health-care action. We need changes in the organisation of the hospital, in the traditional roles of parents of children who have been admitted to hospital, and above all else in the culture of professional workers.

Health-care structures are not necessarily suited to assuring that parents accompany their children at all times. Problems of space, of shared rooms and various other difficulties do not always favour this reality. To this should be added the path still to be taken as regards the culture of the internal working of centres. Today, fortunately enough, nobody contests the fact that parents should not be subjected to visiting rules as regards hospitalisation, but such is not the case in units that are traditionally 'closed', as may be the case with critical care units (CCU, units for new born children…) or, even more, closed places such as operating theatres. In addition, there are regulations which limit entrance to minors and as a result the siblings or friends of a child who has been admitted to hospital are excluded from the possibility of making visits while that child is in hospital. We hear all too frequently nurses tell parents 'please leave for a moment' when they have to engage in some kind of care activity for the child…

The Hospital Friend programme, in its work towards constructing an implementing a model of care that is centred around the family, is engaging in an authentic cultural change that concerns the internal working of the centre. There is a policy of increasing single rooms and services for parents which will have achieved its objective when the general plan of reforms which has already begun has been finalised. What, however, in our view is increasingly important is the model of professional workers: the child is not our child – the child belongs to his or her family. This model of care makes the parents and other actors directly involved in the whole of the process and invites them to absolute involvement in it, from accompanying in the strict sense to direct participation in specific forms of care and treatment.

Together with this idea, it is evident that a policy of adaptation and/or elimination of existing 'rules' should be implemented. We would like to give a few examples of this.

The unit for new born children has faced up to a challenge that would have been unthinkable until a few years ago. Not only is it possible for parents to come into the hospital and stay there for as long as they wish (for them this unit is open round the clock) but we have gone beyond this and visiting hours have been established for the baby's grandchildren and siblings (when the babies are in incubators as well). The neonatal team, understanding to the full the model of care centred around the family, sees in the members of the family who are directly afflicted (grandparents and siblings) an authentic condition of stress which can endanger their emotional balance. In definitive terms, the

family is attended to in concrete terms and it is not the new born child alone who is cared for.

A final detail on this unit: care at the moment of death. The professional workers make available an area for those parents who wish to accompany their child at that moment and thus the baby dies in their arms.

The team of professional workers of the paediatric CCU is making the internal rules and regulations more flexible to the extent that the current structure allows this, while at the same time awaiting the new project that will offer a CUU with single rooms and conditions such as to allow parents to stay there (sofa beds, hygienic services…). The new monitoring technologies will allow us to apply the protocol of minimum intervention which places all of the acoustic stress (monitors, alarms…) outside the room so that inside the room there is an environment of silence. Obviously enough, the availability of individual areas will allow the utmost personalisation of the environment of the child, with his or her 'reference' games and toys, a special interior decoration, etc.

The nurses do not ask the parents to go outside, but, instead, they invite them to work together with the activities they are about to engage in. It is always better for the mother to hold the arm of the child when a blood sample is being taken than making the child feel that he or she is surrounded by two or three people in white coats and is immobilised against his or her will. Most of the time the immobilisation itself is more traumatic than the actual taking of a blood sample.

In the emergency unit no child enters without being accompanied by his or her parents and the children have someone special to accompany them when they enter the operating theatre – a suitably shaped doll who accompanies them until they lose consciousness totally because of the anaesthetic.

3.2 The strengthening and broadening of direct services

In this field we propose interrupting as little as is possible the daily aspects of the child. If we want to think of the fundamental points in the life of a child in normal conditions, probably we will declare that they are: his or her family, school, games, friends… The hours that the child spends in the room should not be allowed to be dead hours. They should be filled with contents that are usual for the child, even though, of course, it is the health of the child that is attended to first and foremost.

The role of the child's school is of fundamental importance not only as an element of recreation but also an important factor of continuity (above all in specific pre-adolescent age bands). In addition, we have the technology to deal with this dimension. The teachers of the children, in fact, are connected with the children through webcams located in the room of the children and the children can thus 'see' their teachers, their schoolmates…

Playing is the quintessential activity of childhood. Through playing, children develop their imaginations, connect to daily reality, and learn about the adult world that surrounds them. At the same time, this enables them to deal with both the vicissitudes that their own growth presents them with and the traumatic situations that they have to experience, of both an internal and external nature.

The playful and creative forms of behaviour of children meet the fundamental requirements of their development. When a child has been admitted to hospital not only do these requirements not disappear but they actually acquire a special meaning as regards his or her psycho-social wellbeing. At times the child's imagination and natural vitality decrease and the child withdraws – he or she stops talking, playing or smiling…We know that some children need to withdraw in order to 'conserve their energy' and address the situation they find themselves in, but we have also observed that if we stimulate them to express themselves, to relate to others, to play and to have fun this can help their mental health and also the more successful evolution of their illness.

To summarise, playing and laughter are a vital need for children and constitute one of the most effective instruments there is in facing up to hospitalisation. Understood as instruments, they are transformed into support for the fundamental work of the child life specialist[1] in therapeutic action with children as regards situations of pain or especially grave interventions.

The child life specialist incorporates medical experiences into the games in order to improve the child's understanding of what is being done to him or her at a health-care level and gives children an opportunity to express themselves and allows them to adapt to their health-care situations through play therapy.

In striving to interrupt as little as possible the daily routine of the life of the child, it is evident that the hospital must have its own life and be a place where things happen. The same events that the child would have celebrated if he or she had not been admitted to hospital must be celebrated. He or she must be able to encounter a magician or a doll in a corridor, or a person playing music. Thus his or her birthday cannot be ignored, and the same may be said of the carnival celebrations, Christmas, Epiphany, the arrival of spring, of autumn…In all of this the voluntary team of the hospital (which contains over two hundred people) constitutes a fundamental part of the Hospital Friend programme.

3.3 Structural aspects

Still today an idea of what a hospital is exists that is centred around the treatment of illness and which bestows very significant relevance on medical technology and the bio-health-care control aspects. However, as regards emotional wellbeing and comfort, this idea of what a hospital should be still has a long way to go. This was the dominant idea of what a hospital should be from the end of the nineteenth century until the end of the twentieth century. Fortunately, in recent decades trends have been observed at an international level which place emphasis on

making technological progress compatible with more realisable projects of achieving the overall wellbeing of children who have been admitted to hospital and their families (this happens, for example, in all the children's hospitals of the United States of America and in some European hospitals as well[2]).

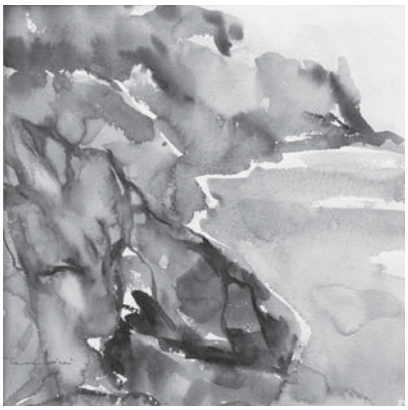
An unknown physical space is transformed into a space to which the child soon attributes meanings which will constitute one of the fundamental bases for how he or she will later remember his or her experience in the hospital. It is easy to understand how for children and their parents, hospitals as a physical and social space are associated with very emotionally negative memories. The design of spaces for children must focus on the form in which they are perceived and interpreted by children and their families And this is our challenge we are facing up to with our reform plan.

Care for children in hospitals will improve if the spaces are conceived of as spaces of overall health for them, which does not mean an increase in resources but, rather, a change in approach as regards their management.

The new image diagnostic service at the St. John of God Hospital

The fundamental principle of these new programmes is based upon the idea that the physical environment must be seen as a part of the process of recovery so that a model of care that is centred around the needs of the child and his or her family is strengthened and developed. Here one may refer to: single rooms with a space for the family relatives; furniture in the rooms which is specifically suited to children as regards colours, forms, scale…; wall decorations of common landscapes and known places; audiovisual equipment of various kinds; coloured pyjamas; the uniforms of the health-care staff; knives, forks and spoons for meals; technology 'concealed' behind sliding screens at the foot of beds (they are only seen when they are used); play areas; areas for families; and areas reserved for parents where they can link up to Internet.

It is clear that certain initiatives will require an additional cost but one is not dealing here with luxuries – a view that despite everything still continues – but, rather, of small details which in the view of a very large number of studies have positive effects on the health of patients. At times with very simple things that are neither expensive nor complicated quality is achieved and added value is bestowed upon the space concerned. One needs only to give more time to this project.



For example: in the daily life of the hospital the children are constantly transferred to other departments and sections (the x-ray department, rehabilitation, a specific laboratory for analyses…); if we think about it, the means of transport that is always used is a wheelchair (obviously other types of transfer require a trolley). Why, then, *always* a wheelchair and not a trolley that is like a toy? At least five of these last could be bought for one wheelchair.

The same should be said about the inside of rooms: is it always necessary to keep in view all the 'artefacts' that make up the head of the bed? In the eyes of the children these beds are not in the least similar to those that they have in their homes. It is absolutely possible to 'conceal' technology behind mobile screens which show that technology only *when* this is necessary. Other examples: in all hospitals information is printed for families. A leaflet with coloured drawings and a format for children has the same cost as one that is 'serious' and cold in tone.

In addition, a white wall costs the same as a coloured wall. And for a little extra money one can replace a white sheet with a coloured one or one with patterns, or a white shirt with a printed one. If one carries out a little 'research' on Internet one is surprised to discover the quantity of health-care products that have been specially designed for children, from phonendoscopes that are coloured and have figures on them to machines to measure blood pressure which are also coloured, and on to stethoscopes in the form of elephant's trunks…the number of such products limitless! It is all a matter of believing that this is important, of dedicating a little time, money and above all else… enthusiasm.

4. Conclusions

With this action plan, which in our hospital is already a reality (the programme is being developed with some services operating to the full whereas others are being implemented and yet others are awaiting funding), we wish to emphasise that a combination of *care* and *accompanying* in our *institutions* can be a perfect combination by which to adapt the hospital environment to the family and social context of children, and that it can bestow added value on care, placing to the forefront the values that characterise, in our case, the institutions of the Hospital Order of S. John of God.

'Treat families as they would like to be treated. If families see the professional worker as defender of their child and his or her family, then probably that professional worker is contributing to improving that child's quality of life'.

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Notes

[1] The child life specialist is a figure that began in the United States of America in the 1980s and was connected with the movement to achieve less traumatic hospitalisation for children in American children's hospitals. This figure is a specialist who is specifically trained to provide children with all the support that they need when health care is provided to them, ad employs a methodology that is very much based on the use of playing as an instrument for learning and for the expression of the child's feelings and fears.

[2] The A. Meyer Hospital of Florence, the Evelinas Children's Hospital of London ,and the Hôpital de l'Enfance in Lausanne.

CLAUDIO M. CELLI

6. Pastoral Care in Health and Care for Sick Children from the Socio-political point of View: the Social Media of Communication

Good communication is at the heart of good medicine. Valid health care needs doctors, patients and parents, as in the case of care for sick children, to be able to communicate openly and sincerely with each other. This insight is expressed in a concise way by the Ethical and Religious Directives for Service in Catholic Health Care of the Bishops' Conference of the United States of America: 'A person who needs care and a health-care professional who accepts that person as a patient enter into a relationship that requires, among other things, mutual respect, truth, honesty and the right confidence. The consequent free exchange of information must avoid manipulation, intimidation or condescension. In this way, the relationship allows the patient to reveal the personal information that is indispensable for valid care and allows the health-care worker to use his or her own professional skill to maintain or restore the health of the patient. The health-care worker and the patient should never act independently of each other; both contribute to the process of healing.

This paper wants to begin with this approach in order to prepare the ground for an exposition that will analyse the use of new information and modern technologies in the care of sick children. These technologies can make communication more immediate and effective but they should not alter its essential human nature. They can bring benefits to medicine and to those who need medical treatment only if communication, which they facilitate, is based upon the values of honesty, respect and privacy.

The increasingly complex context in which health care takes place requires information to be shared by the largest number of specialists possible in order to assure that the patient is benefited by the most research and knowledge, by the most effective therapeutic technologies, by surgery and by pharmaceutical products. The recent developments in information and communication technology have revolutionised the speed with which important news can be exchanged and have made possible the supply of information and having access to it independently of distance. Many different terms are used (tele-health, e-health, online health care and tele-care) but in definitive terms all of these terms refer to the use of information and communication technology (ICT) to assure health care. A recent article on the subject provided an effective summary of the potential developments in this field: 'the progressive increase in the speed of the transmission of data on Internet will allow an audiovisual explosion that will greatly benefit the health-care professional. The multi-media world is truly important in medicine and thus Internet will be encouraged as an indispensable instrument to advance medical education, tele-medicine and the management of health care. The development of the wireless system could be the missing piece in this complex mosaic, establishing a link between the doctor, the patient, electric medical documentation and our daily needs' (L.G. Pareras, 'Minimally Invasive Therapy and Allied Technologies', March 2002).

I would like to emphasise a list of these developments and their use in the provision of paediatric health care, in educational and preventive health care, in the organisation of health services and in care for sick children and their families. Lastly, I would like briefly to identify certain challenges that the new technologies can raise for a culture of health care.

Probably because of the enormous scale and long tradition of mobile medicine – all of us remember the 'flying doctors' – Australia has been a pioneer in the use of ICT for paediatric health care or, as it has been called, 'tele-paediatrics'. A teleconference is used to allow children, together with the local doctors and their families, to have a consultation with the best specialists without having to travel and interrupt their family and school lives. E-mail is used to transmit digital images, x-rays and clinical information to doctors for the purposes of specialist care and to have a second opinion. The recording of all the information of the patient and his or her clinical history online allows a sharing of information with the most important specialists. Teleconferences have also been used for educational purposes and in certain cases they enable the most expert specialists to supervise and direct the action of local nurses and doctors.

It is clear that this technology is not circumscribed by national frontiers because it allows the sharing of experiences and knowledge beyond geographical boundaries. However, the greater use of the potential of these technologies will require action to ensure that access to the new technologies really becomes universal. As Pope Benedict XVI said to those taking

part in a recent conference organised by the Pontifical Council for Social Communications for the faculties of communications of Catholic universities: 'It would be a tragedy for the future of humanity if the new instruments of communication, which allow the sharing of knowledge and information in a more rapid and effective way, were not accessible to those who are socially and economically marginalised, or if they contributed solely to increasing the distance that separates these people from the new networks that are being developed at the service of human socialisation, information and learning'. I would like to invite you all here present today to consider in what way Catholic hospitals, united in their common wish to guarantee, in faithfulness to the example of Christ, care for all sick people and above all sick children, could create networks on a digital basis marked by solidarity and support.

It is clear that the modern technologies of communication are already making the difference in care for children in the developing world. A recent article which appeared in an African review (*Africa Renewal*, April 2008) called attention to the example of Rwanda: 'The little dusty village of Mayange is twenty kilometres from the capital of Rwanda, Kigali. Its polyclinic has a little more than forty beds but it serves a population of 35,000 people. The centre of Mayange could be like hundreds of other health-care structures in the continent that strive to meet the needs of patients will few resources and staff. But thanks to an innovative association that involves the government, non-governmental organisations and private companies the centre in Mayange is able to use mobile phones to offer better treatment…the health-care workers can accede to records on pregnant women thanks to an online database and then, using mobile phones, they can tell who is providing health care to them what to do during an emergency. The memory of each telephone includes a practical guide for the care of mothers and their children, with images and audio instructions that can be sent to the mothers and their families. This project, even though it has been underway only for a few months, is 'really having a major impact", Dr. Joseph Tyarasa told Africa Renewal. "To reduce maternal and infantile mortality we must educate mothers and health-care workers. Now we can send educational messages to their telephones or inform them about vaccinations'.

Leaving aside their use in the direct provision of health care, it is obvious that the new ICT has an enormous potential as regards campaigns of health-care education and the development of strategies of prevention. The mass media have been used, and will continue to be used, to promote a greater social awareness of the dangers connected with the abuse of tobacco, alcohol and drugs, and of the need for healthy hygienic practices. This has allowed a direct advertising campaign and more indirect strategies which use the general media programmes and media figures to promote a greater awareness of healthy choices. The spread of social networks and SMS texting allows the launching of campaigns against viruses with young people and children. Many paediatric hospitals have developed their own web sites in order to promote greater awareness amongst parents of the symptoms of various illnesses and to provide better opinions on specific questions for those who may need them. Many of these web sites have developed a protocol that identifies and addresses the most frequent questions and allows people to act interactively. When I was a member of the governing board of the Baby Jesus Hospital I was happy to support the development of certain initiatives of the same kind.

The new technologies have allowed the obtaining of the maximum efficiency in the organisation of health care. Mobile phones are used by health-care workers to provide live information on the spread of infectious diseases such as cholera and dysentery in children so as to be able to obtain a more effective response from the central authorities. The advance of these diseases in the world can already be monitored through the site www.healthmap.org which was developed by the Children's Hospital of Boston. SMS messages are used to remind young people to take their medicines at the right moment and to ensure that patients remember their clinic and hospital appointments. Online forums have been established to allow children with special illnesses and their parents to remain in contact and to exchange information and experiences with other patients and their families. Media campaigns are used to show the situations of individual children or groups of patient and to gather funds to be used in their treatment or in research.

However, care for sick children is not confined to meeting their strictly medical needs. It also requires concentration on their personal needs. Major opportunities in the use of ICT exist in this field. The presence and the comfort of families is fundamental for sick children and the development of telemedicine can contribute to reducing the time that they have to spend in specialist hospitals far from their families and friends. These developments can also help to make the illness of a child less burdensome for the daily life of the family of that child. When children are forced to spend long periods of time in hospital, as takes place in some situations, the new technologies can help to keep them in contact with their parents, family and friends, and can also help hospitals to respond in a more effective way to the educational and recreational needs of their young patients.

Experience, therefore, has shown that in every sector where the new ICT has been used a change in organisational culture is needed in order to exploit their potential to the full. This is no less true for health care. From a recent Australian analysis it emerged that 'a common and costly error in the development of the service of telemedicine is to concentrate totally on technology; it is essential that the meaning of organisational changes is considered and this is necessary for telemedicine to be integrated like any normal health care service' (A.C. Smith,

Telemedicine and Rural Health Care Applications, 2005). The new work models and the structures of service will require generous and patient action by healthcare professionals and administrators to ensure that sick children benefit from the medical and social advantages that are offered by the new technologies.

The new technologies can also influence the nature of the relationship between doctors, patients and their families. The availability on Internet of a large quantity of medical information means that a doctor will have in front of him or her people who are more informed than was the case with previous generations. For a medical doctor it will be more difficult to have those paternalistic attitudes that were typical of his or her predecessors – but this is not a bad thing. There is still a need for medical professionals to help non-specialists to engage in discernment as regards the information that is available on the web. Rather than complaining that patients and their families have access to unreliable information and information that is at times misleading, doctors and hospitals should direct them towards more reliable and authoritative sites.

As a final challenge I would like to point out how indispensable the observance of privacy is. Privacy has for a long time been seen in medical ethics as a central value. Without the certainty of reasonable privacy, patients will not trust medical doctors and the healthcare system and will not manage to present that personal information that is indispensable in achieving a good medical service. Given that data increasingly ends up online, we must be vigilant in ensuring that suitable protocols exist for the defence of that information and to guarantee that such information is only available to those who have a relevant medical interest in it. This vigilance should increase above all in the case of genetic information on children – the management of which requires especial sensitivity because of the long-term consequences at both a personal and social level that may arise if such information is not suitably protected. Its inappropriate dissemination could create discrimination against individuals by the community in terms of finding a job or obtaining insurance.

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PEDRO ANTONIO REYES LÓPEZ

7. National and International Policies for Health Care; Legislation; Migrations; Economic, Scientific and Technological Resources; Food Policies and Social Hygiene

Life, a gift of God, is the supreme good, and health, a gift correlated with life, is a legitimate human aspiration, a necessity and a social value. Paediatrics, a specialisation which is already a hundred years old, is concerned with the health of neonates, breastfed children, children and adolescents; it follows their growth and development so that they can achieve their full potential as adults. It engages in these responsibilities from conception until maturity and is interested in the emotional, environmental and socio-economic factors that influence the health and wellbeing of patients who are vulnerable and susceptible to very permanent emotional and physical consequences. This awareness, which is connatural to paediatrics, is growing and diversifying nowadays with the unceasing and dizzy advance of science.

At the beginning of the new millennium, the third millennium of the Christian era, the objectives and goals to be reached are a shared and practical reality. There are many obstacles which hinder their attainment and one has with regret to observe that our failings are still very great.

In the field of health, the member States of the World Health Organisation (WHO) established eight development goals for the millennium. Almost all of these countries belong to the WHO and this commitment is very important. As regards these eight goals, we will now examine those which are relevant to the subject of this paper: eradicating extreme poverty and hunger; reducing infant mortality; improving the health of mothers; fighting HIV/AIDS, malaria and other diseases; the assure the sustainability of the environment; and encouraging an alliance at a world level in favour of development. Each one of these has previously established health goals and indicators. I will speak about this sphere of reference, enriching the relevant aspects on which there is information provided by the World Bank and other governmental and non-governmental associations which are concerned with the welfare of children.

Eradicating Extreme Poverty and Hunger

Extreme poverty and hunger are indicators that are linked. For years an arbitrary standard was used to indicate the poverty threshold – one dollar a day. This is not a good indicator because it compares rich countries with poor countries, those that are defined, to employ a euphemism, as being 'developing' countries', and which are greater in number than the former, and compares them on the basis of the international market, in which they compete under different conditions, a market which, in addition, is volatile and unfair, as we have seen recently, and which does not include all goods and service.

A proposal of the World Bank recommends the use of a different indicator, namely PPP or 'purchasing power parity'. This new indicator leaves to one side the international market and limits the conversion to a currency, the American dollar, with the aim of ensuring parity in the obtaining of goods and services that do not form a part of the international market. There are innumerable variables which bear upon the implementation of the new indicator but without doubt we can now have a vision that is nearer to reality. The PPP is flexible and goes from 1.25 to 2 American dollars. At the lowest level we encounter fifteen countries: Chad, Ethiopia, Gambia, Ghana, Guinea-Bissau, Mali, Malawi, Mozambique, Nepal, Nigeria, Rwanda, Sierra Leone, Tajikistan, Tanzania and Uganda. In these countries, which for the most part are African, the average poverty is at the level of 1.27 dollars a day and the pro capita consumption is between $1.03 to $1.87, with an average of $1.40 a day.

The upper limit of PPP, at the present time $2, is applied to an economy which is developing and in transition, for the most part an urban economy. There are data from the year 2005 which place the following countries in this condition: Argentina, Brazil, Bolivia, Cambodia, Chile, China, Colombia, Ecuador, Pakistan, Peru, Thailand and Uruguay.

In this way, poverty is measured as consumption and not as income pro capita. This measurement has a meaning in cases where it has been shown to be effective through surveys that were carried out in Africa and Asia (the Middle East/South-East Asia) employing the criteria of real expenditure with value attributed to income, including self-generated income, which certainly does not reflect market value but which is the best there is according to the experts of the World Bank. There are differences not only at an international level but also within the same nation and they are present in

all countries. In Scotland, which is a part of the United Kingdom, for example, a child who is born in a certain neighbourhood of Glasgow probably has a life expectancy that is twenty-eight years less than a child who is born in another neighbourhood of the same city. For obvious reasons I cannot go further. I have just referred to an aspect of this goal, another is nutrition.

About two years ago, at another conference, I spoke about hunger. Here there have been no conceptual changes: in the world two forms of malnutrition prevail, and they have a greater incidence in rural areas and poor countries, which constitute the majority, but North America, Western Europe and Japan are not excluded from the list, even though one is dealing with specific groups within society. These forms are an insufficiency of proteins, which leads to kwashiorkor (or infantile marasmus), and a general lack of nutritive elements which causes a loss of strength.

We know that there are countries and regions where malnutrition bears upon the origin of diseases and the inevitable deaths of children under the age of five, but we also know that the cause of this situation, using the instruments we have to hand, which in theory are accessible, must be dealt with.

Almost 40% of affections in minors take place during the neonatal period, that is to say during the first twenty-eight days of life, and are caused by conditions which in industrial countries have by now been overcome. About a fourth of these neonatal deaths, which constitute 10% of all those that take place before reaching the age of five, derive from grave infections which are fostered by nutritional deficiency of varying levels, many of which can be prevented by vaccination which is effective and accessible in countries which have organised and financed health-care systems. One should point out the need to sustain the confidence of people in vaccinations and immunisation programmes, which, indeed, are safe and effective. Many factors have contributed to the spreading of false suspicions as regards vaccinations, which still exist amongst parents, in certain religious communities and amongst politicians, and which prevent children from receiving immunisations in time which can then protect them against diseases. Certainly risks exist which vary from vaccination to vaccination but these last are constantly improved thanks to advances in technology. The risks, in addition, are so limited that they are justified by the eradication of viruses or epidemics which lead to infantile paralysis, and by other benefits. We absolutely have to stress this concept in a clear way by speaking with people who still have doubts about vaccinations and convincing them – we have suitable arguments available to us and for this reason this is something we can and must do.

Pneumonia, diarrhoea and sepsis threaten almost 50% of poorer children and this at a time when vaccinations and/or treatment are available and there is a demonstrated cost/benefit ratio. Pregnancy during adolescence, like neonatal tetanus, are responsible for 20% of these preventable deaths. The lack of supervision during pregnancy and non-professional care during childbirth are problems which have been solved in the world, but this does not apply to everybody.

Malaria is avoided through hygiene/health-care services, through mosquito nets impregnated with insecticides, and it is also a disease can be successfully treated. Measles, which can be prevented through vaccination, and AIDS, which when treated with retrovirals becomes a chronic illness, are responsible for 15% of avoidable deaths. Another 10% of avoidable deaths can be attributed to other causes which, I am certain, belong to the group of illnesses caused by parasites and which can treated and cured, amongst which one should list Chagas' disease. If we manage successfully to combat these causes, there will still remain lesions, congenital anomalies and other neonatal disturbances which together make up 8% of the total of causes of death amongst minors under the age of five, and which are preventable, manageable and treatable to a certain extent. For this reason it is inequality that causes death or handicap in minors under the age of five and in large measure in neonates. Personally, I believe that the term 'inequality' is the term that could best describe the situation. Well beyond the individual, social and economic repercussions, malnutrition in all of its forms is a causal factor in 50% of these infant deaths.

The other side of the coin is obesity, a growing problem throughout the world, which affects 25% of children and adolescents. I have available statistics on my country which is second in the world as regards people being overweight or obese as measured by the universal criterion of body weight, which expresses the ratio between the mass and height of an individual and is used as an indicator of fitness as regards weight. The service of paediatric endocrinology of the Federico Gómez Children's Hospital, one of our national health-care institutes, calculates that 40% of the infant population is overweight or obese and it sees such a situation as an 'epidemic'. This does not cause death during childhood but fosters the development of chronic illnesses that have an economic impact which until a few years ago afflicted only adults but which at the present time are also to be found in children and adolescents: 50% of children admitted to this children's hospital are dyslipidemic, 16% suffer from system hypertension, and it is calculated that an obese child is

thirteen times more likely to become diabetic when he or she becomes an adult (type 2 melit diabetes) and nine times more likely to have HAS. There are already consequences during childhood – 20% of overweight individuals have cardio-pulmonary alterations and 15% have orthopaedic alterations. And obese children aged six have a 27% likelihood of becoming obese adults and those who are obese at the age of twelve have a 75% likelihood of having obesity during adulthood. In addition, obesity is a 'pro-inflammatory' condition – high level of cytochin (IL-6 and its result, PCR, TNFα and leptin) have been observed, and with serious consequences.

Obviously there are genetic mechanisms which are at work. There is a FTO gene associated with morbid obesity (IMC > 40), but it is the environmental factor which is of determining importance, in large part that is to say the ingestion of foods such as sweet drinks, chips and 'snacks', which in Mexico are very abundant.

I should say that a major step forward has been taken in the technique of low-cost and effective alimentation through the presence of a traffic light with traditional colours, that is to say red, amber and green which serve to indicate food that is recommended in great quantity, the basis of alimentation (green) and food which, going down, has limitations (here amber is used). Foods which are marked red are those which should only be consumed once or twice a week. This step forward, which started off in England, acts not only to indicate foods that are at risk for obese people but also to teach healthy eating to all children

Reducing Infant Mortality; Improving the Health of Mothers

The fourth goal, naming reducing infant mortality, proposes the reduction by two-thirds of deaths in children under the age of five, lowering death rates in breastfed children and children under the age of five, and increasing the percentage of children who are immunised against measles. This goal is very much linked to the sixth – increasing the health of mothers, with the aim of reducing the coefficient of maternal deaths of ¾ and increasing the percentage of pregnancies and births that are supervised and followed by qualified personnel.

These are goals that are possible for contemporary health care. One need only request that the measures that have been tried and tested and have been demonstrated to be effective in industrialised countries be applied fairly and extended to the whole of the world's population.

It is not ridiculous to expect a substantial improvement but perhaps it will be possible to achieve the first, fourth and fifth goals by the envisaged date if we manage to avoid the selfishness and other maladies which seem to be connatural to man.

Here are some recent statistics from the WHO and the reviews *The Lancet* and *PLoS One*. The first refers to the health of mothers. Every year 500,000 women die because of complications associated with pregnancy or childbirth. The principal obstacle that we have to overcome in order to avoid, at least in part, these deaths, is the low quality of health care because of a lack of access to care and treatment during pregnancy and before, during and after childbirth. This information, which goes back to 26 August of this year, points to five causes that are responsible for 70% of deaths: haemorrhage, infection, dangerous abortions, pre-eclampsia and eclampsia and blocked birth.

The Lancet, in a recent article commissioned by UNICEF, points out that in 2007 9.2 x 10^6 children under the age of five died, and if we consider that almost 40% of these deaths were deaths of neonates, this means that almost 4,000,000 died last year. This reminds us of the importance of reducing the deaths of children under the age of five and of neonates, and we already have a way of doing this.

The review *PloS*, once again in the year 2008, contained a North American study that showed that infections in the amniotic liquid because of bacteria or fungi were present in 15% of premature births. These infections foster premature birth (before the thirty-seventh week of gestation) and, here I quote these researchers, 'if we had been able to identify or prevent' the infections, obviously 'we could have prevented some of these premature births'.

In the United States of America the percentage of premature births is 12% and this is a figure that is on the increase. This study identified the DNA of bacteria or fungi in the amniotic liquid of 166 women with premature births. Through conventional cultivation, infection was found in twenty-five of them and a new unknown micro-organism was found, perhaps a new pathogenic species.

Another problem, namely the vasoproliferative retinopathy of neonates under the age of thirty-five weeks, is a source of avoidable blindness, and its diagnosis and treatment have an important cost/benefit ratio. Phototherapy and cryotherapy are applied with success and over 90% of patients avoid blindness. There is a WHO programme called Vision 20/20 which recommends the use of an ophthalmological examination in premature children at risk, and with good results: the central retina does not become detached, a part of vision is sacrificed but the macula and sight are conserved.

Fairness, a subject invoked frequently in international political debate, is a thorny question. A high-level commission this year recommended three principles for action: 1) improving conditions of life; 2) fighting against the unequal distribution of power, money and resources, the structural factors upon

which conditions of life at a world, national and local level depend; and 3) measuring the scale of the problem, assessing interventions, broadening the basis of knowledge, acquiring specialist personnel expert in the social factors in health, and sensitising public opinion in this field.

These are goals that can be achieved but…The obstacles are not of a technical kind, they have another dimension which has to consider the interests that have been created. We have to change, unite, and perhaps then we will be able to reach our objective. In our times this is a utopia, but there was a time when slavery was accepted as a lasting economic resource.

To achieve the Millennium Development Goals we must strengthen health services at all levels and throughout the world so that the services that are provided in health-care structures and national health programmes are strengthened by users, in the form of community alliances for primary care for mothers, neonates and children as well, because it is families, encouraged by women, who make themselves responsible for seeking help, and who also with a minimal training can diagnose common illnesses which are potentially lethal, assess their gravity, and decide on the need for medical or non-medical treatment, acquire or administer remedies and decide to look for help from a health-are worker. There are many examples of such action in the world, and there are successful programmes which use this numerous and interested unit, which in turn supports them after receiving training.

Educating women, whether they are mothers or not, in communities throughout the world in order to ensure that they take part in health care and maternal, neonatal and infant nutrition is a logical form by which to improve primary health care, above all in countries that do not have environmental services with hygiene/health-care services and health care.

A community in this programme is defined as a group of people who reside in a specific geographical area and share a common heritage, specific interests and activities, amongst which one may list a similar privation of their right to quality health care, to adequate and culturally acceptable nutrition and to a supply of drinking water and hygienic/health-care services. This broad definition allows the creation of community alliances which have shown themselves to be a strategy given the very interesting results in twelve basic practices for intervention in communities. We thus have:

– Maternal breastfeeding as an exclusive method of feeding from birth until the age of six months. Breastfeeding stabilises within a period of four or five days, the quality of the milk can be measured by determining the presence of Na and K in the secretion, and if it cannot be obtained then the maternal milk has to be extracted before it provokes inflammation of the glands.

– Complementary foodstuffs. From the age of six months onwards food of a high energetic and nutritive value is given to children in combination with maternal breastfeeding. This regime is prolonged until the children reach the age of two.

– The administration of food supplements, in particular vitamin A, to those who need it, within a community context, in order to reduce infant mortality between the ages of six months and five years by 20%.

– Hygiene, in particular the washing of one's hands with soap or ashes and the secure destruction of faeces, could reduce the incidence of diarrhoea by 35%.

– Vaccination against measles during the first year of life can prevent many deaths. Vaccination against diphtheria, whooping cough and tetanus, and vaccination with BCG, which avoids tuberculosis and meningitis, and other vaccinations such as oral vaccination against polio in areas where there are risks, form a part of that minimum of six vaccinations recommended by the WHO.

It is evident that there are others which are recommended in societies that have greater health-care services but these six at the least mean an enormous reduction in the likelihood of death and disability, which are avoidable.

The prevention of malaria, even though it is a disease that is still very widespread in many areas of the world, thanks to mosquito nets treated with insecticide provided free in endemic zones, should reduce the incidence of infant malaria and deaths by about 20%.

The promotion of the correct psycho-social development of children through play and a stimulating environment is another goal that can be reached,

The administration of food and liquids to children has been shown to be an effective policy. The idea that illness means fasting has to be overcome.

Home treatment, which is another important policy, avoids the child being transferred to a extraneous environment and the breakdown of the family. There is no reason why minor or moderate infections should be treated in a centre that is generally far away.

To look for medical action, to recognise the moment when children need such action, together with information on signs of alarm, is a strategy that has been shown to be valid.

Also of use are: the use of suitable practices in the treatment of sick children, an appropriate diagnosis and adequate treatment, in addition to the assistance and advice of health-care workers, even though they may not be medical doctors.

As regards prenatal care, expectant women should receive adequate care and this means at least four examinations during pregnancy at a qualified centre, which is not necessarily a medical centre, as well as anti-tetanus immunisation (preferably toxoid), and help for the family and the community. Care during childbirth should also be prepared, possibly at home, as well as during the post-birth period and the period of breastfeeding (least six months).

In addition to these general measures, there are others which are especially important in special areas such as in sub-Saharan Africa where there is HIV/AIDS infection and many orphans. One may also refer to the prevention of violence against children, including traditional practices, the encouragement of the participation of fathers in taking care of their children, and many other measures which, promoted by health-care workers, have obvious and important benefits.

In India, for example, alliances have reduced malnutrition and its consequences. In East Africa HIV infection from mother to child has been reduced and in Uganda a personal behaviour programme – premarriage abstinence and faithfulness – have generated impressive results. Mozambique has reduced the death rate in its population of children under the age of five through the community alliances, and I could refer to other successes which are now being achieved.

Fighting HIV/AIDS, Malaria and Other Diseases

Sub-Saharan Africa is now facing the grave problem of HIV/AIDS infection. There are many social and economic reasons for the spread of the virus but they do not justify this situation. One should remember that this zone has suffered a regression in terms of development because of the direct and indirect effects of the epidemic that is now afflicting it.

The ambitious goal for 2015 is to arrest and begin to reduce the spread of HIV/AIDS and this is a goal that can be reached if the measures that are already available are applied. These are the following: gaining knowledge about the infection in pregnant women between the ages of fifteen and twenty-four; about the percentage use of the condom as one of the contraceptive devices that is used; and about the coefficient of the presence at a school of children who are orphans between the ages of fifteen and twenty-four.

I cannot but cite with admiration one African country, namely Uganda. This is the only African country which hitherto has successfully fought AIDS. In 1992 18% of the adult population of this country was HIV-positive, but by 2005 this percentage had been reduced to 6.7%. No other country, whether in Africa or elsewhere, has managed to reduce the number of HIV-positive people to this extent, and not because of the death of such people but because of changes in personal behaviour which promotes abstinence before marriage and mutual fidelity within the couple. The government has unreservedly supported such behaviour and in contrast with the sexual liberty which is dominant in other countries, which is associated with mercantilism, which in turn produces enormous profits for pharmaceutical companies, in a short time a very important reduction was obtained which I hope will be encouraged in the future.

I wish to emphasise that the fundamental measures are of a personal kind – abstinence and fidelity, and these have been obtained in an African country in which there are many different tribes and religions, with traditions that foster the submission of women. This fact, stressed during the XVII International Conference on HIV and AIDS, which was held in Mexico on 3-8 August of this year, deserves our full attention.

In that same occasion it was stressed that the National Institute of Perinatology of Mexico treated the first pregnant woman to be HIV positive in 1988 and by 2007 it had treated 198 women in the same condition. In this group there was not one case of the disease being transmitted to the neonate.

Mexico is a country with a low level of infection by HIV and even less by AIDS, with the exception of men who have sexual relations with other men, and the contemporary techniques involving the identification of the need for, and the actual administration of, anti-retrovirals, have achieved a success rate to which I have already referred in this paper.

Perhaps we should reflect on the ability of our diagnostic instruments and forms of treatment, which have already been experimented with, and leave somewhat to one side the efforts that have been made to obtain an effective vaccination which, however, as regards to the short- and medium-term, remain vague.

At this same conference attention was called to the fact that according to UNAIDS, the joint programme of the United Nations against HIV, every year 120,000 children contract HIV, and the number of those who are infected in the world, above all in Africa increase by 2.5 x 10^6; 330 x 10^3 die of AIDS and 15.2 x 10^6 have lost one or two of their parents because of the same cause. 90% of new cases of the infection take place by perinatal transmission or breastfeeding and 'the majority of them die before reaching the age of two', as was stated by the Executive Director of UHNAIDS, Michel Slide, at the symposium 'Children and HIV/AIDS: Act Immediately'. Only 6% of people infected with HIV have access to treatment and indeed if they could have anti-retrovirals these children would not die, yet if they become chronic cases…

A final reflection should be engaged in: child and teenage prostitution, a permanent disgrace, despite the international treaties that exist and the fact that one is not necessarily dealing with an economic explanation for these cases, is a 'job' for children, the worst of jobs, according to the International Labour Organisation. The people afflicted by this modern form of slavery explain by saying that they say that they would like to have another 'job', to study, to marry and to have children and…to celebrate their birthdays. A phrase sums up this tragedy: 'I would like to meet someone who loves me'.

Malaria is an enormous scourge in Africa and Asia where Plasmodium falciparum, the most lethal form, predominates. The World Report on Malaria, which was published by the WHO in 2008 (drawing on data from the year 2008), points out that in the world there are 247 x 10^6 malaria victims, that children of the lowest ages run the risk of dying, whereas African and Asian countries have managed to

reduce these deaths through measures of an economic kind, such as mosquito nets impregnated with insecticides and the use of effective drugs and medicines and chloroquine and primaquine, to which is added artemisinin in a combined treatment. This last is derived from a traditional remedy – quinine.

In 2007, in Africa, 125 million people protected themselves with mosquito nets but 650 million people were at risk. The number of protected people increased eightfold between 2001 and 2007 in eighteen African countries and in Eritrea, Ruanda and Saint Tomé and Principe mortality rates were reduced by 50% through three combined measures: the use of mosquito nets, fumigation of internal spaces, and better access to the treatment and control of this disease. Other countries, such as Madagascar, the United Republic of Tanzania, and Zambia have reported important reductions.

The declaration of Dr. Margaret Chan, the Director General of the WHO, expresses a certain optimism: 'this information is the first response to a need. The advances which have been made in the control of malaria underwent a spectacular acceleration in 2006, especially after the appeal made the by the Secretary of the United Nations for the establishment of universal coverage for measures for the control of malaria by the end of 2010. We hope that this broadening of efforts is also reported in the future information notes'.

The Multilateral Initiative for Malaria and the Tropical Disease Research groups have created a 'force' that works with a specific goal, and which, supported by the WHO in Africa, dedicates work sessions to dialogue between African countries and countries from other parts of the world. The last meeting was held in Brazzaville, the Republic of the Congo, so that the seventy scientists responsible for the control of the programmes, as well as others, could review the strategy as applied to Africa. The African participants came from Burkina Faso, Cameroon, the Ivory Coast, Gabon, Ghana, Kenya, Mali, Nigeria, Sierra Leone, South Africa, the Sudan, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe. The European participants came from Italy, the United Kingdom and Sweden. This review approved the allocation of $1,215,496 for two new African research initiatives

Tuberculosis is another searing problem. A third of the world's population has been infected by Micobacterium tuberculosis but a much lower percentage has the disease – about 10 x 10^6, distributed throughout the world. Once again it is Africa which has the greatest problems, not only because of the human cases of TBC, but because this disease also strikes animals, the lions and buffalos of the Kruger National Park, in the touristic area of South Africa, an essential part of the local economy. An increase in the presence of TBC in local livestock is feared.

Since the end of the 1940s there has been effective treatment for this disease but resistance to it has increased and this, together with the HIV/AIDS infection, has had a negative impact on the fragile relationship between human beings and this bacterium. Today this fight has many aspects and one is the diagnosis of latent tuberculosis, which is prevalent and which depends on intradermoreation with the purified protein derivate (PPD) of a strain that is kept in a central laboratory in Denmark. There were serious limitations and now various tests are being revised, some of which have already been accepted, to measure the T immune response and its products in a specific diagnosis.

There are also new pharmaceuticals and new ways of treating cases. Indeed, today there are many ways of treating this disease and there are constant scientific communications on the subject. This is still an 'open' subject with a future that is not very promising.

Other illnesses in our countries are defined as being 'forgotten'. Amongst these stands out Chagas' disease, a parasite-based disease caused by the protozoa Tripanosoma cruzi. This was identified in 1909 by Dr. Carlos J. Chagas in Lassance, un unknown village in Minas Gerais on the banks of the San Francisco river in Brazil. Chagas, who reached the place as a malaria expert, paid attention to a suggestion that had been made by an engineer who pointed to the presence of a hematophagous insect and its possible connection with a human disease. Chagas identified the vector, the triatomin Panstrongylus megistus, and the parasite, which he called Schyzotripanum cruzi, and described its pathogenic capacity in animals. He also described this new disease in the case of a baby girl aged two.

The late consequence of Chagas' disease is a heart disease, a chronic and progressive illness which appears twenty to thirty years after the infection, which for its part takes place during the first five years of life and ends almost of its own accord, nearly always without death.

But chronic Chagas' heart disease does not develop in this way. There is no effective treatment for this parasitosis. In addition, there are doubts about its direct participation in the pathogenesis because there is auto-immunity in those who are chronically ill and there is evidence that it is not only a biological phenomenon but also, presumably, pathogenic.

In addition. Chagas' disease, which was original to, and to begin with confined to, large zones of Latin America, is now a world problem, and given that it can be transmitted through the donation of blood and the placenta, is a disease which is spreading throughout the world and now constitutes a growing threat all over the world, with the aggravating factor that it is not known about and there is no effective anti-parasite treatment available for its chronic stage.

Much time would be needed to talk about the other diseases that are contracted during childhood and which only afflict the population subsequently when there are scarce opportunities for effective action and definitive consequences. I would like to cite only viral diseases such as Rift Valley fever, Ebola and yellow fever; bacterial diseases such as cholera and bubonic plague; parasite-based diseases such as the many caused by intestinal parasites; and protozoa diseases such as amoebic or matzoan diseases – round or flat worms. In some cases these are not treatable and in others they require preventive measures, amongst which we may list access to drinking water, a

generally healthy environment, and personal hygiene in the family and the community and, finally, at a national level as well, as we will now see.

Assuring the Sustainability of the Environment

This goal includes another two: by 2015 reducing by 50% the percentage of people who do not have access to drinking water and care services, and by 2020 managing to improve quality of life for at least100 x 10^6 of the inhabitants of the shanty towns on the outskirts of large cities.

The health indicators here are, first of all, comparing the urban population and the rural population as regards access to sources of drinking water, and secondly comparing the urban population and the rural population as regards to access to quality care services.

The world is working to achieve the first goal of the millennium development goals 7, and only twenty-three countries are behindhand if one looks at the official figures, which, however, are probably not real ones. It is feared that there are at least forty-one countries which will not be able to reach this goal, and in addition in developing countries and advanced countries there are many factors which escape control. In the first category, one inhabitant in every five does not have access to water for human consumption, and one in every two does not have basic health-care services.

In these countries every year 2 x 10^6 of children under the age of five die of diarrhoea. This situation is undoubtedly connected with conditions of life, with a lack of hygiene and drinking water, and with insufficient health care which may explain if not justify that 1.4 x 10^6 people suffer from fatal diarrhoea every year because of bad drinking water, contaminated food, dirty hands and insufficient personal hygiene; 860 x10^3 die because of a form of malnutrition; 2000x10^6 become infected by intestinal nematodes and 25 x 10^6 have permanent disabilities caused by filariasis; 5 x 10^6 develop trachoma which causes blindness; 200 x10^6 suffer from schistosomiasis; and 280x10^3 die from suffocation, and many of these cases take place before children reach the age of five!

In addition there are many vectors of disease which grow in stagnant water and if we were to add diseases such as malaria, oncocercosis, dengue's disease and others…the list would be very long. I am ashamed to see that this is taking place in our world when there are ways of preventing about 9.1% of illnesses and deaths with simple and sustainable methods.

Unsafe water can transport pathogenic agents and toxic chemicals if they are ingested. Services in this field (drinking water, health care, the disposal of solid refuse, and irrigation with treated water) help in prevention but if they are not accessible they become factors which increase the incidence of various illnesses.

Behaviour, through personal, family and community hygiene, including materials for house building, ecosystems and natural resources, can contribute to an increase or a reduction in risk.

In order to prevent at least in part the global impact of illness one should act at a governmental level, with suitable investments and laws, in addition to the adoption of measures at a local level. This mean that cooperation, subsidiarity and – obviously – good will and total trust, are required.

Encouraging an Alliance at a World Level for Development

Cooperation is proposed with pharmaceutical companies in order to provide essential drugs and medicines to developing countries at accessible prices. In this way there will be a substantial increase in the numbers of people who have sustainable access to drugs and medicines, especially the so-called 'forgotten diseases'. In addition, it is necessary to support research and development into aspects of clinical pharmacology, to demonstrate the effectiveness of new drugs and medicines and the combination of drugs and medicines, to develop bio-equivalent generic drugs and medicines in countries, and to generate new jobs and stimulate education.

There is also an initiative of 'The Health in Action' group published in *PloS Medicine* which points to a new pathway for developing countries which have not followed or cannot follow a traditional vigilance as regards epidemics, with offices in Ministries of Health, national institutes, agencies and laboratories with planned activities, and a constant flow of information about the health of the population.

With the support of the Net (Web-accessible information sources) 'Vigilance without Frontiers' has been created, that is to say a network on Internet designed to create a map of health in the world with the control of infectious diseases as its central objective. This initiative is very important because its aim is to publish on the Net useful information, a discussion forum, mailboxes of governments and non-governmental organisations, lists of e-mail addresses, and news about infectious diseases. Electronic information is almost immediate and plays a very important role in following epidemic epicentres which can remain hidden for weeks in the traditional systems of vigilance. In the assessment of information, emphasis is placed on distinguishing between what is 'true' and what us 'false'. This health map is accessible, free, and at the present time available in the principal languages of the world, namely English, Chinese, Spanish, Russian and French, and at the present time a version in Hindu, Portuguese and Arabic is being prepared. The ad-

dress is http://www.healthmap.org/ and it has been operative since 2006.

To end this paper, I would like to say that I have reread a number of documents and I believe that it is possible to have a healthy world, with justice and fairness, by applying knowledge and practices that already exist but which are frustrated at the level of their application for very varied reasons which we can summarise in a single word – 'selfishness'. We will see.

The initiatives that are required to reduce infant mortality are well known. Indeed, less that 1% of deaths of children under the age five have unknown causes and two-thirds could be avoided completely through simple interventions such as control and care during pregnancy and childbirth, the prevention of the transmission of HIV from mother to child, and the early diagnosis and adequate treatment of AIDS. In addition to adequate alimentation for neonates with maternal milk for about six months with complementary foodstuffs from that moment until at least the age of two; the administration of vitamin A; at least six vaccines to avoid serious diseases; oral rehydration and zinc in cases of diarrhoea; antibiotics for pneumonia; sleeping under mosquito nets treated with insecticide; and the early diagnosis and suitable treatment of malaria. These are all measures that can reduce infant mortality.

Efforts should be concentrated on those sixty countries which have a high percentage of infant mortality, including perinatal mortality, which is assessed with reference to two criteria: over 50,000 deaths in children under the age of five and tan annual percentage of infant mortality equal to or higher than 90/1000 live births. In 2003 specialists and scientists, medical doctors and paramedics, committed people, politicians and the heads of health programmes etc., met at Bellagio in Italy and established that these figures must be reduced by 2015, with monitoring entrusted to conferences which should be held every two years. The first such conference took place in 2005 and another was held in Cape Town in South Africa n 2007. These conferences have been encouraging as regards the future.

The sixty countries referred to in 2005 hosted 93% of all deaths of children under the age of 4-5. Amongst these countries there are seven, namely Bangladesh, Brazil, Egypt, the Philippines, Indonesia, Mexico and Nepal, which could reduce infant mortality with little effort, but there are also others where a greater commitment is required.

Various initiatives should be grouped together – those for mothers, neonates and children at the fundamental stages of the life cycle and within the framework of ongoing care.

'Vertical' initiatives in the case of a pressing problem are usually not effective but if they are combined in a sort of 'packet' their efficacy is notably increased, above all if they take place during the key points in the life cycle. There are integrated measures such as vaccination and the administration of vitamin A, care during pregnancy, immunisation with tetanus toxoid, qualified care during childbirth, keeping neonates dry and covered, heart-lung resuscitation if necessary, informing mothers about breastfeeding and special care for low-weight neonates, and the treatment of infections in neonates and mothers, which reduce mortality at birth by up to 72% and beyond. I would like to mention a successful experience in Mexico – diagonal focusing. This refers to the pro-active supply, on a large scale and encouraged by demand, of a series of interventions with a good cost/benefit ratio designed to bring primary health-care services to places where they are requested.

Between 1980 and 2005 Mexico established various programmes: the distribution of salts for cases of diarrhoea, a programme to obtain clean water, national vaccination days, specific anti-measles campaigns, a universal vaccination programme, national vaccination weeks, and national health weeks when vitamin A and treatment against intestinal parasite illnesses were provided. These led Mexico to become one of the seven countries that can achieve the millennium development goals and one of the six priority countries in the programme of the WHO for 2015, which refers to the survival of children.

The strengthening of health-care systems and community alliances. Preventive measures are very important, they require changes in attitudes, a process which must begin in the family, and which must be supported in the community and in schools. Women take part in them with great enthusiasm. Compared to tradition, they change their behaviour, become more educated and trained, and ask for hygienic services, wells, and drinking water. Accessible kitchens promote hygiene and, lastly, in community alliances ties are established between health-care workers and the mobilised community, And they ask governments at three levels for quality health-care services.

An alliance strengthens a feeling of belonging, revitalises health-care services, and reaches the remotest areas. These alliances have been established in the poorest countries of the word and have been shown to be useful.

However all these actions require a legal and economic framework and services which must be sustainable. In a few words – a favourable environment.

Peace is crucial in this case. Countries where there is foreign or civil war are countries which usually have a mortality rate amongst children under the age of five which is equal to or higher than 20%.

Juridical institutions should pass laws that protect work and ensure that they are applied. Fairness as regards work and a dignified job are essential in national and international socio-economic policies.

It is necessary to work to defend women so that they avoid prostitution; to watch over the holiness of marriage and to ensure that young women avoid pregnancy, at least before the age of fifteen; and to help and educate young men and women in order to promote the social and economic autonomy of women. These are all actions that will create a more just, fairer and respectful world, where human rights are a living reality.

To achieve this health-care fairness a secure, well-paid job is required, one that is without dangers

and is also stable, and there should be a right balance between the professional lives and the private lives of people. One has to offer women and men well-paid jobs, taking into account the cost of living, in addition to protecting work. International bodies must ensure that work legislation is respected in both the legal and the illegal sectors, legislation that should assure a balance between working life and private life, and reduce or eliminate – if this is required – physical or psychological risks for all workers.

If we build a just world we will be able to achieve health-care fairness and a salubrious environment for the world's population, so that the burden of preventable illnesses and deaths is reduced to a minimum, which is, indeed, the goal of medicine.

May the Lord help us to ensure that the threat of the cotemporary economic crisis becomes attenuated throughout the world; may there be peace, and may all the efforts of mankind be directed towards achieving the millennium development goals so as to have a better scenario with the presence of the theological virtues: faith, hope and charity.

I hope that this will occur.

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Acknowledgements

Mrs Teresa Mondragón, Office of UNICEF in Mexico, UNICEF-México Paseo de la Reforma 645. Col. Lomas de Chapultepec CP 11000.

Dr. Víctor Manuel Pérez Valera SJ., Departamento de Derecho. Universidad Iberoamericana, Mexico City.

Dr. Dina G.Díaz Espinoza, Lic.Nut, Otilia Perichart, Men C Psicología Diana Pimentel.

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To my son.

VITO FERRI

8. Sick Children and their Families

Any analysis of, or study on, 'sick children and their families', must take into account a large number of variables and contexts that overlap and influence each other. The age and the level of development of the child at the outbreak of the illness; his or her personality; his or her ability to cope; the kind of pathology with its development and its prognosis; therapies; disabilities; and hospitalisation – these are only some of the (simple and complex) variables that are involved.

And the variable that certainly influences the reactions of a child to illness more than any other is the emotional climate that is to be found in his or her family. In addition, the various variables are in their turn made unique by the contexts in which they manifest themselves. The primary context of which a sick child forms a part is his or her family, with its configurations, composition, history, and its resources and life cycles. The family, in its turn, belongs to a social context and to a network of relationships that influence it and are themselves influenced by it. And in contemporary post-modern society the term 'family' has lost its univocal meaning, a meaning was shared for millennia and is now employed to refer to a plurality of situations of cohabitation, even ones without matrimonial ties: situations and relationships are increasingly fluid or 'liquid'. All of this further complicates the study of the questions and issues connected with the subject of sick children and their families.

After making this premise, I would prefer to reformulate the title of my paper which could now be as follows: 'sick children with their families' or even more simply 'children with pathologies, sick with their families'. When a child is afflicted by a pathology, indeed, any pathology, whether a banal one or a severe one, the family itself falls ill and suffers.

Let us enter at an ideal level into these families, let us try to take a few steps forward in their experiences, and to explore these by taking on various positions: let us observe with empathy, let us consider the point of view of the child and the point of view of the various component members of his or her family, and let us also consider the position of the community and of society. To look at the family through the mind of the child I will employ certain results of a study that I carried out, together with Professor Matilde Panier Bagat, on one hundred and fifty-four pictures of their families drawn by children who were organised into four groups on the basis of their pathologies – tumours, deafness, epilepsy and asthma. At the same time, in order to enter the perspective of the parents, I will refer to their testimonies and to my experience as a psychotherapist.

Fragility

Our first step forward in the reality of a family with a sick child makes us encounter fragility. From a psychological point of view fragility, is essentially a condition of vulnerability, of lower resilience, of a lack of protective factors with which to face up to and counter danger and prevent breakdown. The condition of fragility requires attention and care; this request is often tacit, should be understood, read, and taken on board. On parcels that contain, for example, crystal glasses, one can find written in red square letters 'fragile – handle with care' (Fig. 1). This is written using forms and colours that attract people's attention; the letters are oblique, not horizontal, and this is because diagonals particularly stand out. The written word 'fragile' is a linguistic sign, whose meaning refers back to the concept of a risk of breakage; but with this word the intention is to draw attention above all to the need to be careful with these parcels, to 'treat them with care'.

Sick people and children undoubtedly have attributed to them the status of being 'fragile' individuals and thus they are individuals to whom special care and attention should be dedicated. This recognition can be found at every level: the social-health care level, the institutional level, the anthropological level, the ethical level, the biological level, the psychological level, and the spiritual level. Illness, understood as a pathology and a condition, is an amplifier of fragility, above all when it afflicts children. A further amplifier of fragility is the particular perception and portrayal of children in post-modern Western societies (as advertising agencies and the consumption industry well know). There are few children in these societies and thus they are perceived as being more valuable (to take up again the metaphor of the parcel one can amplify the perception of fragility using as a written word the superlative 'most fragile' and printing on the side of the parcel the image of a broken crystal glass or declaring the high value of what is inside). Children today are the subjects of an affective, economic and 'plans for the future' hyper-investment by parents. In addition they are the subjects of a hyper-control as though they were in a state of per-

Fig.1

manent danger from their period as foetuses (one need only count here the number of echograms – usually twice the number that is recommended – and the diagnostic tests that are carried out during the period of pregnancy), constantly threatened by microbes, food adulterations, bad teachers, bullies, road pirates, pollution, paedophiles, drugs and an infinite series of potentially traumatic events. We thus witness the paradox that the illness of a child in Western societies is more frightening today, not least because new vaccines and new diagnostic techniques seems to have made today's parents more alert, more apprehensive and more anxious, rather than, instead, reassuring them and encouraging them.

Like the child, his or her family, as well, is increasingly fragile, even when the members of that family have very good health. This is a fragility which is for the most part spiritual, cultural and social in character. And it is a grave thing that such fragility affects specifically the family as an institution, as a basic anthropological structure, as a protected and protective place – for millennia, indeed, it has been a rampart to defend children, elderly people, the sick and the dying against fragility. A couple of newly weds is in realty an intrinsically fragile reality. They possess in the institution of the family and in the marriage tie a solid base on which to build their domestic hearth and welcome a new life.

Thus when we refer to a family which has a sick child we know from the outset that we will find ourselves faced with a 'complex structure of fragility'. 'Illness subjects to a severe stress the fragilities of all kinds that are present in the family fabric and often leads them to a breaking point'.[1] A sick child perceives his or her own fragility and the fragility of his or her family. This is borne out by the pictures with which the child portrays his or her own family or an imaginary family. These are pictures[2] of exiled figures (Fig.2) who are in difficulty, disrupted, or floating in the air (Fig.3); the houses, which are the symbols of protection and of the child's family itself, are often leaning, dangerous, and in need of repair (Fig. 4); and the figures that are drawn are very small, placed in a corner (Fig. 5) or take refuge from roofs and walls (Fig. 6). At times figures are completely absent in these pictures – there is only a house (Fig. 7) or a landscape, even though the child had been asked to draw his or her family. It is almost as if making the components of his or her family present in a graphic sense could expose them to danger. Or the figures are imaginatively endowed with weapons, armour, magical powers, or transformed into dragons (Fig. 8) which blow fire towards a threatening future and thus compensate for the perception of fragility.

Desolation, Abandonment and Loneliness

Let us now take our second step into the experiences of a family with a sick child. As I necessarily have to confine my paper within certain limits, I will engage in a selection and use a phenomenological filter. Looking through this filter, a reality appears that is dominated by experiences of desolation, abandonment and loneliness.

Desolation is a form of suffering that is little studied by contemporary clinical psychology. It is an experience that cannot be reduced to nosographical representations as is the case with depression, grief and anxiety. In the presence of a severe, acute or chronic, pathology such as cancer, or when a child is born with a physical and/or mental deficit, it is as though the family has been flung from a blooming garden into a desert scorched by the sun. Where until a short time ago there was a magnificent palace now there are only ruins; desolation is an *ex post* experience, an experience of what comes afterwards, an experience of an 'event that has taken place'; it is witnessing in an impotent way what has remained after an existential tsunami has passed through.

Desolation makes its appearance after the initial shock, after the diagnosis, and before the first therapeutic actions. Rosa[3] is the mother of Gabriele. Struck at the age of two by a spinal tumour, the child went into coma. He came out of it disabled and with deficits at the level of his intellect, senses and capacity for movement. Rosa still has pressed into her heart 'the desolation of when we had to bury the idea of a Gabriel like other children and the projects that were connected to this'. A chronic grave illness or a negative prognosis that has struck a child, takes away from his or her parents 'the child of their wishes' and offers them instead another child. In relation to the outside world this 'other child' is experienced as an alien, to be kept hidden away – a creature that is a child but is not 'their' child. This 'robbery', this situation, is experienced as something brutal. And it is often accompanied by a feeling of guilt and great anger towards destiny or God. It may happen that families that were previously believers stop going to Holy Mass, protest against the silence of God, whom they feel has abandoned them, and condemn His deafness to their supplications and requests for a miracle. The family experiences another 'robbery' when the child is forced to spend long periods of time in hospital in the hands of medical doctors, nurses and physiotherapists. These are hands which, however attentive and sensitive they may be, are not the hands of mummy or daddy. In his or her turn, the 'alien-child' sees the whole of his or her family as 'alien', perhaps in order to remain united with it, albeit it in a state of alienation. In some pictures the figures of the imaginary family are all drawn as extraterrestrials (Fig. 9). Finding oneself an 'alien' in what before the illness was daily life, a warm and familial daily life, amounts to desolation. And it is also desolating to be in a society which – as Rosa says – is 'overly standardised and modulated around normal people and which confirms us and supports us in our desolation'.

Another two experiences that are often intertwined with desolation and nourished by it are loneliness and abandonment. An alone and abandoned family runs the risk of losing its cohesion and unity. There are very many examples of couples of parents who have broken the sacred marriage tie specifically when a child of theirs has been afflicted by a grave pathology – one of the two yields and flees. This flight does not always mean a physical and legal separation, there is flight as disengagement – fathers 'who take refuge' in work and mothers

'who take refuge' in absolute dedication to their sick children. There are flights from the roles of husband and wife, even though these two people remain a father and a mother: a sort of 'divorce without a separation'.[4] There are also flights from rationality and faith that lead to superstition and people ending up in the claws of wizards and charlatans who have no scruples. The isolation 'of the' family is at times aggravated by isolation 'within the' family. The pictures of children show families whose component members wander around like ghosts (Fig. 10); they are drawn on the same sheet of paper but they are distant from each other and isolated from each other and from the surrounding environment (Fig. 11). The loneliness and isolation are made more painful by a process of turning in on oneself. This is a reaction of a family which is engaged in the extreme effort of trying to gather all the energies and resources that are available in order to take part in a therapeutic pathway – 'journeys of hope'. Or self-isolation is an extreme and archaic attempt to place oneself in a defensive position: the family blocks itself by taking refuge in a corner of its own existence (Fig.12). 'I feel loneliness', says Rosa, 'every time that the people we meet greet me but ignore Gabriele'. The loneliness, especially if the pathology is the cause of grave disabilities, lies in incomprehension, in shallowness, in the segregation inflicted on these families by a society that is dramatically increasingly eugenic, cynical and utilitarian. A society which, when it does not destroy at the beginnings (as in the case of abortion) its green wood which is adjudged imperfect, and does not

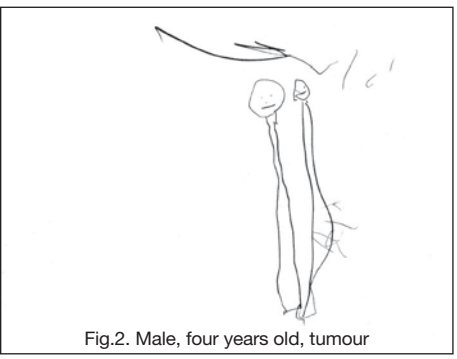


Fig.2. Male, four years old, tumour


Fig.3. Female, four years old, tumour

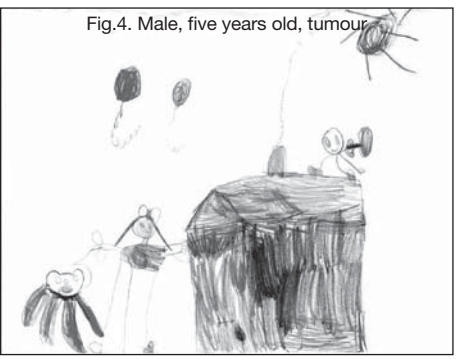


Fig.4. Male, five years old, tumour

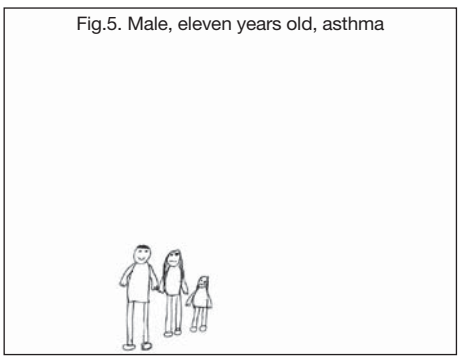


Fig.5. Male, eleven years old, asthma

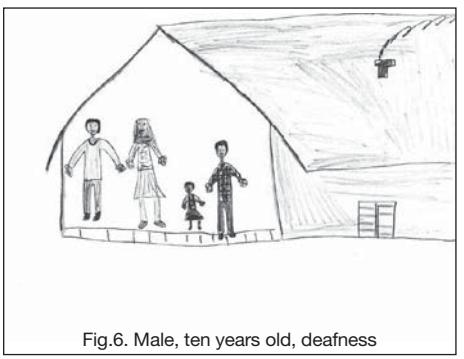


Fig.6. Male, ten years old, deafness

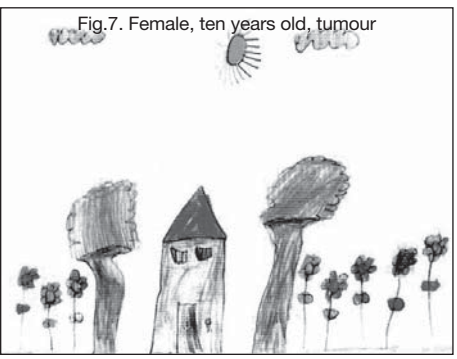


Fig.7. Female, ten years old, tumour

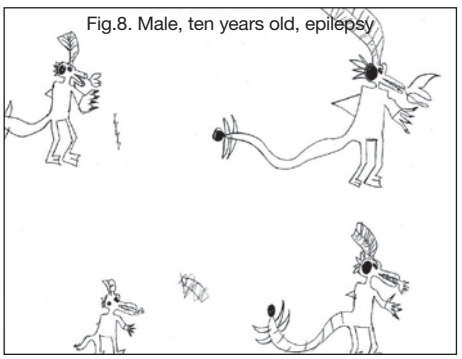


Fig.8. Male, ten years old, epilepsy

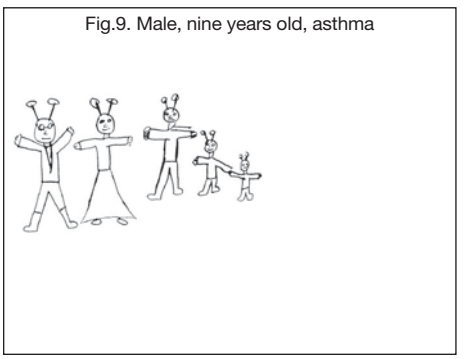


Fig.9. Male, nine years old, asthma

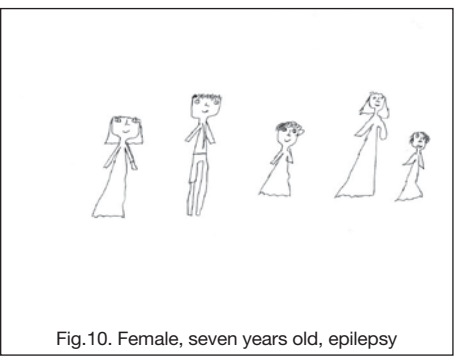


Fig.10. Female, seven years old, epilepsy

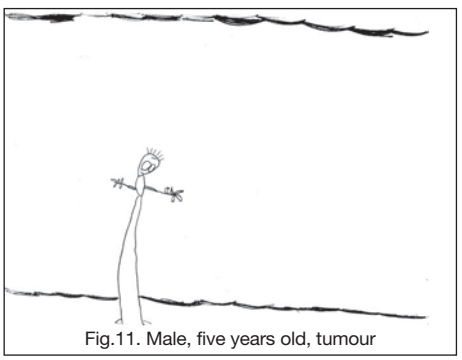


Fig.11. Male, five years old, tumour

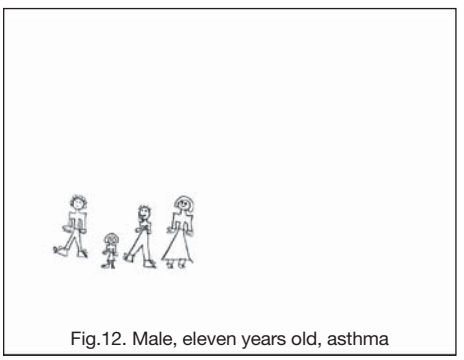


Fig.12. Male, eleven years old, asthma

take down into the valley, because of euthanasia, branches that are considered to be no longer productive and are seen as being burdensome, and thus held to be useless, turns its face in the other direction. A society that brings into play commiseration and pietism: clumsy and hypocritical reactions dictated by the need to protect itself against the scandal of pain. This isolation, when it takes place within the family, can have as its victims the siblings of the sick child. They are the first to experience isolation and desolation when their parents are busy in the hospital or with medical doctors and therapies. Even more painful are the desolation and abandonment of the siblings when they find themselves in the presence of forms of behaviour that involve hyper-protection by the parents towards their sick child, forms of behaviour that run the risk of obstructing his or her development, strengthen his or her status as a sick child or spoil him or her to the point of transforming him or her into a little capricious tyrant. 'Siblings, feeling that they are neglected by their parents, can experience a conflict between aggressive tendencies towards their sick brother or sister and the wish to do something for him or her, and they can also feel a sense of guilt at having destructive feelings towards their brother or sister. The siblings (above all if they are older) of the sick child can perceive the difficulties of their parents and in an attempt to help them that can adopt a parental role towards their sick brother or sister and look after him or her; or they can 'relieve' the pain and disappointment of their parents by trying to engage in compensatory behaviour as regards what the illness of their sick brother or sister impedes him or her from doing'.[5]

Relief and Hope

And here we encounter a third step in the experiences of these families. This is not a horizontal step in suffering but a vertical one, a step upwards: this is the step of relief. *Sub levare*: a movement that goes from below upwards, inverting the direction of suffering (which is *sub ferre*: to 'take downwards'). 'Relief is not a solution, a definitive existential approach; it is, rather, a suspension, a truce, or at least perceived as such. In order to understand the transitory character of relief we can be helped by a analogy with Inferno, Paradise and Purgatory: Inferno and Paradise are not realms of relief; in them everything is complete and definitive: there are no pauses in being blessed or damned. Purgatory, in contrary fashion – specifically because of its transitory character – is a reality that is compatible with relief'.[6] 'The souls of the departed can, however, receive "solace and refreshment" through the Eucharist, prayer and almsgiving' (*Spe Salvi*, n. 48).[7] Together with relief, hope also remains in Purgatory, the 'hope of being lightened from the tribulation (*sub-levare*) to which one is subjected (*sub-ferre*). Without hope, indeed, relief is a concept emptied of its liberating charge: when I suffer I can hope for relief and at the same time when I feel relief I can hope that this state will last a long time. Here, therefore, is the complexity of suffering: it is the raising of the suffering spirit; it is truce, suspension, comfort, cooling, alleviation; it is at the same time a consequence and a source of trust and hope'.[8]

Relief united to hope is a source of joy. Relief, hope and joy: they are not opposed to suffering or incompatible with the condition of illness. Even in a family that is very much weighed down by illness, there may not be recovery but the space for relief, joy and hope does exist. If it is true that a family is a 'place of care and the building up of hope',[9] then it is also a place of joy and relief. This is evident in many testimonies of parents and in the pictures and words of sick children. At times it is the unexpected smile of a child or his or her words of comfort that relieve the whole of the family; at times it is realising that the sick child is first of all a child, a brother, a sister, and that his or her illness or disability belong to the background. Then desolation and the experience of abandonment dissolve: the family acquires a new existential position although all the difficulties and the daily stress remain (Fig. 13 and Fig. 14). The parents begin to see their child in a new way: now he or she is a gift that has taught them the value of small things, of oblative love, and what the real problems are for which it is worthwhile struggling and spending one's life doing. The illness has filtered friends and relatives, thereby giving to the parents only those who love our of love. Faith returns purified; prayer is no longer an anxious request for a miracle but, instead, a search for support, for comfort, for the presence

Fig.13. Female, eleven years old, asthma

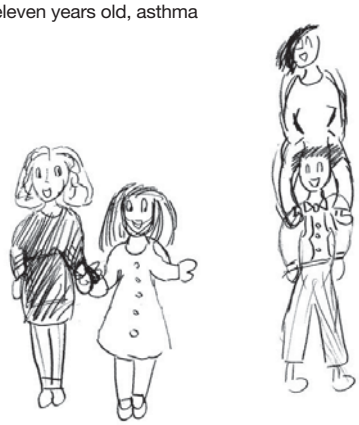
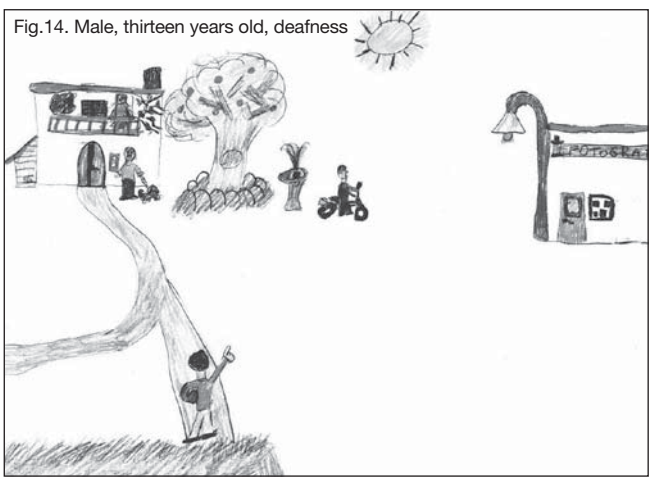


Fig.14. Male, thirteen years old, deafness



of the Lord. Rosa accompanies us in this approach to relief; she states that for her family it is a relief to know 'people who can encounter our fragility because they are not afraid of our fragility or their fragility. People who are not afraid of making a 'bad impression''. Rosa experiences hope 'every time that a person spontaneously draws near to Gabriele without prejudices'. This testimony gives us an example of relief where suffering is not eliminated but, instead, transfigured and sublimated'.[10] It is testimony of mature hope distilled from suffering: not the wish/hope for recovery or being better in the future but a certainty/hope[11] linked to the present moment.

Here, therefore, is the challenge of the illness of the child – it can constitute a source of suffering and a risk that ties, the meaning of existence and of life itself will be eliminated, but it can also be an opportunity to gain a hundred times more: 'good measure, pressed down, shaken together, running over' of meaning and grace will be put onto the lap (Lk 6:38) of these families and through their witness into all of us.

What Should be Done? Unity, Solidarity and Witness

It has been demonstrated that a family with a sick child receives great psychological, social and spiritual benefits from the help of other families. It is no accident that parents who are sorely troubled by the illness or death of their child decide to found an association of parents or families. These associations exist throughout the world: they are based on practical experiences, on a lucid awareness of what the real needs of the families of sick children are, and for this reason they deserve the greatest consideration on the part of the world of health care, science, institutions and all citizens.

The resources of acting in associations and of mutual help between families[12] would lose a great part of their effectiveness if they were not in their turn animated by another great resource to which I have referred on a number of occasions in this paper – witness. Rosa, the mother whom I have chosen as a witness for this contribution of mine to this international conference, expressed its value very well. Rosa realised that her own witness – specifically because she is the mother of Gabriele – to a mother who is experiencing the desolation of having a sick child is much more effective than a whole series of fine words and pats on the back. Authentic, direct and living witness penetrates the heart of the person or the family that is suffering; it has the power to give relief from desolation, from loneliness and from abandonment. Indeed, Rosa, concludes, 'one should not go there to give words, one should give witness of joy, witness of sharing. It would be more difficult to accept it from someone who has not lived the same situation'.[13]

Witness and sharing are even more efficacious if they are organised, guided and connected to a larger project, for example that of the Church. I would like here to refer to a fine reality that I recently learnt about in Palermo. In the diocese of the capital city of Sicily there is a centre or 'pastoral service for disabled people' which was created in 1999 by Cardinal Salvatore De Giorgi to give greater autonomy to a service which up till then, within the other pastoral offices, had not been able to be effective in the work of integrating people with disabilities into the local parish communities. The 'pastoral service for disabled people' has as its target groups families, parish communities, Church movements, pastoral workers, and secular movements which are concerned with disabilities and children's illnesses. It cooperates with other pastoral centres such as the Centre for Youth Pastoral Care or the Office for the Catechesis, in addition to the Centre for Pastoral Care in Health, of which, indeed, it forms an integral part. It organises training courses (for example a sign language course for priests so that they can administer confession to deaf and dumb people as well; or it has trained those who provide catechesis in how children with cognitive deficits should be taught). The 'pastoral service for disabled people' also organises meetings of sensitisation in which broad space is given to witness, a source of authentic hope, by families with one or even more than one sick or disabled child. The objective is to transform the community from being refractory and full of prejudices and fears into a welcoming and 'enabling' community, that is to say one that is able to activate and vivify families who have sick or disabled children so that they can come out of the tunnel of turning inwards on themselves and desolation. And to ensure that these families as well, like the family of Gabriele, can be helped to open their eyes and realise that in suffering it is possible to experience joy and that they in their turn can bear witness to this, making themselves thereby a gift[14] and living hope.

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Notes

[1] Conferenza Episcopale Italiana, *La famiglia nella realtà della malattia*, *XVI Giornata Mondiale del Malato, 11 febbraio 2008* (Camilliane, Cuneo, 2008).

[2] These pictures are taken from the volume by FERRI V. AND PANIER BAGAT M., *Io tra di loro. La famiglia attraverso i disegni di bambini affetti da patologie gravi* (Ma.Gi., Rome, 2000).

[3] Rosa authorised the author to publish her testimony in the hope/certainty that this could be of help to families which have sick children.

[4] SOCCORSI S., 'Esperienze di intervento in un centro per la cura delle leucemie dei bambini', *Terapia familiare*, 2, 1977, pp. 41-57.

[5] FERRI V. AND PANIER BAGAT M., *Io tra di loro. La famiglia attraverso i disegni di bambini affetti da patologie gravi* (Ma.Gi., Rome, 2000).

[6] FERRI V., 'Il vissuto di sollievo', in *Il sollievo, la cura del dolore in tutte le sue dimensioni* (Angeli, Milan, 2003), p.26.

[7] BENEDICT XVI, Encyclical Letter *Spe Salvi*, 2007.

[8] FERRI V., *op. cit.*

[9] Conferenza Episcopale Italiana, *op cit.*, chap.3.

[10] JOHN PAUL II, 'Discorso ai medici e ai malati dell'ospedale "Casa sollievo della sofferenza', San Giovanni Rotondo, 23 May 1987.

[11] Encyclical Letter *Spe Salvi*, n. 1.

[12] *Compendio della dottrina sociale della Chiesa* (2004), n. 246.

[13] Rosa Foti Buzzi, communication to the conference 'L'handicap sfida la famiglia e la comunità', Rome, 8-10 March 2002.

[14] PETRILLO M., 'La relazione genitori-bambino disabile', *Gens*, Nov-Dec 2002.

MARIA LUCIA SPERLINGA, MICHELA BAZZARI

9. Health-Care Personnel and Sick Children

The promotion and defence of the health of children, the quality of life of children and their families, constitute the objectives of all health-care workers who work in the paediatric field.

Those who engage in professional service at the side of children know the relevance that the family and the family environment play in treatment.

The experience of illness and of hospitalisation constitute moments of great difficulty both for parents and for children. The effects of this experience involve the whole of the family at a cognitive, emotional, behavioural, social and spiritual level.

The integration and cooperation of the various professional figures who are involved in treating and looking after a child have as their primary objectives the humanisation of care, the defence of the rights of the child and his or her family, and the sharing and implementation of individual therapeutic plans directed towards the safety and quality of the care and treatment that is provided.

The humanising of care is achieved through providing care for the child and his or her family in an overall way, without ever losing from sight the profound unity of the human being understood as a set of physical, health-care, social and educational needs, together with the need for autonomy and for affective and spiritual fulfilment.

Taking responsibility for all the members of the family unit requires each Christian or secular health-care worker to have the ability *to be present* at their side with authenticity and a readiness to engage in listening and empathy.

These qualities define the relationship of help[1] understood as the capacity of the health-care worker to be himself or herself, the bearer of professional, ethical and religious values, technical expertise and skill, and at the same time a person who is able to maintain his or her own heart open to a profound understanding of the needs of the child and his or her family. Authentic readiness to help and to provide care foster a growth in trust of very young patients and their parents in the team looking after these patients and in the whole health-care structure: this is an indispensable precondition for the successful provision of treatment.

To be in a relationship, to communicate, in particular for medical doctors and nurses, means to interact with the state of mind of the child and his or her family, whether this is expressed or not expressed. This is difficult because this state of mind is conditioned by anxiety, by uncertainty about the future, by pain, by a loss of trust, or by a calling into question of values, including religious ones.

To be in a relationship, for those who provide care and for those who receive care, is to interact with and share a pathway that involves a search for the profound meanings of being born, living and dying.[2]

In nursing care, the whole process of nursing, at every one of its stages (the initial assessment of needs and the identification of the health problem, the planning of care and treatment, the implementation of planned action, the assessment of the procedure that has been implemented and the assessment of results), becomes therapeutic[3] if it is founded on a relationship of health.

There are many moments within this process where the relationship, communication, sharing, the perception of the non-verbal, silent presence and physical contact understood as a 'good touch'[4] and a loving touch, as well as hope, which must always be transmitted, take on for a sick child and his or her parents meanings that are significant, profound and delicate.

Amongst these meanings, in particular, one may specifically refer to: the moment of admission to the hospital and the initial assessment of the overall needs of the child and his or her family; the communication of the diagnosis, above all if it is prenatal or connected with situations of a chronic nature, handicap and a danger to life; the involvement of the parents and the child in the plan of care and treatment; the management of pain; being discharged from hospital and actions taken in relation to health-care education; and death.

At these times a paediatric nurse plays an important role. He or she must act together with all the other professional figures that are needed in order to meet the needs of the child and his or her family. An interdisciplinary approach, in fact, allows a taking on of total responsibility for the whole family unit.

The receiving of the child into the hospital is of fundamental importance. If this is well managed, above all from the point of view of communication, it facilitates the establishment of a relationship of trust with the child, his or her family, and the medical team, as well as an adaptation by the child and his or her family to the health-care structure.

It also allows the gathering of the information that is needed to plan the diagnostic-therapeutic pathway and the nursing care that will be provided.

Admission can be preceded by a stage of pre-admission (visits to a clinic, a day hospital, a day surgery) during which the whole family unit can begin to know the health-care workers and the health-care structure.

From an operational point of view, planned or informal conversations are engaged in that are directed towards learning about the health-care structure, the medical doctor and nurse who will deal with

the case, the list of services and the list of rights of the child who will be admitted, the behaviour that should be engaged in during the admission to hospital, and the systems of support for the child's parents, such as lodgings for the parents, the social services and the support offered by religious personnel.

Parents and their children are informed about the presence of teachers who are responsible for carrying on the schooling of the child during his or her admission to hospital.

For multiethnic families, specific initiatives are envisaged that respect their traditions and their beliefs, together with the presence of cultural mediators.

From a structural point of view, nowadays paediatric hospitals or the individual wards inside structures for adults, allow environments that are suitable for children, ones that are coloured, happy, and where, as far as this is possible, the rhythms of family life can be reproduced and studies can be continued with. The child is assured the pedagogic function of playing, often in situations that are critical as well.

In this way, the environment performs an active and reassuring role which completes the relational, care and therapeutic aspects of the experience of the sick child.

The moment of the communication of the diagnosis of the child's illness is a very delicate stage both for the medical team and for the family. The team is responsible for assessing the moment for this and the form of its communication and should identify those moments and forms which are most suitable for the family unit.

The quality of the relationship and the relationship of trust established with the parents, ad the presence and the support of professional figures who are experts as regards the processes of communication, can facilitate the acceptance of diagnoses that are difficult to accept, and in relation to which the family may express strong emotional reactions involving fear, guilt, frailty or opposition.

The presence of a nurse helps in this moment as well in the observation of the behaviour of the parents which is, indeed, extremely subjective, and in gathering valuable information for the medical team in order to plan actions that involve the provision of support.

The environment must assure the existence of tranquillity and privacy.

It is necessary to use simple language and a gentle tone. The parents must be stimulated to engage in dialogue and in discussion. A readiness to engage in listening, empathy, and respect, as well as a loving presence, creates those conditions which are needed to make the parents feel free to express what they feel and to express their feelings.

Above all at this stage, hope must accompany the diagnostic-therapeutic prospects, the prognostic expectations, the possible risks, and the quality of future life.

Instruments that provide information such as brochures, pictures or films can complete the information that has been provided and help parents to express aware and informed consent.

The child must be enabled to understand his or her condition, without being frightened, using simple forms of communication and ones that are suitable to his or her age, and he or she should be helped to express what he or she feels and understands.

Playing, playacting and drawing are privileged channels of communication by which to enter into a relationship with the child. They help him or her to assimilate information and to express the negative feelings that are associated with his or her illness.

At this stage physical contact understood as good and loving touch – a holding of his or her hand, a hand on his or her shoulders or back, hugging children, cuddling them, and communicating to children and their families warmth, solidarity, understanding, sharing and support – is of great value.

The involvement of parents and patients in the plan of treatment and care acknowledges that they have an active, informed and aware role in the necessary therapeutic choices that are made, with full respect for their rights and the religious values of their cultural and ethnic contexts.

It allows the child and his or her family to mobilise unsuspected resources of strength and courage which are valuable in achieving the therapeutic result that is desired.

The humanisation of care for the child means that the pain provoked by the illness or caused by diagnostic and therapeutic initiatives can today be controlled thanks to specific protocols which are drawn up on the basis of scientific evidence.

The development of anti-pain treatment can allow the child the right to maintain a good quality of life and respect for his or her dignity as a human being.

Discharge from the hospital and health-care education can facilitate the return of the child to his or her home and may involve initiatives directed towards the governing by the family and the patient himself or herself, above all if an adolescent, of his or her state of health, both in terms of prevention, therapies and rehabilitation and in terms of suitable lifestyles.

The use on this occasion as well of instruments of information such as brochures and videos, and active teaching methodologies such as demonstrations and exercises, together with good communication, allows nurses and medical doctors to provide all the information and tools that are necessary to the child's family at home.

The death of a child, which is devastating and destabilising for the family, but not only for the family, can be shared in if a real relationship of help is present. Only in this way can one become an intimate partner in such an immense and unjust pain, which can be worked through, accepted and, thanks to faith, transformed into the

most intense and profound moment of the lives of human beings. For this reason, on a par with professional and technical skills and expertise, the skills and expertise in communication of nurses and medical doctors should be acquired in basic training and developed in refresher courses.

The individual growth and maturation, of a professional and ethical kind, of the individual health-care worker can enrich skills and expertise in communication, enlarging that dimension of understanding which comes from the bottom of the heart.

Lastly, given that care for sick children and the relationship with their parents is a relationship of reciprocal help, made up of giving and having, I would like to share with you everything that I have learnt and received from them during my years of professional practice.

From children I have learnt the value of innocence and joy which are of help in overcoming difficulties and pain rapidly, rediscovering a smile immediately after crying. I have leant to provide simple answers to difficult questions, and to express feelings.

I have leant to remember that innocence, joy and trust are qualities that are not lost as one goes through life and that they mark out the human spirit, in suffering as well.

From parents I have leant courage and devotion, and always to keep hope alive even when there seems no grounds for this in rational terms; as well as solidarity which always unites and sustains; sacrifice, the ability to accept difficult things and difficult situations. From both children and parents I have learnt the value of health and of life, which always deserves to be lived.

I am grateful to all those that I have had an opportunity to draw near to because I have read in their eyes profound doubts, fears and feelings that I felt were my own. And together we have gone through and shared a part of our lives while sharing its goal – the overall well-being of children.

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Notes

[1] C.R. ROGERS, *La terapia centrata sul cliente* (Feltrinelli, Florence, 1970).

[2] Pontificio Consiglio della Pastorale per gli Operatori Sanitari, *Carta degli operatori sanitari* (Vatican City, 1994).

[3] C. CORTESE AND A. FEDRIGOTTI, *Etica infermieristica,* 3rd. edition (Sorbonne, Paris, 1992).

[4] M. BAZZARI, *L'assistenza infermieristica: l'importanza della comunicazione con il bambino e la famiglia, Atti del convegno ' Il trattamento delle cardiopatie congenite nel bambino. Aspetti scientifici ed etici'* (Genoa, 2003).

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PASCUAL PILES FERRANDO

11. Religious Orders and Congregations and Sick Children

Introduction

As on other occasions when I have been invited to give a paper at these international conferences I accepted with satisfaction and enthusiasm. I looked for data on this subject and I did not find any specific orientation. I consulted a historian of the religious world who on other occasions had enlightened me. He was not able to help me on this occasion because of a lack of evidence and he apologised for not being able to help me. A major solution for everyone today is research on internet. The solution was not a complete one. I have directed my paper taking as a basic point of reference the title of this twenty-third international conference of the Pontifical Council for Health Care Workers – 'pastoral care for sick children'. I hope that what I will say will fill us with satisfaction at what the Church, with its Orders and Congregations, has done for sick or needy children. In this paper will not touch upon the subject of teaching.

1. Jesus of Nazareth and Children

The evolution of history has led us to take into consideration, with the development of law, of ethics, of anthropology, of psychology, of theology etc., the dignity of people. Men, but not all men, have always had greater recognition. *Women and children* have received lesser attention. In his Letter to the Galatians (3:28) St. Paul states that there is no distinction between men and women. But in some places this statement is not yet applicable. Jesus Christ defended children and wanted them near him; he acted for them: 'Let the children come unto me for to them belongs the kingdom of heaven' (Mt 19:14; Mk 10:14). 'Whoever does not receive the kingdom of God like a child shall not enter it' (Lk 18:17). 'Truly I say to you unless you turn and become like children, you will never enter the kingdom of heaven' (Mt 18:3). 'Whoever receives this child in my name receives me; and whoever receives me receives him who sent me; for he who is least among you all is the one who is great' (Lk 9:48).

These texts are an expression of how Jesus loved children; how he kept them in his heart; how he saw them in their innocence and character as citizens of the kingdom of God; how he chose them precisely because children have to walk towards a maturity that is not only physical but also human and spiritual in nature.

2. Jesus of Nazareth and the Sick

The nearness of Jesus to the sick is very visible in the Gospels. His words were often accompanied by signs and most of these signs were for sick people or people in need. He was well aware of his mission. At the beginning of his public life (Lk 4:18-19), when reading the prophet Isaiah, he confirmed this. Later (Lk 7:22), faced with a question posed by the Baptist, he answered: 'Go and tell John what you have seen and heard: the blind receive their sight, the lame walk, lepers are cleaned and the deaf hear, the dead are raised up, the poor have good news preached to them. And blessed is he who takes no offence at me'. He did this on a massive scale, and all of those who came to him were cured: 'That evening, at sundown, they brought to him all who were sick or possessed with demons. And the whole city was gathered together about the door. And he healed many who were sick wit various diseases, and cast out many demons'. He did this to confirm that he was the Son of God: 'Whenever you enter a town and they receive you, eat what is set before you; heal the sick in it and say to them, 'The kingdom of God has come near you''.

3. The Medieval Hospitaller Orders

For Jesus, caring for the sick was fundamental. It was a sacred obligation. Like Jesus, the Church took on the ministry of healing, being sensitive to the needs of people. During the tenth century in Europe the Hospital Fraternities came into existence because of the devastating plagues and epidemics that spread because of the excessive growth in towns and cities. The crusaders took responsibility for extending in the continent the institutions that provided care to the sick. A reading of the Gospels led to the discovery of the poor, sick and needy Christ. In caring for the sick one cared for Christ himself.

A large number of *Hospital Orders* arose during the medieval period. The other hospitals not run by religious were subject to the local bishop. There were also Orders that lived in communities and made a fourth vow: care for the sick. There were some Orders that cared for sick people in their homes like the Oblates, the Augustine Hospitallers, the Hospitallers of St. John of Jerusalem, etc. The most famous were: the *Hospi-*

tallers of the Holy Spirit which was founded by Guy de Montpellier in the year 1075. They accepted the rules of St. Augustine. In Spain they were present in Cadiz, Puente la Reina, Seville, and Menheusa. The Hospitallers of St. Anthony were also known as the Regular Canonics of St. Augustine and St. Anthony of Vienna. Founded in *1095* in a hospital near to Vienna that was known as the House of Alms, they grew during the twelfth and thirteenth centuries. In Spain they had a foundation in Cervera (*1215*) and then in Lerida (*1271*). There then followed a large number of foundations, in Catalonia, Castile and Andalucía.

In *1120* a brotherhood was created that was dedicated to care for lepers in the Hospital of Jerusalem which adopted the rules of St. Augustine and was then transformed into the Order of St. Lazarus and spread with its hospitals and homes in France, Germany, England and the Low Countries. Another Congregation of lesser importance was that of the Canonics of the Holy Sepulchre which was created in Jerusalem in *1144* by Arnolphus of Rohes. The members of this Congregation were much concerned with hospital care and moved to the West after the fall of Jerusalem in *1187*, becoming at the end of the fifteenth century a hospital Order.

In *1218*, as a result of St. Pedro Nolasco, another secular brotherhood arose in Barcelona of a military/care character which was transformed into an Order in *1253*, adopting the name of Our Lady of Mercy. The aims of the members of this brotherhood were both military and care-orientated (hospitals and the redemption of prisoners), although within a short space of time the military dimension lost importance.

4. The Culture of Care and Care for Sick Children

When were sick children taken into consideration? We may believe that this had always taken place although there was an advance with the development of respect for the rights of children. The Church had a tradition of providing care to the sick, a tradition of hospitality. Sick people were cared for and amongst these there were children, but it has not been demonstrated that there were institutions expressly dedicated to them. The first house of the Hospitaller Brothers of the Teutonic Order in Germany was founded in *1299* in Kunitz, near to Berne. It was dedicated to providing care for the such, amongst whom were children, and was also responsible for education. The hospital tradition proliferated during the Medieval period with the hospitals created in the West (House of God or Hotel of God).

The most famous was the *Hotel Dieu* of Paris, of the beginning of the seventeenth century, where Mother Geneveuve Bouquet established a novitiate. It had a social mission but did not provide hospital care to sick children, When the Hospital for Sick Children was created, the *Daughters of Charity* of St. Vincent de Paul and St. Luisa Marillas, supported by Louis XIII and Louis XIV, came to belong to it. This hospital was founded in *Paris* (France) in *1802* and was specialised in providing care and treatment to sick children. A series of foundations for sick children began.

The Children's Hospital of London was founded in *1739* by the philanthropist Captain Thomas Coram. It took in abandoned children and provided them with an education and accommodation and food. The *Baby Jesus Paediatric Hospital was founded in 1869 in Rome*, the Vatican City (Italy). It expressed its Christian witness at an institutional level through the provision of charitable care in the health-care field. It was a part of the Roman welfare network. Because of its prestige, from 1880 onwards it was a point of reference for all Italian paediatrics and it obtained a high level of specialisation in care and treatment for not only Roman and Italian but also European children. In 1985 it was recognised as being an 'Institute of Care for Admissions of a Scientific Character' and it is one of the top three paediatric hospitals in Italy. It is recognised in line with the UNI regulations as ISO9001: 2000. Its motto is 'Care for Children, Serve Them'.

This hospital is the property of the Holy See. It is a work held very dear by the Holy Father. It is conceived as an IRCSS in order to advance with progress rapidly but in a way that is consistent with a Christian vision of existence and respect for the person, humanising science and technology and making them a sign of Jesus Christ.

The Baby Jesus Hospital was founded in *1877* in *Madrid* (Spain). It imitated the initiatives that had existed for some time in Rome and Paris. It opened with clinics for medicine, surgery and ophthalmology. It is seen as the cradle of paediatrics in Spain. Mariano Benavente, who is called the physician of children and is seen as the father and founder of the speciality of Spanish paediatrics, worked in this hospital.

The Children's Hospital was founded in La Plata, Argentina, in *1887*. The Blessed Ludovica de Angelis, the Daughter of Mercy, who worked with great success during the first half of the twentieth century, worked in this hospital.

The Hospital of Nens was created in *Barcelona* between *1886 and 1890* thanks to the efforts of the Company of the Daughters of Charity of St. Vincent de Paul. Their generous spirit has always assured the wellbeing of patients and those most in need. It was *15 May 1886* when Dr. Francisco Vidal Sikares and Sister Mercedes Viza created a dispensary. Four years later they created the Hospi-

tal of Nens for the poor of Barcelona, thereby beginning a great story of charity and help for children and those most in need. Since 1980 this hospital has been a non-profit-making charitable/social foundation under the patronage of the Children's Hospital of Barcelona, whose objective is the provision of medical care and treatment to children, as well as preventive medicine and teaching carried out principally in Catalonia, but open and present outside this region. It is one of the pioneers in care and treatment, in teaching and in research in the field of paediatrics. It has all the specialities with some excellent equipment, but its activities must be placed within a juridical, technical and deontological context made up of a team of people who are highly trained at a professional and human level. Thanks to its human team it is ready to perform the function that belongs to it at a social level in line with its identity. The patronage committee is made up of eighteen people, eleven of whom are Daughters of Charity, and it is chaired by the Provincial Sister, Sister Maria Dolores Cruz Arbeloa Quarte.

5. Hospital Orders and Sick Children

As is the case with other religious institutes, the hospital Order to which I belong, and which is clearly defined by the charism of hospitality, is dedicated to the sick and to people in need. Children are present in its institutions to the extent that these care for them. St. John of God in his second letter to Gutiérrez Lasso on two occasions refers to children of the ages of five and seven when he describes the kinds of sick people to be found in his centre. Without engaging in an exhaustive study, because that is not what I am interested in at the moment, I would like to observe that my personal experience began when I entered the Order in the year 1964.

I entered the Order and began as a member of a psychiatric institution named *Sant Boi de Llobregat* (Barcelona) where amongst the various adult units there was one for slightly and heavily intellectually disabled children and teenagers with some forty beds or hospitalisation. The province had nursery-hospitals for people with polio, with a ward for children and a ward for adolescents in *Barcelona*, *Valencia*, *Calafell* (Tarragona), *Manresa* (Barcelona), *Palma de Mallorca*. It administered a foundation for epileptics in *Madrid* with two departments for children and one for adolescents, and about 130 children and adolescents took part in a programme centred around its day hospital.

Our tradition has remained, with paediatric services in many general hospitals or centres for disabled people, where, indeed, we are present. Indeed, we could present our Esplugues Hospital (Barcelona) as a diamond-point centre because it is for mothers and their children. In 2006 a strategic plan was presented called Paidhos, from the Greek, which was chosen because of the meaning that it has for us. The seven letters come from the initials of the words in Spanish that express the contents of this programme: neighbours, accessible, investigators, lecturers, hospital, open and solidarity-inspired. I will concentrate here only on the word 'hospital': a model centred around the person.

Strengthening the Dimension of a Lovable Organisation

Plan for an improvement in the administrative procedures. An exhaustive analysis of all the administrative processes of the hospital will be completed and actions directed towards its improvement will be proposed that involve their decentralisation, simplification, and their being brought closer to the users.

Plan for the improvement of the accommodation sector. All the aspects that are connected with the comfort of the children and their families while they are in the hospital. The plan will incorporate actions that bring our accommodation services closer to the users.

The opinion of the users. Studies of perceived quality will be completed, the management of suggestions will be improved, and communication with users will be increased in order to go beyond the classic systems of reception, appeals, and disruptions.

Hotel for the associations of the parents of patients. The relations with the associations will be strengthened in order to ensure that their participation is a real element of therapy and support. The hostel for the associations will provide an answer to their needs for space, channels of information, a presence in the hospital, etc.

Complementary services. Viability studies will be carried out in order to give out for tender non-care services that can meet the complementary needs of families.

Guaranteeing the Values of Hospitality in the Internal Culture

The hospitality area. A hospitality area will be created that will coordinate the current initiatives that complement the care that is provided with the values of hospitality.

Programme for the dissemination of values. The hospital is an organisation centred around the person. The patient and his or her family are the centre of our activity. A programme for the exploration of values that help in generating their presence and dissemination will be drawn up.

From religious service to spiritual service. The growing heterogeneousness of the users of the hospital requires greater efforts in order to assure respect for cultural and religious diversities. The service of pastoral care will be the guarantor of this need, with the allocation of appropriate areas and interlocutors.

The presence of voluntary workers. Volunteers are an important key in our centre and come to constitute a permanent observatory of our reality, helping us to discover new needs. They will continue to be incorporated into the new areas that are created. The training programmes will be improved and volunteers will be present in central areas of participation of the hospital.

Bioethics. Here we mean training in bioethics as a fundamental part of the exercise of good practice. A systematic programme for

the training of professionals will be implemented.

6. Orders and Congregations that Have Cared for Sick Children

I do not want this section to be a list. But I would like it to be a demonstration of what the Church has achieve in practical terms through its various religious families in favour of sick children. It is my intention to count up some of the institutes that have progressively appeared over time.

The Servants of the Poor. This group was founded in Somasca, Bergamo, by St. Gerolamo Emiliano and St. Pius V approved its existence as an *Order in 1567*. Their priorities were the poor and abandoned children who wandered the streets.

The Order of St. Camillus de Lellis. Ministers of the Infirm. As early as *1586 Sestus* V had approved and confirmed that first 'company' as a 'congregation', that is to say he gave it its first ecclesiastical recognition as a form of religious life but still without the tie of public vows. In *1591* it was declared a religious Order by Gregory XIV. In that year Camillus and his followers professed that they would place themselves at the service of the sick to the point of placing their lives at risk. This last is the principal and characteristic vow of the Order.

The Daughters of Charity. These were founded by Vincent de Paul and Luisa de Marillac in *1617*. Their convent was the homes of sick people, and their cloisters were the streets of towns and cities. They were founded with a strong character of providing care. They renewed the attention that was paid to hospitals, to orphanages, to old people's homes, to homes for adoption, to psychiatric institutions and to help centres in the France of their epoch.

The Hospital Sisters of the Holy Cross were founded in 1792 as a sisterhood of charity or the Pious Association of Sister Nurses dedicated to service to the poor at the General Hospital of the Holy Cross of Barcelona. In *1927* this was transformed into the Congregation of the Sisters of the Holy Cross. Amongst the various foundations there is the 'Stauros' Clinic for Children in Barcelona.

The Sisters of Charity of St. Anne. Their history began in *1804* and more specifically at the Hospital of the Holy Cross in Barcelona where there was a group of volunteers who dedicated themselves to the sick of the hospital. A hospital of the eighteenth century was the refuge of every kind of pain. We should not think of the rapid hospitalisation of our days. A hospital was a refuge of people passing by, a home to take in orphans, a place for the recuperation of sick people, a place to care for the demented, a home for prostitutes, and for giving birth in the case of unmarried mothers…it was as if all the social works that we know today were concentrated in an individual place.

We encounter Father Juan Bonal, the chaplain of the hospital, and Maria Rafols, amongst the volunteers of this confraternity. Barcelona sent volunteers to the existing group in the Hospital of the Holy Cross. A Zaragoza arrived in 1804 and 12 brothers and 12 sisters to provide care in the hospital on 1 January 1805. In this way there began the history of the new Congregation founded by Mother Rafols and Father Bonal.

The Hospital Sisters of the Sacred Heart of Jesus. This Congregation was founded in Ciempozuelos (Madrid-Spain) in the year *1881* by St. Benito Menni, a priest of the Order of St. John of God, together with Maria Josefa Recio and Maria Augustias Giménez, who were chosen by God to care for people with mental disturbances and who in their work united two fundamental criteria: charity and science.

The name Hospitallers of the Sacred Heart is an expression of the charism of the Congregation because the reason for its existence within the Church is the practice of hospital charity, experienced in the state of religious consecration according to the model of perfect charity, Christ symbolised by his heart. Amongst their sick people they have children and adolescents in their hospital centres and centres for rehabilitation.

The Daughters of Mercy. These were founded by Maria Josefa Rosello and have a woman religious of great holiness and devotion in Sister Ludovica de Angelis who moved to La Plata, Argentina, in *1907* and became the soul of the children's hospital there until she died in 1652. She was beatified by John Paul II in the year 2004.

The Sisters of Providence were founded by Emilia Tavernier Gamelin in Montreal, Canada, in 1844. She was known as the 'mother of the poor', the 'angel of prisoners', and the 'providence of the fortunate'.

The Adoring Slaves of the Most Holy Sacrament and of Charity were founded by Mother Micaela of the Most Holy Sacrament in Madrid and approved by the Holy See in *1861*. Moved by charity they were devoted to sick young people in the Hospital of St. John of God and the saving of young people of bad behaviour.

The Angelic Religious were founded by Mother Genoveva Torres Morales who, after a long experience of suffering, founded the first house in Valencia in *1911*. Her charism is directed towards 'alleviating the loneliness of people caused by difficulties of the body and the spirit'.

The Sisters of Charity of Miyazaki were founded on 15 August *1937* in Miyasaki (Japan). At the present time they work in nurseries for children, in hospitals, in clinics, etc.

The Religious Congregation of the Sisters Servants of God was founded in *1939* in Barcelona by Dolores Permanyer i Volart who, in flanking divine action, germinated the seed of the foundation inherited from Father Jacinto Alegre, under the spiritual direction of Father Juan Guim, the co-founder. A new family of the this priest thus came into existence. It would dedicate itself to the poor and the sick, many of whom would be children and adolescents.

The Missionaries of Charity were founded by Blessed Teresa of Calcutta. This small society with twelve members was established in *1950*. At the present time they have various expressions: active and contemplative sisters, active and contemplative brothers, priests, co-workers, the Corpus Christi movement, the Lay Missionaries of Charity, and volunteers.

Sister Cecilia Montana, a native of Lesotho (a State with South Africa), a Salesian, works in the Don Bosco Centre in a programme for the prevention of HIV called 'Love Matters'. In the continent of Africa there are twenty-five and a half million people with HIV and twelve million orphans.

USG, a health committee. The men and women religious of this deal with the HIV pandemic and have a programme made up of eleven works, amongst which one is for orphan children and children with HIV.

The Order of Minor Friars in the Holy Land**.** *The Bethlehem Emergency Programme*. F. Pierbattista Pizzaballa, at Christmas 2007, drew up and implemented this programme for maltreated and sick children in situations of difficulty in the land where Jesus was born.

7. Prizes

For symbolic reasons I would like to refer to these two prizes that were awarded to our institutes and our people: Mother Teresa of Calcutta was awarded the Nobel Peace Prize in *1979*. The Daughters of Charity of St. Vincent de Paul were awarded the Prince of Asturias Concord Prize in 2005.

8. The Church and Society are Called to Continue to Act Faced with Weakness of Children

The whole of the above reflection leads us to continue to work for humanity with our expressions based upon the charity of Christ. We are in the world to bring the salvation of Christ. We must do this with the Word, we must do it with our lives, loving as Christ and our founders loved. May this contribution be a remembrance and an appreciation of much of what has been done, may it also be a stimulus to continue what we are doing, and a call always to love with great hope, trusting in God and people.

9. Conclusion

I will finish with two appendices. Solely as witness to the support that has been received for our mission.

Rev. Fr. PASCUAL PILES, O.H.
Superior General
of the Order of St. John of God,
Member of the Pontifical Council
for Health Care Workers,
The Holy See

Projects for a bank called for by religious Congregations for situations to which sick and marginalised children belong to the full, granted in 2007.

Let us guarantee the future. Young people with disabilities in Ghana (Africa)
Sponsors: the Benito Menni Foundation, the Hospital Sisters of the Sacred Heart of Jesus. Sum called for: E 20,792

Nutritional care in Wale Wale, Ghana, for undernourished children and women.
Sponsors: the Juan Bonal Foundation, the Sisters of Charity of St. Anne. Sum called for: E27,802.

Construction of an Ama Mayte hearth home for orphans in Equatorial Guinea
The first native female Congregation in Africa, the Missionaries of the Immaculate Mary, founded in *1809* in Equatorial Guinea, is celebrating the bi-centenary of its foundation, and continues to provides care to the most marginalised children in Africa, orphaned and abandoned children who although many in number when this Congregation was founded now with civil wars in the African republics, boy soldiers and HIV, have grown notably. Given this anniversary, we want to restore some of this Congregation's ancient orphanages, but this time with the name of hearth homes. Sum called for: E 796,259.

Training and alimentation for the O. Social de Dar Driouch, Nador Marruecos
The Daughters of Charity of St. Vincent de Paul. Sum called for: E 67,000

Twinning of the Hospital of St. John of God with the Lunsar of Sierra Leone
The Hospital of St. John of God, Esplugues. Sum called for: E 150,000

Prevention of the Transmission of HIV in Ruanda, Africa
The Juan Bonal Foundation, the sisters of Charity of St. Anne. Sum called for: E 7,303

Food project to help children with malnutrition in Ruanda
The Missionaries of Sacred Hearts. Sum called for: E 9,153.

Vehicle for a medical clinic in Palmarin-Facao (Senegal)
The Kalao Benefit-Cultural Association, NGO. The Daughters of the Sacred Heart of Mary de Palmarin. Facao, Senegal. Sum called for: E 26,0000.

The Historical Evolution of Neonatology

Year	Person	Event
715-673BC		The oldest reference to a caesarean operation (Roman law of Numa Pompilius)
98-138	Soranus of Epheseus	Greek physician, practised in Rome, wrote on the treatment of neonates and was of great influence during the XV century
C. 6		Help for the orphans of Treves
C. 13		Hospital for orphans, Pope Innocent III
C. 15		Neonates have a soul
1538	Henry VIII	Appearance of the Bills of Mortality
1640	Louis XIII	The Foundlings Hospital is inaugurated
1650	Chamberlen	Invention of obstetric forceps
1662	Graunt	Analysis and publication of the Bills of Mortality
1691	Ruysch	First report on the clinical reality known as Hirschsprung's disease
1733	Calder	First reported case of duodenal artresia
1741	Coram	Inauguration of the Foundling Hospital in London
1753	Roederer	First publication on the right average between weight at birth and size
1769		Inauguration of the Clinic for Poor Children, London.
1780	Chaussier	First use of oxygen (O2) with neonates
1788	Beardsley	First description of hypertrophic stenosis of the pylorus in children
1795		Inauguration of the Ospedale des Enfants Trouvés (Hospital for Orphans), Paris
1797		First description of the transposition of the large vasa
1802		Inauguration of the Hôpital des Enfants Malades, Paris, the first paediatric hospital
1802	Heberden	A description of hydrocephalus in children is published
1803	Hey	First successful closure of an onphalocele
1814		Foundation of the Maternity Hospital in Paris
1821	La Jumeau	First public demonstration of an auscultation of foetal cardiac frequency
1834	Blundell	First description of an endotracheal intubation for the reanimation of a neonate
1835	von Rühl	First known use of a warming tub (*Wärmewanne*), St. Petersburg
1836		Compulsory registration of births in England
1839	Frolich	First description of the prune belly syndrome
1847		First use of ether as an anaesthetic in obstetrics
1851	Marchant	First report of gavage alimentation in children
1852	West	Foundation of the Great Ormond Street Hospital, London, the first children's hospital in English-speaking countries
1854		Foundation of the first paediatric hospitals in North America: the New York Nursing and Child Hospital and the Children's Hospital of Philadelphia
1857	Denucé	First public description of an incubator in Western literature
1861	Little	Cerebral paralysis (CP) described and related to asphyxia and traumatic birth
1870		Beginning of the Infant Welfare Movement
1879	Credé	Silver nitrate for ophthalmia neonatorum
1880	Tarnier	Presentation of the closed incubator by Tarnier-Martin, in Paris
1880	Winckel	Trials with a 'permanent water bath' for premature babies, Dresden
1882	Biedert	Caloric milk treatment for two hours at a 100 degrees for artificial feeding
1883	Auward	Presentation of an individual incubator by Tarnier-Auvard, the Maternity Hospital, Paris
1884	Tarnier	Gavage alimentation

1888	Hirschspung	First description of stenosis of the pylorus
1888	Fallot	First description of association of the defect of the ventricular sect, stenosis of the right ventricular infundibule, overlaying of the aortic valve on the right ventricule and right ventricular hypertrophy (now known as Fallot's tetralogy)
1889	Tarnier	First use of oxygen (O2) for premature babies
1891	Bonnaire	First description in literature of the use of oxygen (O2) for premature babies (used by Tarnier in 1889)
1891	Lion	The posterior thermo-regulated incubator industrialised by Paul Altmann in Berlin
1891	Rotch	Portable incubator by Rotch, Boston
1892	Budin	The *Consultations de Nourrissons* established (nursing consultations)
1893	Henry	Tent for very weak children at the Maternity Hospital of Paris
1894	Townsend	Description of 'haemorrhagic illness in neonates'
1894		First milk depots
1896	Lion	Inauguration of the *Oeuvre Maternelle de Couveuses d'Enfants*, Paris
1896	Councy (?)	Exhibition of an incubator for children at the Berliner Gewerbe-Ausstellung
1897	Councy (?)	Exhibition of an incubator for neonates at the Victorian Era Exhibition at Earl's Court, London
1897	Eisenmenger	Description of congenital cardiopathy associates the ventricular sect defect (VSD), lung hypertension, shunt from left to right and an overlaying of the aortic valve, later known as Eisenmenger's complex
1898	Councy	Exhibition of an incubator for neonates at the Trans-Mississippi Exhibition, Omaha, Nebraska
1899	De Lee	Presentation of a new incubator and the lying-in-hospital system
1899	Ahlfeld	First successful treatment of onphalocele through the external treatment of the sack with alcohol
1900	Budin	Publication of *Le Nourrisson* (*Nursing*) in France
1900	Councy	Exhibition of incubators for neonates at the World Exhibition, Paris
1901	Councy	Exhibition of incubators for neonates at the Pan-American Exhibition, Buffalo, New York
1902	Heidenhain or Aue	First successful repair of a congenital hernia of the diaphragm
1903-1933(?)	Councy	Exhibition of incubators at Coney Island
1904	Zahorsky	Exhibition of incubators for neonates at the Sales Exhibition of Louisiana and the World Fair, St. Louis
1906	Councy	Exhibition of incubators for neonates at the Leis and Clark Exhibition, Portland, Oregon.
1907	Budin	Publication of *The Nursling* in England translated by Maloney
1908	Carrel	First transfusion for haemorrhagic illness in neonates
1908	Garrod	Description of the 'innate errors of the metabolism' and their hereditary transmission according to Mendel
1909		Foundation of the Empress Auguste Victoria Haus, Berlin, a centre for teaching and research in the prevention of neonatal mortality
1911	Hess	Open neonatal cradle heated by electricity (thermal cradle)
1911		Baby tents in Chicago
1912	Blackfan	Machine for blood samples from neonates
1912	Ramstedt	First successful treatment of stenosis of the pylorus by pylorectomy
1913	Richter	Trans-thorax binding of a tracheoesofagical fistula
1914	Hess	Combination incubator at the Michael Reese Hospital, Chicago
1915		Exhibition of an incubator for neonates at the Panama-Pacific International Exhibition, San Francisco
1915	Helmholtz	Intravenous transfusions and blood extraction from the longitudinal breast
1916	Ernst	First successful surgical repair of duodenal congenital atresia
1919	Sidbury	Transfusion through the umbilical vein for haemorrhagic disease in neonates

1920s		Births in hospitals increase from 5% to 60% in the major cities of the United States of America
1922	Hess	Premature births wards at the Sarah Morris Hospital
1922	Hess	Publication of *Premature and Congenitally Diseased Infants*, the first book of texts on premature babies in North America
1922	Hess	First transport incubator for neonates
1925	Hart	First external transfusion for foetal erythroblastosis
1928	Fleming	Discovery of penicillin
1930		Foundation of the American Academy of Pediatrics (AAP)
		Foundation of the American Board of Pediatrics for the certification of the speciality
1933		Exhibition of an incubator for neonates at the International Exhibition for the Advance of the Century, Chicago
1934		Modification of a heated incubator for the administration of oxygen
1934		The five Dionne twins
1934	Følling	Discovery of phenylheturonuria (PKU)
1934		First vehicle for the transport of neonates, Chicago
1935		American Academy of Pediatrics (AAP) defines prematurity as weight at birth lower than 2,500 grams
		Clinical use of Sulfas
1936	Abbot	Publication of the *Atlas of Congenital Heart Disease*
1937		Treatment with vitamin k in coagulation disturbances in neonates
1938	Andersen	Meconium ileus is related to cystic fibrosis
1938	Gross and Hubbbard	Successful binding of the permeable a direction artery (PDA), Boston
1939	Runge	Description of the dysfunction of maturity related to placental dysfunction
1939	Councy	Exhibition of incubators at the World Fair of New York
1941	Levine, Katzin and Vogel	Rh isiommunisation established as the cause of foetal erythroblastosis
1941	Gregg	Congenital cataracts are related to epidemics of measles
1941	Florey and Chain	First clinical use of penicillin
1941	Clifford	First clinical recognition of retrolental anastomosis (RLF)
1941	Haight	First successful anastomosis of a tracheosophageal fistola
1942	Terry	First published description of retrolenticular fibroplasis (RLF)
1942	Diamond	A connection is established between isoimmunisation Rh and foetal erythroblastosis
1943	Blalock and Taussig	First 'blue baby' operation (Blalock-Taussig or BT shunt)
1944	Miller and Olney	Angiocardiogram for children with congenital heart disease
1944	Haight and Towsley	Successful repair of artresia of the oesophagus
1944	Willi	Description of 'malign enteritis in the first three months of life'
1945	Craaford and Nylin	A successful correction of the coartation of the aorta is described
1946	Diamond	External blood transfusion through the umbilical vein for the treatment of foetal erythroblastosis
1946	Smith	Publication of *The Physiology of the Newborn Infant,* first text book on neonatology in North America
1946	Ehrenpreis	First diagnosis of Hirschsprung's diseases in neonates
1946		The Hill-Burton measure, federal help in the building of hospitals
1946		First randomised control study on humans (effectiveness of stretptomycin for tuberculosis, England)
1947	Taussig	Publication of *Congenital Malformations of the Heart*
1947		First report on the use of polyethylene catheter for external transfusion through the umbilical vein
1947		First public exhibition of the isolette (based on the Chapple incubator)
1948		The World Health Organisation defines prematurity as a weight at birth of less than 2,500 grams
1948	Peller	First use of the term 'perinatal'
1949		Use of DES to prevent premature births
1949		DTP vaccines
1949		Cornell offers institutes for the treatment of children for doctors and children

1949	Smith	Dehydration and fasting for premature children
1950	Bloxsom	The Bloxsom air lock system is shown
1951	Cambell	Retinopathy in premature babies associated for the first time with the use of oxygen
1952	Apgar	The Apgar score is used for neonate prognosis
1952	Watson and Crick	The structure of DNA is correctlydescribed
1952	Schmid and Quaiser	First clear description in the literature in English of necrotising enterecolitis as a distinct clinical entity
1952	Patz	First initial evidence with some defects connected with procedure that link excessive oxygen to retinopathy in premature children (ROP).
1953	Donald	Description of the natural history of the distress syndrome and its radiological correlation
1953	Love and Tillery	Stern traction for respiratory distress syndrome (RDS)
1953	Rickham	First neonatal surgery unit, the Alder Hey Children's Hospital, Liverpool
1953	Emerson	Invention of high-frequency ventilation (HFOV)
1953-1954		Tested study: excess of oxygen leads to retinopathy in premature babies (ROP). Cooperative study published by Kinsey in 1955. First randomised study tested in neonates
1954	Pick	Clinical association between little neonates and placental insufficiency
1954	Clifford	Clinical description of the 'postmature' neonates
1954-1956		Increase in kernicterus due to the prophylactic use of sulfas
1955	Gleiss	Tested study: the retention of liquid during the immediate postnatal period is not useful
1956	Silvermann	Tested study: sulfas increase the risk of kernicterus
1956		Tested study: the Bloxsom system is not effective
1956	Tjio and Levan	First publication of the number of human chromosomes (46)
1957-1959	Hodgman	Grey baby syndrome due to the prophylactic use of cloramphenicol
1957	Salk	Vaccine against polio
1957		Commercial production of needles with brackets for neonatal canalisation
1957		Introduction of thalidomide in Europe
1958	Silverman	Tested study: hypothermia leads to lower survival rates
1958		Availability of intracatheters in various models
1958		First air transportation of a neonate, Denver, Colorado (DC-3)
1958	Cremer	First description of the effect of light on bilirubin, *The Lancet*
1959	Avery	Surfactant deficiency is the cause of the respiratory distress symptom (RDS)
1959		Trysomy 21 is identified in Down's syndrome
1959		Intravenous liquids (IV) in neonates with distress respiratory symptom (RDS)
1959		First report of catheterisation of the umbilical artery to obtain blood gas samples
1960		Vaccine against measles
1960	Shaeffer	First use of the terms 'neonatalogy and 'neonatologist' in text books
1960-1961		Congenital defects related to thalidomide
1961		The WHO distinguishes prematurity from being under weight
1962	Koop	First units for surgical intensive care in the United States at the Children's Hospital of Philadelphia
1962	Saling	Foetal blood samples for Ph monitoring
1962	Weller and Neva; Parkman, Buescher, and Artenstein	Isolation of the measles virus
1963	Liley	First report of an intrauterine foetal transfusion
1963	Guthrie	Phenylketonuria (PKU) screening test
1963		Patrick Bouvier Kennedy dies of respiratory distress syndrome (RDS), with 34 weeks of pregnancy, weight 2,100 gg.
1963	Lubchenco	Standard tables of weights, lengths and perimeters of the brain according to ages of gestation, based upon Denver data. Introduction of the concepts of adequate, little and large for ages of gestation (AEG, PEG, GEG)

1963	Mustard	Repair of the transposition of the large vasas (Mustard's procedure)
1963	Liley	First published description of an intrauterine transfusion with a foetus with haemolytic illness
1963-1964		Measles epidemic in the United States
1964	Eickhoff	First report of neonatal septicaemia by group B streptococcus
1965		First course and programme of practical nursing paediatrics (PNP) at the University of Colorado
1965	Gluck	First neonatal intensive care unit at Yale New Haven Hospital, New Haven, Connecticut
1966	Usher *et al.*	Physical characteristics for the calculation of gestational age
1966	Rashkind and Miller	Development of the technique of atrial sectostomy (this is transformed into Exchange therapy for neonates with the trans position of the large vasas
1966	Meyer *et al.*	Vaccine against measles
1966	Freda	Commercial availability of RhoGAM
1967	Northway, Rosan and Porter	Broncopulmonary dysplasia (BPD) described
1967		First transportation of a neonate in a helicopter, Peoria, Illinois
1967	Guthkelch	Treatment of hydrocephalia with Holter's valve
1967	Hon and Quilligan	Description of three types of deceleration in foetal cardiac frequency
1967	Kantrowitz	First cardiac transplant in a neonate, Brooklyn, New York
1968	Fontan	Fontan's procedure as palliative surgery for the functional unique ventricule
1968		Availability of monitors for foetal cardiac frequency
1968	Amiel-Tison	Neurological calculation of gestational age
1968	Wilmore and Dudtrick	First published report on the total intravenous nutrition of a neonate
1969		Launch of vaccine against measles (attenuated lives viruses)
1969	Lucey	Tested study: treatment with phototherapy for hyperbilirubinemia
1970		Publication of standardised techniques for the catheterisation of the umbilical artery
1970	Dubowitz	Score method for gestational age based on physical and neurological characteristics
1970		First report of photocoagulation with con arco di xenon per la ROP
1971	Gregory	Use of continual pressure of the aereo pathway (CPAP) for the distress respiratory syndrome
1971	Gluck *et al.*	Calculation of pulmonary maturity for amniocentesis (L/S ratio)
1971		Policy of the regionalisation of perinatal treatment of AMA
1972	Shannon *et al.*	Description of hyperoximia test for congenital heart disease
1972	Kirby	Intermittent mandatory ventilation (IMV) for respiratory distress symptom (RDS) – BabyBird ventilator
1972		Tested study for prenatal glucocorticoids for the prevention of the respiratory distress syndrome (RSS)
1972		Catheterisation of the umbilical arteries as routine use
1973	Jones, Smith, and Ulleland	Clinical description of the foetal alcohol syndrome
1973		Transcutaneous monitoring of PO2 in neonates
1973	Klauss and Fanaroff	Publication of *Care of the High-Risk Neonate*, first edition
1974	Sharpe	The observation is published that indometacin produces an intense and persistent contraction of the arterial duct in living beings
1974		The certification begins of perinatology (obstetrics) as a sub-speciality
1975		Parenteral alimentation (TPN) in neonatesbecomes routine
1975		The certification of neonatology as sub-speciality (paediatrics) begins
1975	Olley and Coceani	Prostaglandin E can keep the arterial duct permeable
1975		First use of the oxygenisation of the extra-corporeal membrane (ECMO) in neonates
1976	Anderson Nicholson and Heird	Tested study: total parenteral alimentation in premature babies
1976	Jatene	First successful operation of arterial switch for large vasa
1979		Transcutaneous monitoring of PCO2 in neonates
1979		Tested study: treatment with indomethacin for the permeable duct artery (PDA) in premature babies

1979	Ballard	Score system for gestational age simplified (modified Dubowitz)
1979		FDA approves ritrodrin for treatment of premature birth
1980	Fujiwara	Description of surfactant for the treatment of respiratory distress syndrome (RDS)
1980		Description of high frequency ventilation
1980-85		HIV epidemic due to transfusions
1981	Greenberg	Endotracheal administration of epinefrin (adrenalin)
1981	Harrison, UCSF	Successful foetal surgery for obstructive uropathy
1982		The Baby Doe trisomy 21 case with artresia of the oesophagus
1982	Gershanik	Adverse effects of benzyl alcohol
1983		The certification begins of nurses specialised in neonatology
1983		The AAP and the ACOG publish *Guidelines in Perinatal Care*
1983-1984		Intravenous vitamin E (E-Ferol) causes phallic, renal and hepatic ascites, thrombocytopenia and death in low-weight neonates
1984		Jet ventilators
1984	Bailey	Baby Fae, first heterologous transplant in neonates at the Loma Linda University Medical Center
1985		Tested study: ECMO with children respiratory deficiency
1985		Tested study: cryotherapy for retinopathy of premature babies (ROP)
1985		Child Abuse Prevention and Treatment and Adoption Reform Act (United States)
1987		Pulse oximeter in neonates
1987		Neonatal resuscitation programme promoted by the AAP and AHA
1989	Harrison UCSF	Successful foetal surgery for congenital diaphragm hernia
1990	Harrison UCSF	Successful foetal surgery for cystic adenomatoid malformation CCAM)
1990		High frequency oscillatory ventilation (HFO) appears in commercial
1990		The FDA approves treatment with surfactant for the respiratory distress symptom (RDS)
1991	Ballard	New Ballard score (NBS) for gestational age, extended to extremely premature babies of less than 26 weeks of gestation
1991	Mc Namara	Tested study: cryotherapy versus laser in the treatment of retinopathy in premature babies (ROP)
1992	Harrison UCSF	Successful foetal surgery for the resection of a sacrococcygeal teratoma
1992		Guide of the AAP for chemoprophylaxis of group B streptococcus
1992		The AAP recommends the supine position in sleeping for children after a reduction of 30-40% in the incidence of SIDS (sleeping infant death syndrome)
1996		Recommendation of the CDC for the screening and chemoprophylaxis of group B streptococcus
1997		The FDA approves the use of nitric oxide for pulmonary hypertension in neonates
2000	Collins and Venter	The initial mapping of the human genome is completed

ALBERTA PARAYRE

12. Volunteers and Associations Dedicated to Care for Sick Children

This paper is entirely based upon my personal experience as a woman volunteer during a five-year period in a paediatric hospital and later as the person who was responsible for the coordination of the department of volunteers for the same hospital for eight years. I believe that it is of fundamental importance to offer a brief description of this work.

The St. John of God Hospital is a mother-child university hospital. It was the first of its kind with this specialisation to be founded in Spain and it has been in Barcelona for more than one hundred and thirty years. All of the specialisations of paediatrics (children from the age of 0 to 10) and obstetrics/gynaecology are practised in this hospital

At the present time our hospital discharges 25,000 people every year, receives more than 200,000 visits for external consultations, and deals with more than 115,000 emergencies. 4,000 children are born in this hospital every year and 14,000 surgical operations are carried out. 1,226 professionals and 265 volunteers work in our centre.

The beginning of voluntary work in our centre was linked to the when this hospital was given its present location in the year 1973. *This was an initiative of this centre*, following the charism of hospitality stressed by the Hospital Order of the Brothers of St. John of God, and had the objective of offering a complementary service of care in line with a humanisation of care for children and those family relatives who accompany them.

Over time the hospital has undergone various transformations in a process of modernisation and adaptation to the needs of care and treatment. Voluntary work has evolved with this process and over recent years it has come to play a fundamental role in the model of care and treatment of our hospital. It has ceased to be a *pleasant* complement and has come to constitute an irreplaceable and necessary complementariness, both for our patients and for their family relatives, and, indeed, for the professional workers themselves. For this reason, we believe that it is very important for us to explain and share this enthusiasm-generating journey. We can say, without any fear of exaggeration, that the voluntary services impresses its own personality on our hospital.

From our long experience we believe that in the process of healing of a child not only pharmaceuticals are necessary, as well as high technology. The richness and the complexity of life at its first stages also requires a climate of trust, love, respect, joy and comprehension, and at every moment we should adapt ourselves to the psychological age of children without forcing them to behave as adults. So that all of this can take place, an essential factor is that when a child enters the hospital the family should find the support that is needed as regards the many difficulties and sufferings that this situation will generate in his or her life.

1. Why We Do This. The Sick Child, an Analysis of this Reality

When a child falls ill, the whole of his or her family falls ill with him or her. The daily routine of all of its members becomes altered because of new priorities; the family structure changes and in many cases the family's economy is damaged. All the members of the family feel afflicted by that unexpected news which, without any prior notice, comes to alter all the plans of the family.

For some parents, the acceptance of the illness of their child is very difficult. Human suffering, especially if it strikes a child, is a mystery, and as such we cannot understand it in its totality. We can, however, share it.

We tend to differentiate the suffering of a child in relation to an illness from the suffering of adults in relation to the reality of the suffering of a child. The first depends a great deal on the second. A child lives united to the feelings and the emotions of his or her parents. Although the physical umbilical cord was cut at the moment of his or her birth, there is a psychological, affective and spiritual umbilical cord which keeps him or her united to his or her parents. It is for this reason that in the experience of the illness the maturity and hope of the parents is of determining importance. It is for this reason that we cannot separate accompanying a sick child from accompanying his or her parents. In the same way we cannot forget about his or her siblings. The capacity of the family to assimilate this situation by normalising it is the key to the sick child having an environment that helps him or her to live his or her situation in a positive way and to fight in a resolute way to recover his or her health.

For a child, it is easier to accept his or her illness with normality than is the case with adults. This is because he or she preserves intact the concept of vulnerability and recognises that he or she is in need and is dependent on adults. He or she only needs to keep those people who generate in him or her trust and love near to him or her. For the child to feel safe he or she needs to keep at his or her side his or her family and for it to transmit trust, safety, strength and hope. This does not mean that we should fake certain unreal feelings when we are in his or her presence. It is very difficult to deceive a child and he or she perceives more the state of mind of

those who are around him or her than their words. A child understands the serene tears of his or her mother when faced with his or her pain better than a fake and absurd happiness that he or she does not understand and which provokes a feeling of incomprehension, insecurity and rejection. What can help the child is the resoluteness of his or her family relatives in relation to his or her suffering, not their denial of this suffering.

With respect to everything that I have said hitherto in this paper, we can observe that the accompanying that is provided to a sick child is the mission of his or her parents and family relatives since the child in his or her situation of illness is more of need of that accompanying than ever before. But we also know that the illness of the child and his or her admission to hospital is a situation that generates in everyone a profound tiredness, feelings of powerlessness, insecurity, loneliness, abandonment, fear…These are all situations that are flowing over with problems where practical and apparently simple things such as going to lunch, eating, having a shower, or having fun can be the cause of greater stress and if a rapid solution is not provided they can be the straw that breaks the back of a patient who is already heavily burdened.

I would like to emphasise that whereas for everybody the situation of illness of their child is difficult to bear, this is true in a very special way of people who are immigrants. They find themselves in a situation of greater vulnerability, precariousness and lack of help. Many of them do not have family relatives or friends who can support then and to this are added difficulties at the level of language and a number of cultural customs that are different from ours. A single description of immigration cannot be engaged in because immigration is as varied as its countries of origin. But for all immigrants admission to a hospital means obeying and accepting certain rules which for many can be difficult and for some even incomprehensible. This category needs the help of voluntary workers in a very special way, as well as our comprehension, adaptation to, and acceptance of, their differences.

2. Some Practical Observations

After engaging in this brief analysis, we can already propose certain practical guidelines that can help us in understanding voluntary work in hospitals for mothers and children, a category to which our hospital belongs. The suggestions that are made here seem to me to be of relevant significance and for this reason I venture to suggest that they are principles for action that are of great value.

1. We should see the child in his or her totality, and this means that the care that we provide should include in an inseparable way care for his or her family environment.

2. For the child to receive very good care from his or her parents, they very often need our help and support. This help and support is nearly always in relation to basic things such as making breakfast and eating, dealing with bureaucratic matters inside and outside the hospital, moments of conversation, and sharing their worries, joys and fears.

3. In no case do we seek to replace the parents as regards their responsibility for providing care and help to their children. Rather, we seek to help them to optimise their situation and thus to improve their relationship with their sick child and the rest of the family.

3. Why We Do This

After the above brief discussion, we can say that we have placed voluntary work in its context of hospitals and the reality of sick children. It is here that there begins the irreplaceable mission of volunteers. *What contribution can voluntary work make*?

The principal objective of voluntary work is to ensure that a hospital is as least traumatic as possible for children, seen in their inter-relationship with their families. And not only this but also that the period in the hospital turns out to be a positive experience. It is very moving to hear many children say when they are discharged: 'I am going home very happy, this hospital isn't bad, I was happy here!'.

Speaking from a strictly professional point of view, I believe that volunteers should *not contribute anything*. Rather, they should be a channel[1] where all the components are diluted, being a factor of support that is determining in ensuring that this support reaches the child and his or her family, adapting to them in their concrete circumstances, providing an answer to their needs of both a material and spiritual nature.

The mission of volunteers is to facilitate the normalisation of the admission of children to hospital and to help the process of their illness.

We never tire of repeating that a sick child continues to be a *child*. We strive to ensure that he or she will go on *feeling that he or she is a child*, facilitating everything that he or she needs: games, books, handcrafts, suitable areas, moments of playing, moments of company…so that from his or her experience of hospital he or she can *go on feeling that he or she is the same child as before*, possibly a more mature one, since a hospital can be a true school for values and aspects of life in which he or she was not interested prior to entering hospital or which he or she had perhaps not even thought about.

A period in a hospital can be a time of grace, a place to learn and to receive, and, as a consequence, a place to recognise that one should give to others. A volunteer with his or her nearness, readiness to help, and example of self-giving and dedication can be a key figure for sick children.

4. Who We Are

Voluntary work in a hospital in a developed country is not free manu-

al labour; nor is it cheap labour. It takes the place of no professional and does not make up for a lack of staff. A volunteer is a person who with his or her presence in the complex and multiple reality of a child's illness shows both the child and his or her parents that they are not alone and that what happens to them is of importance for the voluntary workers himself or herself, for the professionals of the hospital and for the society that is represented by the hospital.

This important mission of volunteers is expressed at a practical level in an almost infinite series of simple tasks that I will now not list but will describe with reference to their principal characteristics. In this way we will see who a voluntary worker is when we see what a voluntary worker does.

5. What We Do

*The multiplic*ity and variety of the actions of voluntary work can be seen reflected in the following actions which we see as characteristic of its function at the service of sick children.

1. The mission of a voluntary worker in a paediatric hospital is to give parents and family relatives that support which is needed so that they can feel sustained, accompanied and flanked in this difficult circumstance.
2. To foster a happy climate and one that is full of hope and love.
3. To give all the support that is needed to children in relation to all their needs so that the experience of their illness is not a traumatic one but can even be an experience of grace, growth and love.
4. To offer a resource to professionals so as to give to the children and their family relatives everything that goes beyond their profession and which can improve their quality of life during their admission and even contribute a benefit to the development of their treatment.
5. We can say that this also reduces the stress of the nursing staff because they know that they can follow and resolve many situations which, were voluntary workers not to exist, would certainly cause a deterioration of the environment, even constituting a cause of worry and conflict.

6. Identification with the Institution. Integration with the Centre

It is absolutely impossible for a team of volunteers to carry out their mission if they are not part of a total integration with the hospital, that is to say they must be wanted and accepted by the management of the hospital, by every section chief they encounter in their work, and, lastly, by the professionals themselves with whom they cooperate directly. This condition also requires that volunteers identify with the centre they work with, with its principles, and with its philosophy of care.

For voluntary workers to be in real terms complementary to the professionals, it is of fundamental importance to inform them beforehand, and even to plan together, all the programmes and activities that they will engage in, with their adaptation to the specific characteristics of each centre, to the needs of that centre, and to what it can achieve.

7. Organisation/Coordination/ Selection/Formation

From everything that has been said hitherto in this paper, one can deduce that although the contribution of voluntary workers is of such a richness that it is difficult to measure, for it to be such a structure is needed that supports this contribution, an exhaustive coordination that organises it, and also a committed training that makes it suitable, as well as an ongoing verification of the performance of tasks and in a special way a following and accompanying of each volunteer so that he or she can be helped to resolve in a healthy way the situations of suffering that can afflict him or her and to ensure that these are a factor for growth and not for dismay and the abandoning of voluntary work. Not all people are prepared for a voluntary service that has these characteristics (with good will alone one can commit grave errors).

It is easy to understand from everything that has been said in this paper that a person who wants to be a voluntary worker in a paediatric hospital, in addition to having the right profile, will need to have a very practical and updated training at a general and specialised level according to the kind of service that he or she will carry out. For this reason, it is absolutely necessary that anyone who is planning to become a voluntary worker should be ready to learn and should have available the time that is needed to take part in a training that will help him or her so that he or she can perform his or her work with the necessary guarantees, as regards his tasks, in his or her relationships with other voluntary workers and with the professionals, the patients and their family relatives, and with himself or herself. We must learn where to locate out limitations, not creating attachments, dependencies or feelings that can even obstruct our work and the work of other voluntary workers. This is a matter of not becoming hard but of knowing how to locate ourselves in the places where we work. Illness illuminates our fragile reality and faces us with our limitations of both a physical and psychological nature. It also tests our capacity to adapt.

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Note

[1] An inert medical substance that is mixed with pharmaceuticals in order to give them substance, form, taste and other qualities that facilitate their dosage and use.

PATRICK THEILLIER

13. Spiritual Support for Sick Children: the Sacraments and Prayer

I feel honoured to have been invited to this important international conference on 'pastoral care for sick children' and I warmly thank His Eminence Cardinal Barragán. When I learnt of the subject that had been assigned to me I wondered whether an error of identity had been committed. I am not a religious, I am simply a member of the lay faithful! I am a father and I have six children and I am also a grandfather with seventeen grandchildren. I am a medical doctor, that is certainly true, but above all else I have for ten years been charged with receiving people who have been *cured* in my capacity as head of the Medical Office of the Sanctuaries of Notre Dame de Lourdes…The matter was clear: I was confident that the Holy Spirit could not but have inspired this choice and I perceived that I had to address this argument primarily beginning from my personal experience as the head of a family and as a medical doctor who is the President of the International Medical Association of Lourdes.

This year we are celebrating a jubilee which commemorates the one hundred and fiftieth anniversary of the apparitions. For one hundred and fifty years, in fact Lourdes has been known for its miracles of healing. Just as one could understand the point in that far off age, so, also, today, in the twenty-first century, we have to be realistic: it is medical science that works 'miracles'…! So, what do visitors who come from all over the world and who belong to all cultures, races, languages and even religions come to look for in this Marian sanctuary which is eminently Catholic? This is the mystery of Lourdes.

In this jubilee year over nine million pilgrims have come, the most distinguished of whom was the Holy Father Benedict XVI. We were struck by his goodness, simplicity, sweetness and benevolence. Yes, indeed, Lourdes attracts simply because, I believe, Mary has also been present, the Mother of God.

It should be known that the first miraculous healing concerned, indirectly, a child who was still in the womb of his mother. This happened on the night of 28 February/1 March 1858, three days after the discovery of the spring by Bernadette. Catherine Latapie, who was cured in the grotto that night, prayed to begin with as follows: 'Virgin Mary, give me the time to return home and bring my child into this world'. And three hours later she gave birth to her child, who was called Baptiste. Later, this child would become a priest. This first healing was connected to the new life of a future minister of the Lord: the sign seems to me to be clear.

Another child was healed and one might almost say brought back to life a short time afterwards: the very young Justin Bouhort who at the age of two was on his deathbed. A charitable neighbour was already preparing his death shroud! His mother wrapped him in her apron, took him to Massabielle, and immersed him in the frozen water for over ten minutes. Rather than dying, over the next few hours life and vigour came back to him. He was to live until 1935.

The examples of healings involving children at Lourdes are much more numerous than one might think. I should also cite the example of Delizia Cirolli who was cured at the age of twelve of bone cancer in her right tibia, a condition which meant that she was going to have her leg amputated. Her parents refused this operation and then, after she had left the hospital of Catania, they took her to Lourdes thanks to the generosity of the whole of the village where she lived, in eastern Sicily. And although nothing happened while she was actually at Lourdes, the people of her village, rather than giving up hope, continued to pray regularly for a cure for months. And when they had already prepared her funeral clothes, Delizia got up one morning and was certain that she had been cured. Medical science confirmed this fact a short time afterwards. She was the sixty-fifth woman to receive a miracle from Lourdes.

It is often thought that the pilgrims who go Lourdes are only people of a certain age. Instead, for some time, and with increasing frequency, an increasing number of young people and children, both in organised pilgrimages and individually, have gone there. I will give three examples of this.

The oldest annual pilgrimage is that of the HCPT (the Handicapped Children's Pilgrimage Trust) which is known as the 'rainbow pilgrimage'. This organisation was created in 1956 by a young British doctor, Michael Strode, who was an Anglican until the year 1945 when he converted to Catholicism. In 1954, with his friend and colleague Peter Keevney, he had the idea of taking to Lourdes, within the framework of the Birmingham pilgrimage, a group of disabled children, something that was not customary at the time. Michael Strode wanted the children to be treated like all the other pilgrims and to take part in the devotions which up to that time were not for the sick and disabled pilgrims – for example the spectacular Marian procession '*aux flambeaux*'. What better place than Lourdes to fulfil this wish? Lourdes, the place where the Virgin Mary left to men a message of hope through the intermediation of

Bernadette Soubirous, a frail fourteen-year-old girl who belonged to a family that was poor and rejected by everyone.

It should be known that the HCPT organises the largest pilgrimage of the British Isles. This year, with its twin organisation the Irish HCPT, 5,500 pilgrims were taken to Lourdes, of whom there were 2,000 disabled children in precarious conditions and organised into two hundred small groups with their own styles and colours, each one with a group head, a chaplain, and a nurse. Each child was accompanied by at least one volunteer. Special medical care for the children was also envisaged.

The most moving pilgrimage from Italy is the one organised by UNITALSI for children. This was created in 2004 and arose from the experience of the international children's pilgrimage that had taken place in the sanctuaries of Notre Dame on the occasion of the centenary of UNITALSIS. The theme of the pilgrimage – 'Children of Peace' – took practical form in a pathway of faith that was implemented in a special way for children: understanding and help were at the service of the children in order to enable them to grow and to build a world of peace in their daily lives.

For the fifth edition of 'Children of Peace', whose theme was 'Our Home in the Heart of Bernadette', UNITALSI chose to enable the children to discover the figure of this saint, the seer of Lourdes. The experience of that year was placed under the emblem of universality. The children were offered various opportunities for cultural exchange through games. In particular, they were encouraged to reflect upon the following fact: throughout the world there is a 'Saint Bernadette', a model of saintliness lived in simplicity and humility for everyone.

One should realise that amongst the 8,000 participants there were 3,000 children and 2,100 volunteers, amongst whom there were health-care workers to accompany them!

This pilgrimage is a stage in accompaniment towards faith, a true catechesis which also involves the families of the children taking part. This stage is placed within a process of awareness of peace, which began in Assisi and then went to Gardaland (a sort of Disneyland in North Italy) where children were able to observe that although it was a place for games it was not a place of peace! The children then went to Lourdes before ending their journey of discovery in the Holy Land.

During the five days that were spent at Lourdes they were able to follow the exercises of piety that are specific to the sanctuary – the saying of the rosary in the grotto, the Eucharist, the procession, and the *via crucis*. They received the sacraments of baptism and confirmation, as well as that of first communion, but not that of the anointing of the sick, given the wish that was present to remain within an approach involving life and joy.

At the Prairie they were also encouraged to open themselves up to other countries of the world with a replica of a monument that is famous in their own countries (for example the Coliseum in Rome) together with the portrayal of a developing country.

Another pilgrimage which for some years has been dedicated to children, this time a French pilgrimage, is 'Lourdes Cancer Espérance'. This was created twenty-one years ago with the aim of taking cancer victims at all stages of their illness, whether the illness was visible or otherwise, on a pilgrimage to Lourdes. At the beginning the idea was to take care of children so as to enable parents afflicted by this malady to take part in the pilgrimage which had been organised specifically for them. Rather than creating a mere nursery for them, a true pilgrimage for children was created under the guidance of a children's nurse, who in turn had as her head the medical doctor leading the pilgrimage. Then, gradually, this pilgrimage brought together children who were themselves afflicted by cancer and a group of teenagers, who were themselves in some way afflicted by cancer and who wanted to undertake a pilgrimage suitable to their age, was added.

The children are welcomed during the daytime so that they can reach their parents and the delegation in the hotel for supper and the night. In the room where they meet there is a corner for prayer where they can come together. The approach is to organise a real pilgrimage and infuse the message of Lourdes in small doses, in particular thanks (here as well) to Bernadette. The programme, adapted to the theme of each year, is the following:

The first day: they all meet each other and point to where they come from on a map of France. Then, together, after an action of grace, the final programme is adapted to what is requested. In the afternoon the children greet Mary in the grotto and then they visit the places where Bernadette lived during her life in Lourdes (both the museum and the 'steps' of Bernadette, as well, this year, as the journey of the jubilee which begins at the baptism fonts of the parish church, a trip to the *cachot* where the Soubirous family lived, and then the grotto of Massabielle where the apparitions took place, and lastly to the place where Bernadette took her first communion. The evening is free or the children take part in a festival of light.

The second day: this takes place outside the area of the sanctuaries with an excursion to the village of the youngsters who witnessed the apparitions, which is in the hills; to the sanctuary of Bétharram near to Lourdes; to Bartrès where Bernadette was a shepherd girl; and to numerous convents in the town. At mid-day the children go on a picnic where most of the time there is a bishop or a head doctor and in the afternoon meetings are organised with their parents for a period of dialogue when they can express themselves on the subject of their illness and their visit to Lourdes. A Holy Mass ends this important day.

The third day: in the morning the vigil of the evening, and the ceremony for the anointing of the sick in the chapel, are both prepared. The afternoon is for relaxation: the swimming pool, songs and games, etc. In the evening there is participation in the vigil in the company of the animator.

The fourth day: the Eucharist with the adults. At the end of the Holy Mass there is a release of balloons with messages written on them by the children. Friendship toasts to say goodbye with the handing over a small souvenirs mark the end of the fourth day.

One can see that contact is maintained with the adults and especially with the parents. The meetings and the sacrament of the anointing of the sick are always the strongest moments of this pilgrimage.

Here, therefore, are three examples of the welcoming of sick children in their bodies and through their families, given that it is known that the illness of a father or mother can have an enormous influence on the health of a child who may fear, often with good grounds, the worst!

These are three different approaches where, on the one hand, there is an emphasis on pedagogy directed towards life being stronger than death, and on the abandoned of our difficult world, and, on the other, an overall welcoming of the family is engaged in, another important factor in the equilibrium of children.

One can also see that the sacraments are used in a different way, especially as regards sick people. The sacrament of reconciliation, on the other hand, is always offered and most of the time it is very much engaged in by children who do not yet possess the self-love of adults, which, indeed, impedes many adults from entrusting themselves to divine mercy.

In other places or in other pilgrimages, and in particular in the new charismatic communities, children many also be invited to pray for adults. I had an experience of this with one of my children when he was six-years-old, a moment that was very difficult for him. My wife and I had spoken about him to a Jesuit priest who told us that the request had to come from him. We thus spoke to him and to our great surprise he agreed. And when the priest asked him what he was asking Jesus for, he replied spontaneously: 'peace and joy in men's heart'!

To end this paper I would like to say how much I thank the Church for everything that she has given to parents such as ourselves so that we could bring up a family, in particular the importance of the sacraments. I will never be able to stress this enough! I fear that all too often we are too cold as regards the spiritual expectations of children in general and of sick children in particular, both as regards an explicit pathology and with respect to an illness that I would define as being 'familial', and this when one knows how much a family without spiritual support can be pathogenic.

Prayer and sacraments are fundamental in the building up of a family and I would like to thank God that I experienced the joy of celebrating our forty years of marriage last year in Lourdes, and I cannot resist projecting an image of this souvenir which shows that I am not lying…

Allow me to finish with the icon of the mosaic of the Virgin with child, asking the question: are we really certain that a child is '*capax Dei'*, capable of God, and capable of his young age? Psychologists teach us that from conception onwards a foetus in the womb establishes an intimate union which is not oral but which is rich in resonances of every kind, not only with his mother but also with his father, his siblings, in short the nuclear and wider family unit. This 'osmosis' is translated into an interdependence which is biological, psychological and also spiritual in character. The pathway followed by a child in the womb of his mother is already subject to the work of grace, the breath of the Holy Spirit. How much is a child sensitive to the environment in which he lives his first few years, to the witness of our spiritual lives, to the example, lived in truth, of the love that we should give him day after day!

Should not our support for sick children perhaps first of all pass by way of a return to childhood by us, for a new birth, that birth about which Christ speaks to Nicodemus, thanks to the mediation of he who gave to us as our Mother, who generates us to true life – the Virgin Mary?

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JUAN DE AGUIRRE

14. The Visit to a Sick Child

In Holy Scripture we find testimony on a number of visits that can illuminate the subject of this paper. They are visits of salvation which bring good news. They often take place in contexts of weakness, of poverty and of humility. In this sense the visits of Elijah to the widow of Zarephath, who is ready to die together with her child (1K 19:9ss), the visit of the Angel to Mary for the Annunciation (Lk 1:9-20), and in turn the visit of Mary to her cousin Elizabeth, one of the many sterile women to which Holy Scripture refers (Lk 1:26), are paradigmatic.

In all these visits a general schema is repeated: 1) an arrival and a greeting; 2) "do not be afraid"; 3) the declaration; 4) a question or a doubt ("how can this be?"); and 5) an affirmation of the omnipotent love of God and then a departure.

This schema can act as a map for us when we prepare to organise our visit. These are visits to one person in particular and not 'to the sick' in general. God has something special to say to each individual person. There is room for uncertainty and doubt. Confidence comes from the love of God. In these three Biblical passages there is a growth in sweetness in those who visit which can characterise our indispensable evolution as workers in pastoral care in health. Mary is a model to be followed: her declaration is 'sharing' the joy that the 'wonders' of God produce. She is a companion until the last moment, a silent companion who passes by almost unobserved. She is calm, warm and light, like Grace itself.

General Aspects

1) The visit: faced with the force of the concept of a 'sick child', at times the fact to which we refer, namely the visit itself, at times passes unobserved

– A visit speaks to us of friendship and respect. It is an affable proximity that tries to accompany and please those whom we visit. We try to make them spend some pleasant moments or we strive to alleviate their pain and tribulation. We do not arrive with impositions or in a way that irritates.

– A visit speaks to us about an invitation. When the person who receives a visit is not in the mood to receive us, then, without being offended or irritated, we withdraw, and this is even more the case when one is dealing with a sick person.

– A visit also speaks to us about respect for the place where the visit takes place. If it is we who are engaging in the visit, this is because we enter a foreign land. The 'home' of a brother deserves especial respect. We do not enter a home of another person to do or say what we want, even when that 'home' is a hospital room.

2) The sick child: now we can turn our gaze to the sick child.

– When we uphold the dignity of the human person from conception inwards, we also include in this children themselves. This means that we visit people who have the right to decide and to be treated and respected in their belief.

– The protagonist of our visit is the sick child. We ourselves are not the centre of action. It does not matter if we are clumsy or have to be in uncomfortable situations if we have given of our time or if we have something important to say.

– There is an exercise that is always difficult –'putting ourselves in other people's shoes'. Let us try for a second to imagine ourselves outside our own homes, worried about our health, tired and sick, receiving a visit from medical doctors or nurses; we are being treated and we are in pain. This brief description applies to almost all sick people even when we do not take into account operations, the provision of serums, probes, drainages etc.

– To visit a child means to enter his or her family unit which includes his or her parents and siblings. It is often the case that these children cannot speak or they are very little and in this case our visit is to the parents.

Elements to be Borne in Mind

It is impossible to create one single schema for visits to sick people because the realities are many in number and are not similar. We would have to draw up a whole host of schemata equal in number to the people we visit. I will here refer to a number of general elements that should be borne in mind. I will then point out certain elements that should be avoided, and, lastly, I will try to formulate some objectives for our visits to Christ, the sick child.

General elements

– The health-care situation of the child: we should ask the medical doctors or the personnel of the department what kind of care we should offer to that child. We should act so that no harm is done to the sick child (we should not pay a visit to him or her if we have influenza, for example, and if necessary we should wear masks). It is also important for us to wash our hands so as not to spread viruses and bacteria.

– The age of the child. I have already pointed out that many of these children are very little and in this case the dialogue will be with the parents. With little children the dialogue takes place in a more playful way and with adolescents we can engage in deeper communica-

tion. As a general rule I would say that children who are suffering from long illnesses and invasive forms of treatment demonstrate a (forced and painful) earlier process of maturation. I have noticed this in children of all ages. It is as though their experience 'matured' them earlier, endowing them with greater capacities for reflection.

– The family situation. The traditional structure of the family has changed notably in recent times. The hospital population perhaps responds more to these 'new forms of the family' than to those who take part in the lives of our Christian communities. These are the so-termed 'enlarged' families with half-brothers or children from new couples of parents. It often happens that when visiting sick children the partners of the parents of the child are introduced to us. The taking of drugs has extended to almost the whole of society. All of this presents greater difficulties and poses new challenges when we seek to engage in a dialogue with these sick children and their families. In this complex situation we should not forget about the children afflicted by AIDS, who are generally orphans or belong to families that have totally broken down.

– The social situation. In the public hospitals of my country the social situation of the families of children admitted to hospital is somewhat desperate. The social levels of the children being treated correspond to the enormous differences and distances that can be observed throughout society, that is to say rich families, middle-class families, poor families and very poor families. It is often the case that we come across families of migrants who have languages, cultures and religions that are different from our own. At other times we help families in which upbringing and the 'formation' of communication or thought are so limited that our visit is almost reduced to 'gestures'. In these cases as well we should be extremely prudent so as to avoid misunderstandings.

– The accommodation situation. Most of my experience comes from a children's hospital but I have observed that this hospital, while it acts as an 'aggressor' in relation to the child and his or her family environment also works in promoting the receptivity of the patient. It would appear that not being at home makes children more permeable as regards our visits. In the same way, we should take into consideration whether the visit takes place in a room where there is one bed or where there are many beds. I would say that rooms with a number of beds foster the initial dialogue of friendship and that rooms with a single bed allow a deepening of communication once a tie has been established.

Actions to be avoided

– I have already referred in this paper to the dignity of the child and respect for his or her decisions and his or her wishes. This obliges us to respect his or her wish to receive a visit or not to receive a visit. We have to assess whether his or her negative attitude corresponds to a fear that he or she will be attacked once again. In this case the ability of the pastoral worker lies in defeating this fear slowly and with sweetness (in the same way in which the Grace of God works in us). But we have to accept the possibility that the child will not want to receive our visit. In this assessment that we carry out it is necessary to take into account the wishes of the child's parents. In concrete terms: if the child does not want to receive us, we should confine ourselves to a greeting and to offering our help whenever it is needed. In his textbook on bioethics, Msgr. Sgreccia bases his position in this interdisciplinary science on the personalist tradition. He writes in that work: 'The personalist tradition has its roots in the very reason of man and in the heart of his freedom: man is a person because he is the only being in which life becomes capable of reflection on itself, of self-determination'.[1]

– We live in a difficult epoch as regards the painful cases that present themselves marked by sexual abuse and to which the Holy Father has referred – for example at the time of the World Day of Youth. For this reason, I suggest that one should never enter the room of a child who is alone. We can ask other pastoral workers to accompany us or a health-care worker that we know. If this is not possible, we should postpone the visit. In the hospital there will be many other children who can receive a visit from us.

– Along the same lines, I would suggest that children should not be touched or raised up on one's own initiative. Many parents ask us if we want to touch their children or ask us to bless them or to place our hands on them. To wait for this offer to come from them is a further demonstration of respect and pastoral prudence. Time will lead to closer ties of friendship between us and the children and their parents. Tender and warm physical contact will then take place in a natural way. Patience is another aspect that must characterise workers in the field of pastoral care in health.

– I remember that fifteen years ago, when I began my work as a chaplain, I was surprised by a rule of the management of the hospital: 'do not sit on the beds of patients'. With time I understood that 'his or her bed' is all that the patient possesses, his most intimate place. If the child wants to, and can, he or she will leave his or her bed in order to be with us.

– I suggest that we should not base our visit essentially on the presents that we bring. Not becoming Father Christmas allows the freely-given character of the meeting to remain prominent.

Amongst the actions that should be avoided, I would like to dwell on one in particular. It may happen that

we feel tempted to imitate members of other groups (religious or otherwise) in their methods of irruption and insistence. I will here refer to certain characteristics of those who visit the sick and think of their wellbeing and not of profit:

– We come to see the sick child if he or she allows us to do this. No to force. Once again I would like to emphasise the character of the 'visit' which figures in the title of this paper.

– We do not engage in proselytism. We do not try to increase the number of our members, nor do we persuade people to abandon their beliefs. The success of our mission does not lie in recruiting another member to our 'club'. Our mission will have been carried out if we provide a 'Christic' presence for Christ the suffering child.

– In the same way we do not attack any religious sign of the sick child or his or her family. We do not speak in a pejorative way about his or her beliefs or 'amulets' even though they may appear to us as superstitions. If time allows us to create a new friendship, then we will have the time of share our opinions with them.

– We do not fill the sick child with fear or his or her family with guilt by suggesting that there is a connection between the child's illness, the actions of the family and the devil. We do not attribute to the illness the characteristic of being a 'divine punishment'. We preach only one God, who is Love.

– We do not impose sacraments or religious practices. We invite and we offer our cordial help in the most sensitive way possible. It is important for us to understand that our urgency in bringing sick children a sacrament (baptism, reconciliation or anointing) is more connected with our unresolved worries than with the 'provident mercy of God'.

– In the same way, we offer our prayers by leaving open the possibility of praying together with the patient, in our communities or in our personal prayer.

– We do not promise miracle cures. The Hope that does not disappoint is not based upon certainty of a cure. For this reason we do not impose religious practices of our personal devotion (novenas, veneration of a specific saint, etc.) with the promise of improvements. We can always share a prayer or a devotion by explaining that it helps us or that it does us good.

The Visit to a Sick Child

In one of the waiting rooms of the outside consulting clinics of my hospital there is a mosaic to whose creation I contributed by providing the initial idea and the design. It is the Holy Family but with a special feature: the Baby Jesus is lying down and has a fever; Mary places a damp cloth on his forehead and St. Joseph draws near with a wooden little horse in his hand. The idea came to me because in my very many visits to children I have experienced something that is paradoxical: I was a representative of Christ who brought the Good News to Jesus himself, a child and a patient. Remembering this helped me to correct any temptation to place myself at the centre of the scene and it required me to be attentive and creative in my pastoral mission. This is what we must be in the presence of God – a presence different from the presence of other people. To achieve this distinctive presence our senses must be especially alive. Somebody said that if God gave us two eyes, two ears, and a mouth this must be because He wants us to observe and to listen twice as much as we speak.

Observing

– The circumstantial situation: whether the child is calm or worried, feverish or playing. Whether other children in the room are asleep. On this depends whether we enter the room or not and whether we enter the room for a longer visit or only to greet the child and offer him or her our help.

– It may happen that the child is well and that he or her does not want to play or engage in dialogue or that he or she is watching a television programme or is playing a game. Once again, this will guide our visit. Not taking away from the child a moment of rest or distraction is another way of telling him or her that his or her wellbeing is important for us.

– Whether the child is a boy or a girl. It often happens that chemotherapy and a lack of hair makes it difficult to tell whether the child is a boy or a girl. For this reason it is a good idea to ask the child its name. Usually a child's eyes shine up when he or she pronounces his or her name. In the middle of illness this is a way of affirming his or her living presence.

– We also observe whether the child has some visible religious signs (crosses, medallions, printed paper, rosaries or images), of a Christian nature or otherwise. This enables us to being a more 'familiar' communication if he or she belongs to our creed or one that is more attentive if he or she does not or if no religious sign is to be seen.

Listening

– The child: whether he or she expresses enthusiasm about the meeting, fear or tiredness. Whether he or she wants to play or show us something that he or she has made. Whether he or she wants something. We also listen to, and try to interpret, his or her silence, which can be a silence of wellbeing or of distrust.

– The parents: it is probable that they want to express their thoughts with the sole purpose of being listened to; at times, however, they are looking for approval for their reflections. They, too, can have questions that they want to pose to us.

– The medical doctors and the nurses: they can tell us about the medical situation of each child but they can also tell us about the situation of the child's family. Their being under the same roof means that they can see the family group throughout the day and for this reason they can provide us with valuable elements which we can bear in mind. In addition, they can provide us with technical considerations regarding the need or otherwise to use masks, gloves, etc. It may also happen that the visit is impeded, something that we accept with simplicity.

– The sounds of the room: whether there are machines that are switched on (a television, a drip feed, etc.), breathing, weeping, laughter, and, as I have already observed, silence.

Dialogue

– I have already said that more than speak we should listen.

– I would now like to say that more than teach we should learn.

– At times we can answer. However we should often say that we do not have answers or we should know how to remain in silence since many questions do not search for an answer but solely express a worry.

– It is also important for us to know how to ask. One must be dealing with questions that are sufficiently broad and deep to give freedom to the child and his or her family. These kinds of questions allow light and demanding answers to be given but they also give rise to distinctive and profound answers. Some of the questions that are most commonly asked are: are you tired? What do you need in your home? Are you afraid? What would you like to do or have? What do you want to know?

– To engage in dialogue is to generate space for the deepest and truest questions. It is obvious that pain, especially physical pain, is widespread in the animal world; 'only the suffering human being knows that he is suffering and wonders why…This is a *difficult question,* just as is a question closely akin to it, the question of evil. Why does evil exist?' (*Salvifici Doloris* n. 9).

A Final Observation

We must be eyes that look beyond. Eyes able to look without the professional prejudices of the health-care team or the affective involvement of the family of the child.

Taking care of a child and his family means being able to listen to what other people cannot listen to. It often happens that fathers tell me about the gravity of the illness of their child (a gravity which in their view the child does not know about). In beginning a dialogue with a child it frequently happens that the child tells me that he or she is very ill but he or she does not want to worry his or her parents. It has sometimes happened to me that the child has asked for the sacrament of reconciliation in order to be alone with me and ask me about death or heaven.

We are also people who can say something distinctive: generators of true and certain hope. A hope that includes pain, a succession of chronic events, disability and death.

In addition we are those who look for a presence of 'not knowing', in 'not knowing what to say' and 'not having anything to say' as well. We must also be witnesses to mystery – the mystery of pain and of the cross. The encyclical *Salvifici Doloris* at n. 13 declares: Love is also the richest source of the meaning of suffering, which always remains a mystery: we are conscious of the insufficiency and inadequacy of our explanations'

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Note

[1] ELIO SGRECCIA, *Manual de Bioética* (Ed. Diana, Mexico, 1996), p. 73.

Pontifical Council for Health Pastoral Care

Pontificio Consiglio per la Pastorale della Salute

June 8, 2009

HEADLINES

Message of His Holiness Benedict XVI for the Seventeenth World Day of the Sick

«It is, indeed, necessary to affirm with vigour the absolute and supreme dignity of every human life.» [View more]

HIGHLIGHTED

Resignation of the President of the Pontifical Council for Health Pastoral Care and appointment of the successor

The Holy Father Benedict XVI has accepted the resignation of His Eminence Javier Cardinal Lozano Barragán, from the office of President of the Pontifical Council for Health Care Workers (for Health Pastoral Care) due to age limit, and appointed Bishop Zygmunt Zimowski of Radom, Poland, to succeed him, elevating him at the same time to the dignity of Archbishop. [View more]

NEWS UPDATE

Alarmante nexo entre pobreza y patologías visuales, advierte el dicasterio para la Salud

«La santé est une tension vers l'harmonie et vers Dieu»

La souffrance doit être combattue, déclare le card. Barragan

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