DOLENTIUM HOMINUM

No. 58 – Year XX – No. 1, 2005

JOURNAL OF THE PONTIFICAL COUNCIL
FOR HEALTH PASTORAL CARE

Proceedings of the XIX International Conference

Organised by
the Pontifical Council
for Health Pastoral Care

Palliative Care

November 11-12-13, 2004

New Synod Hall
Vatican City

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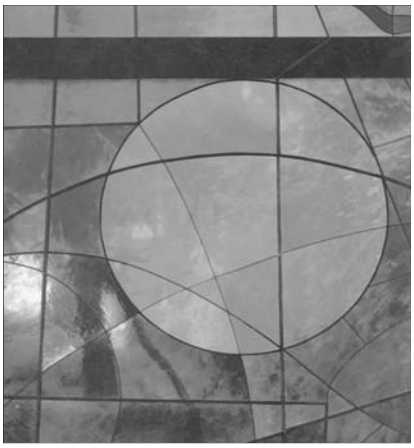

Editorial and Business Offices: Pontifical Council for Health Pastoral Care
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Published three times a year. Subscription rate: 32 € postage included

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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The illustrations in this edition are taken from the book:
"Taranto: la Chiesa / le Chiese"
edited by Cosimo Damiano Fonseca
Editor Mandese, Taranto, 1992

ADDRESS OF HOMAGE TO THE HOLY FATHER

Most Blessed Father,

We very much thank Your Holiness for the great task entrusted to our Pontifical Council for Health Pastoral Care to work with you in providing responses to the ultimate existential questions of human life. This is why we have organised this nineteenth international conference on 'palliative care'. Although we live in a world that is in a certain sense globalised by secularisation, the extreme questions do not fall silent: what is the meaning of pain, of suffering, and of death?

Thus yesterday, during this conference, after reflecting on the meaning of pain and of suffering, as Your Holiness illustrated that meaning in the Apostolic Letter 'Salvifici Doloris', we engaged in a description of the contemporary situation as regards palliative care, the relevant scientific data, and the treatment of pain; what palliative care is and what it is made up of, what euthanasia is and its juridical aspects, and the history of palliative care within the Church.

Then we began to devote ourselves to illuminating these realities with faith in the light of the death and resurrection of Our Lord, who makes himself contemporary through the sacraments of the sick: the Anointing of the Sick and in particular the Eucharist as Viaticum, which require in our times a very strong faith. We then considered the difference between proportionate and disproportionate forms of palliative care.

These last subjects have been studied this morning. And specifically as a culminating point of this illumination, we now wish to ask Your Holiness for your truly authoritative words that will guide us in relation to these grave problems.

I would like to introduce to you, Holy Father, our participants, who have come from seventy-six different countries and are above all specialists in so many nations, great authorities in their fields, who have enlightened us and will enlighten us with their great and acknowledged expertise.

Your Holiness, we implore you to give us your words and ask that we may receive your awaited blessing,

Vatican City, 12 November 2004

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

ADDRESS OF THE HOLY FATHER JOHN PAUL II

Euthanasia Must Be Avoided

Your Eminence,
Venerable Brothers in the Episcopate,
Dear Brothers and Sisters,

1. I am pleased to welcome you on the occasion of the *International Conference of the Pontifical Council for Health Pastoral Care* which is taking place at this time. With your visit, you have wished to reaffirm your scientific and human commitment to those who are suffering.

I thank Cardinal Javier Lozano Barragán for his courteous words on behalf of you all. My grateful thoughts and appreciation go to everyone who has made a contribution to these sessions, as well as to the doctors and health-care workers throughout the world who dedicate their scientific and human skills and their spirituality to relieving pain and its consequences.

2. Medicine is always at the service of life. Even when medical treatment is unable to defeat a serious pathology all its possibilities are directed to the alleviation of suffering. Working enthusiastically to help the patient in every situation means being aware of the inalienable dignity of every human being, even in the extreme conditions of terminal illness. Christians recognise this devotion as a fundamental dimension of their vocation: indeed, in carrying out this task they know that they are caring for Christ himself (cf. Mt 25: 35-40).

'It is therefore through Christ, and in Christ, that light is thrown on the riddle of suffering and death which, apart from his Gospel, overwhelms us', the Council recalls (*Gaudium et Spes,* n. 22).

Those who open themselves to this light in faith find comfort in their own suffering and acquire the ability to alleviate that of others. Indeed, there is *a directly proportional relationship between the ability to suffer and the ability to help those who are suffering.* Daily experience teaches that the persons most sensitive to the suffering of others and who are the most dedicated to alleviating the suffering of others are also more disposed to accept, with God's help, their own suffering.

3. Love of neighbour, which Jesus vividly portrayed in the Parable of the Good Samaritan (cf. Lk 10: 2ff.), enables us to *recognise the dignity of every person,* even when illness has become a burden. Suffering, old age, a comatose state or the imminence of death in no way diminish the intrinsic dignity of the person created in God's image.

Euthanasia is one of those tragedies caused by an ethic that claims to dictate who should live and who should die. Even if it is motivated by sentiments of a misconstrued compassion or of a misunderstood preservation of dignity, euthanasia actually eliminates the person instead of relieving the individual of suffering.

Unless compassion is combined with the desire to tackle suffering and support those who are afflicted, it leads to the cancellation of life in order to eliminate pain, thereby distorting the ethical status of medical science.

4. True compassion, on the contrary, encourages every reasonable effort for the patient's recovery. At the same time, it helps draw the line when it is clear that no further treatment will serve this purpose.

The refusal of *aggressive treatment* is neither a rejection of the patient nor of his or her life. Indeed, the object of the decision on whether to begin or to continue a treatment has nothing to do with the value of the patient's life, but rather with whether such medical intervention is beneficial for the patient.

The possible decision either not to start or to halt a treatment will be deemed ethically correct if the treatment is ineffective or obviously disproportionate to the aims of sustaining life or recovering health. Consequently, the decision to forego aggressive treatment is an expression of the respect that is due to the patient at every moment.

It is precisely this sense of loving respect that will help support patients to the very end. Every possible act and attention should be brought into play to lessen their suffering in the last part of their earthly existence and to encourage a life as peaceful as possible, which will dispose them to prepare their souls for the encounter with the heavenly Father.

5. Particularly in the stages of illness when proportionate and effective treatment is no longer possible, while it is necessary to avoid every kind of persistent or aggressive treatment, methods of 'palliative care' are required. As the Encyclical *Evangelium Vitae* affirms, they must 'seek to make suffering more bearable in the final stages of illness and to ensure that the patient is supported and accompanied in his or her ordeal' (n. 65).

In fact, palliative care aims, especially in the case of patients with terminal diseases, at alleviating a vast gamut of symptoms of physical, psychological and mental suffering; hence, it requires the intervention of a team of specialists with medical, psychological and religious qualifications who will work together to support the patient in critical stages.

The Encyclical *Evangelium Vitae* in particular sums up the traditional teaching on the licit use of pain killers that are sometimes called for, with respect for the freedom of patients who should be able, as far as possible, 'to satisfy their moral and family duties, and above all... to prepare in a fully conscious way for their definitive meeting with God' (n. 65).

Moreover, while patients in need of pain killers should not be made to forego the relief that they can bring, the dose should be effectively proportionate to the intensity of their pain and its treatment. All forms of euthanasia that would result from the administration of massive doses of a sedative for the purpose of causing death must be avoided.

To provide this help in its different forms, it is necessary to encourage the training of specialists in palliative care at special teaching institutes where psychologists and health-care workers can also be involved.

6. Science and technology, however, will never be able to provide a satisfactory response to the essential questions of the human heart; these are questions that faith alone can answer. The Church intends to continue making her own specific contribution, offering human and spiritual support to sick people who want to open themselves to the message of the love of God, who is ever attentive to the tears of those who turn to him (cf. Ps 39: 13). Here, emphasis is placed on the importance of *health pastoral care* in which hospital chaplaincies have a special role and contribute so much to people's spiritual well-being during their hospital stay.

Then how can we forget the precious contribution of volunteers, who through their service give life to that *creativity in charity* which imbues hope, even in the unpleasant experience of suffering? Moreover, it is through them that Jesus can continue today to exist among men and women, doing good and healing them (cf. Acts 10: 38).

7. Thus, the Church makes her own contribution to this moving mission for the benefit of the suffering. May the Lord deign to enlighten all who are close to the sick and encourage them to persevere in their different roles and various responsibilities!

May Mary, Mother of Christ, accompany everyone in the difficult moments of pain and illness, so that human suffering may be raised to the saving mystery of the Cross of Christ!

I accompany these hopes with my Blessing.

Palliative Care

PROLUSION

JAVIER LOZANO BARRAGÁN

Pain: Enigma or Mystery

PAIN IN THE APOSTOLIC LETTER ‘SALVIFICI DOLORIS’ OF JOHN PAUL II

As we dedicate this XIX International Conference of the Pontifical Council for Health Pastoral Care to Palliative Care, we must in the first place determine what palliative care is. It obviously concerns pain. Since this Pontifical Council is the instrument of the Holy Father for Health Pastoral Care, it is logical that we ask the Supreme Pontiff what his notion of pain is. The opening reflections of this International Conference aim at responding to this question, and our remarks thereupon will serve as the basis for our study.

We do not like limits. We are used to ‘ultra plus’. However, suddenly what is without limits appears absurd, in the same way that what has limits also appears absurd. This is the problem encountered by postmodernity when it speaks about the parologism of instability. In a mechanistic approach a non-limit requires a final cause and a limit requires a reason. Yet it is said at the present time that both requests should not even be made because the daily should not be gone beyond; at the most one should search for a merely descriptive sequence and nothing else. Only a descriptive analytical approach appears to be authorised, an approach in which one becomes accustomed to seeing only one thing after another in a mere concatenation, just as a line follows from a point and a level from a line, without a strictly mechanistic mentality being superseded.

From the discovery of the map of the human genome, which as a whole resembles a piano that has three million keys and which has to be played during the whole life of a living being, and from an observation of the diversity of genes, because all of them are different, one sees that it is impossible to understand the beginning of life, and as a result everything, from a mechanistic vision of one thing following another, is subjected to another vision – that of simultaneousness, of totality. A perspective involving relationships thus becomes imposed: one point has a relationship with numerous other points.[1] The analytic method must necessarily be followed by the synthetic one, for otherwise it is not possible to arrive at the reality being investigated.

To this vision of totality the ‘ultra plus’ belongs. There can be no doubt about this, but many reservations are involved. We are used to knowledge that is equivalent to a manipulation of its original meaning, that is to say what is knowable and what is transformable; what can be manipulated is instrumental reasoning. Now, in many fields we must locate ourselves at another level, not the instrumental knowledge of dominion but the knowledge of observation that is beyond an aspired-to aesthetic knowledge and will lead us to respectful admiration and even humble worship – wise reasoning.

This is the perspective with which we can enter deeply into the question of pain and acquire deep knowledge of it so that we can go beyond the perspective of enigma. Such knowledge can only be surrounded by a halo of mystery that is worshipped.

I have been asked to expound the incomparable thought of John Paul II on human pain. First of all, I will make a general reference to summarising data on the physiology of human pain, and given the openness of the Holy Father to all the values of humanity it seemed to me interesting to allude to the cores of the thought on the subject involving four solutions that have been produced outside the Christian framework and to enter into dialogue with them. Because of the requirements of brevity, I will only do this in a schematic fashion. Their essential contents will be described and then an attempt will be made to point out some prospects for dialogue. I will allude to Hinduism, Buddhism, Islam, and the traditional religions of Africa, which have many common elements with the traditional religious thought in other parts of the world.

INTRODUCTION

1. Medical Observations on Pain

‘Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, from which the organism suffers.’[2]

Pain could be a symptom of an

illness or be an illness itself. In the first case, it constitutes a useful sign of physiological alarm; in the second instance it has no goal and could be a starting point for another psychological or organic pathology. From the part of the organism where it originates, it is transmitted through the nervous fibres, and when it reaches the spinal cord it rises to the cerebral cortex, where both the nociceptive stimulus and the elaboration of symptoms of pain is perceived**.**

Pain could appear in an acute or chronic form. Acute pain appears suddenly and has a limited duration. It stops within a short time of the treatment of the illness that causes it. The chronic pain (illness) has a prolonged duration (over three months) and causes an elevated psychco-organic impact on the patient. At times it also continues after the healing of the illness that caused it (neuropathic pain, herpes zoster) or it accompanies an incurable illness.

The intensity of pain is suggestive (threshold of pain): there are people who bear the pain more than others; one often observes a difference in pain tolerance by the same person depending on the cause of the pain and above all according to his psychological situation.

2. Cores of the Solutions to Pain in the Great Religions outside the Framework of Christianity

In *Hinduism* the cause of suffering is the 'Karma', which is the consequence of *bad actions* that have been carried out in this life or during previous reincarnations. The freeing of the Karma comes from *knowledge of Truth*, and from the proclaiming of the Word of God. God Himself will solve the situation. There are also other causes of this malady, and they are gods, the world, ignorance, and suffering.

In *Buddhism* the problem of pain is expressed in the four noble truths: 1. everything is suffering; 2. its cause is *passion-selfish worry*; 3. it is eliminated only in Nirvana, which is achieved in part in this world but also to the full in the future; 4. the path to Nirvana is the eight forms of righteousness, that is to say righteousness of vision, of thought, of speech, of action, of life, of efforts, of attention, and of meditation.

In *Islam* suffering is caused by *opposition to the proclamation of the Word of God*. God Himself will deal with pain. There is also a Shiite current within Islam that proposes vicarious suffering. According to this approach, Al Hally, who died crucified in Baghdad in 922, was the redeemer.

In *traditional African religions*, suffering is caused by spirits or ancestors who have been offended by crimes against life or other *moral offences* such as theft, slavery, etc. It is dealt with through sacrifices, once the offended spirit has been identified.

Like a constant, we find that in the schema of each of these great religions the cause of suffering is sin. For Hinduism, we are dealing with bad actions or Karma; for Buddhism, passion-selfish worry; for Islam, opposition to the word of God; and for the 'natural' religions of Africa, which are very similar to the traditional religions of other parts of the planet, the cause of suffering is crimes that have been committed. From this point of view, we are not far away from Christianity, even though in Christianity the cause of suffering is sin, albeit sin of a very special kind – original sin.

The strongest difference lies in the solution to suffering. The most distant thought to Christianity is Buddhism given that in this religion suffering has to be overcome through a purely human action, namely the *eight forms of righteousness*. On the other hand, the other great religions always offer a link with the divine as a solution. We may say that Buddhism is full secularisation (as a system of thought it is atheist and it only becomes theist, so to speak, in its form of popular religiosity). Instead, in Hinduism the Word of God is the solution; in Islam, once again the Word of God; and in traditional religions, sacrifices to God.

Within this framework I will now outline the key features of the thought of John Paul II and will take them from his apostolic letter *Salvifici Doloris*.[3]

The title that was suggested to me for this study, namely 'Pain: Enigma or Mystery', seems to me to be very opportune. For Pope John Paul II pain is an enigma that is solved only with reference to mystery. Before addressing the subject in detail I would like to engage in a terminological clarification: when reference is made to pain, on the whole reference is made to suffering caused by physiological events. The other term that is used is 'suffering'. When this latter term is used one has in mind something that is greater, reference is made to the whole gamut of human pain – physical and mental pain, material or spiritual pain. In outlining the thought of John Paul II I will employ the word 'suffering', in which I include both physical pain and any other kind of pain. I will address the subject of my paper in three parts: the first part deals with suffering as an enigma; the second discusses suffering as a mystery; and the third is a commentary on the doctrine of John Paul II.

I. THE ENIGMA OF SUFFERING

The Pope begins his analysis of the problem of suffering with this question. He does not conceal the fact that one is dealing with something that is complex and enigmatic, something that is intangible, something that should be treated with respect, with all possible compassion, and with fear as well. But this does not justify trying to understand it because this is the only way of overcoming it. Subsequently, I will make some references to delimit the field by speaking about the range of suffering and its subject, observing at the outset that misunderstanding about suffering can even lead to a denial of God.

The Pope says that suffering goes beyond illness because there is both physical suffering and moral suffering.[4] In addition to individual suffering there is collective suffering, which is due to the errors and transgressions committed by men, and in particular to wars. There are moments when this collective suffering increases. Suffering has a subject and that subject is the individual. However, it does not remain confined to the individual but generates solidarity with other people who suffer since the only person who is especially aware of this is man and the whole man. Suffering thus implies solidarity.[5] It is difficult to define the cause of suffering, or of the evil that is joined to suffering. Man asks God about this and he frequently denies God because he thinks that he cannot find a reason for his suffering.[6]

At the outset it is necessary to locate the enigma in its rightful dimension and to begin to look for its cause. The Pope says that suffering is an experience of a denial of a good. The denial of a good is the evil. Thus the cause of suffering is an evil. For this reason, suffering and evil are to be identified with each other. As regards evil, this is denial; it does not possess in itself a positive entity and thus it cannot be a cause or a positive principle. Its origin is a mere denial. There are as many evils as there are absences; an evil generates pain, sadness, dismay, disappointment, or even despair, according to its intensity. It exists in dispersion, but at the same time involves solidarity. Given that denial is its starting point, a question is posed: why has this denial taken place, what has caused it?

In order to answer this question, the Pope abandons the terrain of the enigma and moves on to that of mystery. He does not try to do this with the cloudy obscurity of a myth but enters to the full into the core of Christian faith. In Christian faith mystery is not obscurity but dazzling clarity. The Greek root of the term helps us to understand it somewhat, those words that mean to close one's eyes. Not in the sense of proceeding blindly but of closing one's eyes when one is dazzled, as occurs when one looks directly at the sun. It is the light alone that dazzles, it is the excess of luminosity that prevents us from looking ahead, from looking at what constitutes the mystery of suffering. In addition, Christian mystery is not only something that one contemplates; it is also something that one experiences. Only in the experience of mystery can one enter its comprehension. Only in living out the mystery of Christian suffering can one understand a little of what suffering means, and, as the Pope says beforehand, transcend it and rise above it. I will now attempt a description of suffering.

II. THE MYSTERY OF SUFFERING[7]

Emphasis may be placed on three themes that the Pope addresses in the pathway that introduces us to the mystery of suffering: evil and suffering; Christ taking on suffering; and the value of human suffering.

1. Evil and Suffering

In order to enter the mystery of suffering we do so with the guidance itself of God, and it is to Revelation that the Pope brings us in order to then proceed to advancing to mystery. The Holy Father tells us that in the biblical language of the Old Testament, at the outset, suffering and evil were the same. But thanks to ancient Greek, in particular in the New Testament, there is a distinction between suffering and evil. Suffering is an attitude that is active or passive in relation to an evil, or to express the point more precisely, in relation to the absence of a good that one wishes to have.[8]

Indeed, in the Book of Job and in some of the other books of the Old Testament the answer is that the cause of evil lies in a transgression of the natural order created by God. Suffering and disorder are said to be the same thing or at least it is thought that suffering is caused by disorder. This is the thesis of Job's friends.[9] However, God rejects this thesis in affirming the innocence of Job, and his suffering remains a mystery: not all suffering comes from transgression and this attests to Job's uprightness. This is a prefiguring of the Passion of the Lord.[10] In addition, it is stated that suffering is a trial that is imposed to correct people, that is to say so that evil can be followed by good, for the purposes of conversion, for the reconstruction of good.[11]

2. Christ Takes on Suffering and Transforms it

The Pope then takes another step and comes to the centre of the mystery of suffering in the following way: during his mortal life Christ suppressed pain through miracles. He took on the pain of everybody and consciously suffered it on his cross.[12] The only response can come from the love of God on the cross alone.[13] The solution to the problem of suffering is given by God the Father: it lies in the fact that He 'gives' His Son. Evil is sin and suffering is death. Through his cross Christ defeats sin and defeats death with his resurrection (Jn 3:16).[14]

In the song of the Servant of God, in the prophet Isaiah, one can see with even greater force than the gospels what the passion of Christ actually means. It is redemptive suffering. Its profundity is to be measured in terms of the profundity of the historical evil of the world and in particular because the person who suffers it is God.[15] Christ provides an answer to the problem of suffering with the same subject of the question: he offers all his readiness to help and compassion; his presence is effective: he helps, gives, and gives himself.[16]

3. The Value of Human Suffering

Suffering generates love for those that suffer, a disinterested love directed towards helping them by alleviating their suffering. This is now done in an organised and official way through health care organisations and their professionals, and also through volunteers. This is a real vocation, especially when a person is joined to the Church through the profession of Christian belief. In this field, the help that families provide to their sick relatives is important. Those who act not only on behalf of sick people but also to drive off a series of evils also belong to the category of Good Samaritans: those who fight against hatred, violence, cruelty, against every kind of suffering of the body and the soul. Each man must feel that he is called in the first person to bear witness to his love in suffering and he must not leave official institutions to themselves.[17] The parable of the Good Samaritan converges with what Christ says in the Final Judgement: 'I was sick and you visited me'. Christ himself is the person who is looked after and taken care of; the person who fell into the hands of robbers. The meaning of suffering is to do good with suffering and to do good to those who suffer.[18]

The Pope concludes by observing that the mystery of man is revealed in Christ, and the mystery of man is in a special way the mystery of suffering. The enigma of pain and death is revealed in Christ. Only in love can one find the salvific response of pain. May the pain of Mary and the saints help us to find this response! May suffering be transformed into a spring of strength for the whole of mankind!

3. COMMENTARY

1. Epistemological Status

In order to have a more effective understanding of the thought of the Pope, an epistemological note is required. Knowledge has already been spoken about in this paper in a special way: the reverent knowledge that worships. Now we can be more specific: we are dealing with thought that is only understood through faith. At this level we are not in something that is irrational, or in a perspective characteristic of Heidegger that involves a confused and cloudy mystery that is beyond linguistic analysis. It is certainly the case that the concept of knowledge analysed from the logical perspective of language is not adequate: language observed by scientific experience or by the logical formality of the language itself, even when placing it in a specific game of language itself, religious language. And it is certainly the case that we are not in a sort of parologism of instability or 'small tales'.

We must begin from the objectivity of knowledge and its logical rationality, understanding that knowledge is true when there is a correspondence between it and surrounding reality. From this starting point, the knowledge of faith enjoys full rationality, not in the sense that its contents are rationally demonstrable but in the best sense, i.e. that it is completely rational to believe, and that its contents do not have any contrary reason which can lead the fact of believing in them to be seen as absurd, even though they cannot be demonstrated internally to be credible since they go beyond the rational domain, although, and I repeat the point, they do not deny that domain. Statements of faith are based upon the rational demonstration of the fact of Revelation and the historical fact of Christ as God made flesh, his passion, his death and his resurrection. Despite this, although it is rational to believe, it is not obligatory, because on the one hand faith remains a gift and a gift of God, and on the other, even when receiving the divine offer of believing man remains free to agree to this offer.

Once this epistemological premise has been established we can enter the thought of the Pope because it advances not within an invented religious ideology but by expounding the historical central contents of Revelation on the mystery of suffering and pain.

2. The Gradual Approach of the Thought of John Paul II

I think that the unfolding of the thought of the Holy Father rises by six steps towards the fullness of the mystery of suffering and pain. These steps can be summarised in the following fashion:

1. Suffering is not in itself bad but is the effect of a negative cause. Evil is not a positive entity but deprivation. Deprivation does not require a positive cause but the search for who gave rise to that deprivation.
2. Sin is at the origin of deprivation. The sin committed by a man propagates itself through human solidarity. Sin can be eliminated through suffering itself in a context of solidarity that is completely special in character.
3. Such solidarity can only be given by God. This gift of solidarity is the meaning of the Incarnation; it is the meaning of Jesus Christ. For the sake of such solidarity Christ completed the elimination of sin through his suffering in his life, passion, death and resurrection. This divine action was an action of the

Most Holy Trinity because the Eternal Father gave His Son to mankind so that mankind could be redeemed through the action of the Holy Spirit. The Holy Spirit is the Love of the Father and the Son, and only through the Love of the Spirit can mysterious redemptive solidarity take place.

4. Through the solidarity of Christ with the whole of mankind, the human pain of all time was suffered by Christ in his passion and redemptive death. Thus human pain, suffering, was transformed from something negative into something positive, a source of life, because it became redemptive.

5. Every person in their suffering is joined to the suffering of Christ and in this way, mysteriously, their suffering becomes a source of life and of resurrection. Pain and suffering are the door by which we can encounter Christ and experience in him his presence as life and resurrection through the work of the Spirit of Love, the Holy Spirit. This is what Our Lady the Virgin Mary did at the outset, and with her all the saints.

6. This definitive destruction of suffering through suffering leads us to destroy contemporary suffering with a whole series of means at our disposal as well, as is the case with the Good Samaritan.

3. The Core of the Mystery of Suffering

The Pope thus places us in the core of the mystery whose light dazzles us. This is because we are in the intimacy of the Most Holy Trinity, in the loving reality of the unity of God in the trinity of the Persons, and we are in the density of that mystery, the central mystery of the whole of the Christian religion, not in an abstract way or closed up in an immensity of distance but in a nearness: in human history into which irrupts the eternity of temporality, through the historicity of the Incarnation of the Word, his birth, life, passion and resurrection.

4. Understanding the Mystery

This is a Trinitarian and Christological mystery in which the absolute fullness of life is achieved through death, and it is called death and resurrection. Here we are in the core of Christian mystery. This core is accessible only if we experience it: if someone remains outside it, he cannot experience its efficacy and find the solution. The solution to the mystery of evil is not obtained solely through a theological exposition but also through an experience of something which when looked at for a period becomes obscured because of its excess of light, but which nonetheless is very real, the most real reality, we may say, because it is the only way by which to achieve happiness.

In this way we are inside the core of salvation. This is the core of Christianity. Tertullian said '*Credo quia ineptum*'. In experiencing relief from evil through suffering and through the cruellest suffering, the cross, the summary of all imaginable sufferings, this '*ineptum*' becomes '*aptum*', the most just and rational that we can imagine, because it is the only way by which to experience happiness.

a. From Suffering to Solidarity

For this reason, the mystery of pain moves from pain in itself to the mystery of solidarity. Solidarity as the foundation of the whole of existence is not only good will towards everyone, a way of committing oneself socially and being aware that we all belong to the same race, culture, nationality etc. It is also to experience a tie between all human beings so internally that this is not a qualification that comes to us once we exist – it is existence itself. It belongs to the divinised human life itself as a gift received by the person who takes part in the mystery itself of the life itself of God. The life of God is infinitely perfect in each of the divine persons through the internal solidarity that exists between the Father and the Son and the Holy Spirit. This infinite solidarity is the infinite Love, the Holy Spirit, which is poured into our hearts, the infinite love that is God Himself. The mystery of suffering is to be found in the mystery of Love, in the mystery of the Spirit.

b. The Constituent Solidarity of Man

In this way, the mystery of suffering-love enters the very constitution of God made flesh; the Son was made flesh by the work of the Holy Spirit. As Christ is the innermost model of every man, the Holy Spirit, the Love of God, redemptive suffering, enters the objective constitution, we may say the ontological constitution, of mankind. But differently from a cold objectivity, it is something that belongs to our being in its objectivity but with the utmost loving solidarity, because it is, and it depends on, our free will so that we can accept it or reject it. In accepting it we become men totally through suffering-love; in rejecting it, in contrary fashion, we destroy ourselves as men through suffering-hatred.

c. Suffering from the Resurrection

The Pope is aware of the difficulties that are encountered in thinking in this way, and for this reason he tells us that the reality of solidarity-based suffering is understood only through the resurrection. From our solidarity with the highest expression of life – the risen Christ – we can understand our loving solidarity with Christ suffering on the cross. Just as the risen Christ and Christ in his resurrection includes the resurrection of mankind, of all of us and of each one of us, so also in the suffering of Christ are included the sufferings and pain of all of us and of each one of us. There is no separation between the resurrection and the cross, but instead a convergence both in Christ and in us. Thus the Pope says that Christ contains in his glorified body the signs of his own wounds.

d. The Meaning of the Glorious Cross

Thus one grasps and understands what would otherwise be an unsustainable paradox, a scandal and an example of madness, namely how the cross is glorious, that is to say how the cross from being the most fearful evil of total death becomes the glorious beginning of the whole of the second creation. The nothing from which springs this new world of happiness, this definitive Heaven, does not spring from an innocent nothing but from a guilty nothing, that highest evil of sin, and which in definitive fashion leads to the cross. And from the cross, not because of the cross but because of the omnipotence of the Father and the solidarity-Love of the Spirit, the Word made flesh recreates in us the authentic Adam, the man of truth, the model projected by God for the whole of eternity, so that we can be authentically human.

Conclusion

The only way by which to decipher the enigma of pain and suffering is the path of love. A love that is able to transform nothing into full reality: the lack of meaning, the lack of direction, the radical anticulture, contradiction and death, into fullness of meaning, full direction, ascendant culture, glorious affirmation, and life; madness and foolishness into what is wisest and most sensible. And the intimate solidarity of triumphant love that revives in loving solidarity in the most terrible suffering that kills. It is victory over death.

In this way, John Paul II leads us to peer in a dazzlingly mysterious way, which is the only valid approach, into the meaning of human pain; and the enigma finally becomes a mystery. A joyous mystery that is luminous and full of happiness. This is the paradox that becomes logical again through the Omnipotent Love of God the Father, His Spirit, and it has its effectiveness at the culminating point of the history of humanity when He grants us intimate solidarity with all men in the Easter of the Word made flesh.

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Notes

[1] Cf. V. Cappelletti, ‘Il genoma umano, analisi storica e considerazioni etiche’, in Pontificia Accademia Pro Vita, *IV Assemblea Generale, 23-25 Febbraio 1998.*

[2] Definition by the International Association for the Study of Pain.

[3] John Paul II, apostolic letter *Salvifici Doloris, on the Christian Meaning of Human Suffering* (Vatican City, 11 February 1984).

[4] *Salvifici Doloris*, n. 5.

[5] *Salvifici Doloris*, n. 8.

[6] *Salvifici Doloris*, n. 9.

[7] The subjects that the Pope addresses in *Salvifici Doloris* in relation to suffering as a mystery are:

evil and suffering: initial identification, first reference to its cause, correction by God, evil as a source of good, destruction of evil by Christ through his miracles (destruction of illnesses and death), evil as a source of good.

Christ takes on suffering: the destruction of evil and suffering,the taking on of suffering by the Father, evil is not suffering but its cause, in eliminating the cause one eliminates the effect, suffering eliminates suffering, infinite suffering, absolute and total elimination.

Human suffering: eliminating human suffering through human suffering, sin as the cause of suffering, the loving paradox, the goodness of suffering, the substituting of the suffering of Christ, participation in suffering, participation in suppressive suffering, alleviating suffering, summary of the mystery.

[8] *Salvifici Doloris*, n. 7.

[9] *Salvifici Doloris*, n. 10.

[10] *Salvifici Doloris*, n. 11.

[11] *Salvifici Doloris*, n. 12.

[12] *Salvifici Doloris*, n. 16.

[13] *Salvifici Doloris*, n. 13.

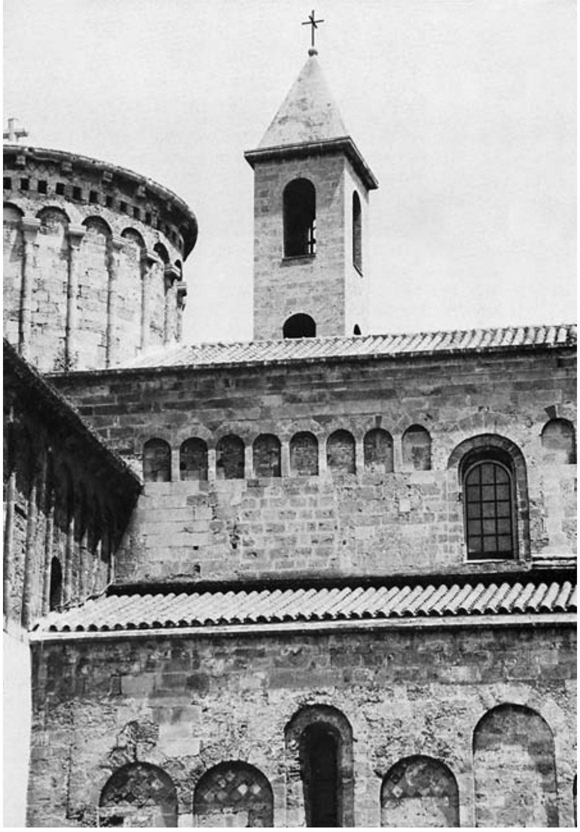
[14] *Salvifici Doloris*, n. 14.

[15] *Salvifici Doloris*, n. 17.

[16] *Salvifici Doloris*, n. 28.

[17] *Salvifici Doloris*, n. 29.

[18] *Salvifici Doloris*, n. 30.



CECILIA SEPÚLVEDA

Palliative Care: a Perspective from the World Health Organization

WHO's definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems that are physical, psychosocial and spiritual. Palliative care affirms life and regards dying as a normal process and intends neither to hasten nor to prolong death. Today there is wide recognition that palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness, in conjunction with other therapies that are intended to prolong life. Palliative care should be offered as needs develop and increase towards the end of life and continue beyond death during bereavement.[1] It should be provided alongside potentially curative treatment.[2]

The need for palliative care worldwide

Tens of millions of people suffer from life threatening conditions in the absence of adequate palliative care. The majority of these cases are in low- and middle-income countries where there is a high and increasing burden of chronic life-threatening conditions, such as cancer and HIV/AIDS. In low resource countries quite often there is little accessibility to prompt and effective treatment for these diseases and the majority of cases are diagnosed in late stages. The provision of palliative care is usually the main feasible alternative to respond to the urgent needs of the sick and their families and improve their quality of life.

While the physical, emotional and spiritual needs of the patients and their families are all considered important concerns in palliative care, persistent pain is a major public health problem, accounting for untold suffering and lost productivity around the world.

When evaluating the needs of cancer and HIV/AIDS patients, unrelieved pain is among the most frequent and dramatic because it affects all dimensions of human life, producing emotional distress and social impairment that can even result in total invalidation in the case of severe pain. The majority of these patients experience pain quite often along the course of the disease which grows in severity and intensity during the terminal phase. It is estimated that around 50% of HIV/AIDS patients and 80% of cancer patients suffer from moderate to severe pain in the terminal phase. By applying these percentages to the number of deaths for each disease in developing countries, WHO estimates that there are over 4 million HIV/AIDS and cancer patients in terminal phase that suffer each year from unrelieved moderate to severe chronic pain in the developing world (Table 1).

WHO's efforts have played a major role in the progressive expansion of a global network on pain relief and palliative care formed by numerous national and international organizations. Despite the substantial efforts from the WHO and partners which has lead to significant progress in the development of guidelines, educational materials and country projects, there are still important gaps to be bridged.

Many countries have not yet considered palliative care in their health agenda. Several initiatives have developed as 'islands of excellence' not well integrated into the country's national health policies and therefore have not yet had a significant impact on the population of patients in need of palliative care. In the majority of developing countries there are serious impediments to opioid availability. Important regional and global health initiatives dealing with related issues have not explicitly considered palliative care among their priorities. Furthermore, palliative care has a low profile in the education and training of health professional even in the developed world.

Table 1. Estimates of Pain Burden in Palliative Care for Cancer & HIV/AIDS in developing countries

	Estimates of patients in terminal phase based on number of deaths in 2001*	Prevalence of moderate to severe pain in terminal phase	Number of terminal patients in need of pain relief
HIV/AIDS	2,866,000	50%	1,433,000
Cancer	3,600,000	80%	2,880,000
Total	6,466,000		4,313,000

* World Health Report 2002

WHO's recommendations for developing palliative care

WHO has developed recommendations on pain relief and palliative care addressing policy and management issues that are contained in the publications listed in table 2:

Table 2. WHO Publications on pain relief and palliative care and opioids control policy

- *Cancer pain relief and palliative care: a report of a WHO expert committee,* WHO 1990.
- *Cancer pain relief: with a guide to opioid availability,* WHO 1996.
- *Symptom relief in terminal illness,* WHO 1998.
- *Cancer pain relief and palliative care in children,* WHO 1998.
- *Achieving balance in national opioids control policy,* WHO 2000.
- *National cancer control programmes: policies and managerial guidelines,* 2nd ed WHO 2002.
- *Palliative care: symptom management and end-of-life care. Interim guidelines for first-level facility health workers,* WHO 2003.
- *A guide for patients, family members and community care givers.* Caregiver booklet, WHO 2003.
- *Better palliative care for older people,* WHO Regional Office for Europe 2004.
- *Palliative care: The solid facts,* WHO Regional office for Europe 2004

Key components of a comprehensive public health approach for palliative care include: development of policies, education and training, provision of good quality care, and the availability of medicines for pain relief and symptom management.

Adequate policies should ensure that palliative care is integrated into the continuum of care of chronic life-threatening conditions, with special emphasis on home-based care to ensure wide coverage. Palliative care must not be something that only specialised palliative care teams, palliative care services or hospices offer when other treatment is withdrawn. It should be an integral part of care and take place in any setting.[2]

WHO has recommended a relatively simple and inexpensive three-step approach to relieving mild, moderate and severe pain in cancer and HIV/AIDS. The method includes opioid pain medications such as oral morphine which is the drug of choice as it is easy to use, is very effective for treating severe pain and has a low cost when bought directly to manufacturers.[3,4] However, opioids analgesics are not adequately available in most of the world, in particular in developing countries and limited resource settings. This is due to a variety of economic, social, cultural, and health system factors, including excessively strict national regulation of narcotic drugs, fear of abuse, addiction and diversion (INCB 1996). Thus national drug control policies should be developed in a balance way to achieve availability of opioids medications while ensuring their adequate control and avoiding diversion. The guidelines 'Achieving Balance in National Opioids Control Policy' provide guidance to governments to analyse and improve their regulatory systems.[5]

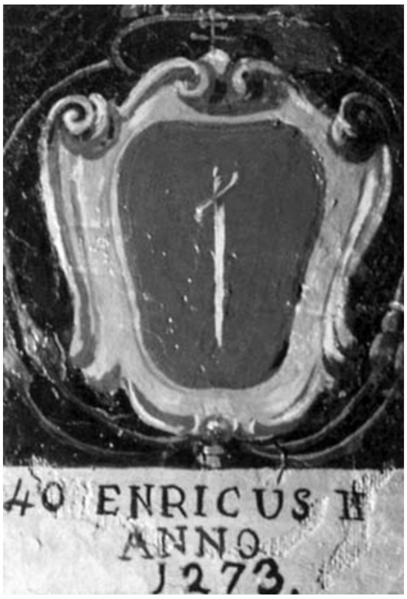
At a country level, it is acknowledged that situations differ widely. WHO has developed general recommendations for countries according to the level of resources available that can be adapted to each country situation. Overall, it is recommended that all countries implement comprehensive palliative care programmes at all levels of care and ensure availability to palliative care medications. These programmes should provide pain relief, other symptom control, and psychosocial and spiritual support. Countries with high levels of resources should ensure that national pain relief and palliative care guidelines are adopted by all levels of care and that, nationwide, there is high coverage of patients through a variety of options, including home-based care.

In low and medium resource settings it is important to ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care, and that there is high coverage of patients through services provided mainly by home-based care.[1]

WHO's HIV department has developed a new series of education materials that integrate palliative care into the continuum of care available to HIV patients, both before and during antiretroviral therapy. The materials include two new books: *Palliative Care: Symptom Management and End-of-Life Care* for primary health care providers and the accompanying *Caregiver Booklet for patients and community and family care givers*. The palliative care modules cover management of symptoms during acute and chronic illness, end-of-life care, and education for patients, families, and community caregivers. The goal of the materials is to expand rural access to palliative care by empowering patients and lay caregivers to provide high-quality care at home with the help of appropriate education materials.[6,7]

WHO ongoing initiatives

At present, WHO in collaboration with partners is both undertaking and developing activities related to palliative care through various WHO programmes and is also working for developing a joint strategy for assisting countries in developing adequate policies and implementing programmes that fully integrate pain relief and palliative care into the continuum of care of chronic disease, particularly cancer and HIV/AIDS.



The WHO Cancer Programme considers palliative care one of its key priority areas within its comprehensive framework for cancer control programmes which include development of evidence-based interventions from prevention to end-of-life care, as described in its publication on national cancer control programmes.[1]

Within this context in November 2004 a Consultation on Strategies to improve Cancer Control Programmes in Europe was held in Geneva. Seventeen countries from Western, Central and Eastern Europe participated. One of the main conclusions of the report states the need for reinforcing prevention and palliative care, both of them usually neglected in favour of treatment oriented approaches.[8]

In addition, the WHO Executive Board passed a Cancer Prevention and Control Resolution (EB114-R2) in May 2004. This resolution emphasises the need for developing and strengthening comprehensive cancer control programmes and recognises the provision of palliative care as an urgent humanitarian responsibility. The resolution will be adopted at the 58th WHA in May 2005, and WHO together with its partners will work to implement it, focusing on low- and middle-income countries.[9]

The WHO project *A Community Health Approach for Palliative Care in Cancer and HIV/AIDS Patients in Africa* was developed with the purpose of promoting a public health approach to palliative care. It is a joint cancer and HIV/AIDS project including Botswana, Ethiopia, Tanzania, Uganda and Zimbabwe. The project report contains the situation analysis and assessment of palliative care needs for HIV/AIDS and cancer patients in the five countries. A preliminary estimate is that about 1.6 million individuals or approximately one percent of the population in these countries need palliative care services annually and there are clear gaps in the ability of existing health services to provide even basic palliative care. The greatest needs of terminally ill patients were for adequate pain relief, accessible and affordable drugs, and financial support. Stigma stands out as one of the major issues felt by most of the patients with HIV/AIDS and their families.[10]

The WHO HIV/AIDS Department is planning to organise professional palliative care on a district clinical team model, with teams composed of patients, family, and community caregivers, first level facility health workers, and district-level palliative care nurse-specialists or doctors. The district model will enable WHO to expand access to palliative care and oral morphine for pain relief into the homes of the most peripheral sub-districts, thus achieving broad access to an essential set of palliative care interventions.

Future Challenges

As outlined, a number of initiatives are underway, often targeting the important needs of cancer and HIV/AIDS patients, but applicable to those affected by other diseases in need of palliative care. Emphasis is given to advocating palliative care as a global public health problem and the need for joining efforts across disease programmes and other related initiatives within WHO and beyond to ensure effectiveness and efficiency.

WHO, in close collaboration with the International Narcotics Control Board (INCB) and the WHO Collaborating Center for Pain and Policies Studies Group, is promoting balanced regulatory approaches so that control measures may not unduly restrict the accessibility to opioids.

Challenges in the near future include the validation of models for implementing effective and efficient palliative care programmes in different resource settings. These programmes need to be accessible to all patients and their families in need of this care by giving special emphasis to community and home based care and adequate referral systems.

The WHO HIV/AIDS 3x5 initiative, which promotes the accessibility to antiretroviral therapy, as well as the implementation of the Cancer Prevention and Control Resolution in low- and middle-income countries, which promotes the comprehensive approach to cancer control, might provide unique opportunities for testing models which effectively integrate palliative care into the continuum of care of cancer and HIV/AIDS patients.

WHO is seeking to strengthen its collaboration with the numerous governmental and nongovernmental organisations working in the field of palliative care. We share the same goals, and by combining our efforts and creativity we have greater potential to contribute to the wellbeing of the millions of people that every year are in need of pain relief and palliative care worldwide.

Conclusion

Significant progress has been made in the development of palliative care worldwide in the last decade, but there are still important gaps to be bridged. Many countries have not yet considered palliative care as a public health problem and therefore it is not included in their health agenda. Similarly, most regional and global health initiatives have not explicitly considered palliative care among their priorities. Several initiatives have developed as 'islands of excellence'. These initiatives have not, however, been well integrated into the country's national health policies and therefore have not yet had a significant impact in the population of patients in need of palliative care. In many countries there are serious impediments to opioid availability, a key element to pain control. Morphine consumption is especially low in most developing countries. Consequently, there is no doubt that there is a need to advocate worldwide for adequate policy development for palliative care and assist countries to develop affordable and sustainable models that integrate palliative care services to existing health systems, tailored to the specific cultural and social context.

Dr. CECILIA SEPÚLVEDA
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[8] *Strategies to Improve and Strengthen Cancer Control Programmes in Europe*, WHO 2004.

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I Section

The Contemporary Situation

FIORENZA DERIU

1. The Catholic World and Palliative Care: a Survey Carried out by the Pontifical Council for Health Pastoral Care

Commencing in January 2004, the Pontifical Council for Health Pastoral Care planned and then carried out a survey of a hundred of centres managed by entities belonging to the Catholic world in Europe and the world that are specialised in the provision of palliative care.[1]

The gathering of information was carried out through the sending of a semi-structured postal questionnaire to be filled in by those responsible for some of the centres of the Catholic world that are most representative as regards the provision of assistance to patients who need palliative care.

These centres were suggested by the local bishops responsible for pastoral care in health in their countries. The questionnaire was drawn up by a commission of experts on the subject matter of the survey and was organised into five subject areas. These were as follows:

a) structure and organisation;
b) pastoral activity;
c) activity involving the provision of assistance;
d) local support networks;
e) educational and training activity.

The definition of 'palliative care' adopted in this study is the definition of the National Council for Hospice and Palliative Care Services of the World Health Organisation, which was subsequently modified by the Ministerial Commission for Palliative Care of 1999. For this reason, palliative care may be defined as care intended to improve the quality of life of the patient but not intended to bear on the actual control of the development of the illness. Palliative care upholds life and sees dying as a natural event, 'one of the possibilities given to man to be lived out with responsibility', as Giovanni Franzoni would say. Forms of palliative care neither accelerate nor delay death: they provide relief from pain and other disturbances connected with pain; they integrate the psychological and spiritual aspects of assistance; they help patients to live in an active way until death; and they support the family during the illness and in the working out of mourning.

The typology of centres that the study group decided to observe was limited to hospices and operational hospital units providing palliative care. This decision was bound up with the fact that these two realities interpret two approaches to the terminal patient that are typical of two moments in the evolution of the concept of 'taking care of'.[2] Following in a summarising form certain reflections made by Prof. Gracia, a lecturer in bioethics at the Complutense University of Madrid, the concept of 'taking care of' has gone through three periods of evolution: the first, which resisted until the beginning of the 1940s, was characterised by assistance provided to the terminal patient that was of an intuitive and empirical kind and was totally and exclusively the responsibility of the traditional family group, which was patriarchal and based upon a rigid separation of roles and responsibilities between who was responsible for production (the men) and who was responsible for the work of looking after children, elderly people and the disabled during all the stages of the life cycle (the women). The second, which lasted throughout the 1960s and the early 1970s, took place as the ability of the family to take care of the terminally ill entered into crisis and the specialisation of intensive hospital and tertiary assistance advanced. During this period from the control of pain there was a move, thanks to the contribution of Saunders, to seeing assistance for the terminally ill as overall assistance: the hospice movement was born, 'a middle way between the hospital and the home', a place in which pain is reduced and it is possible to offer the patient and his family comfort and assistance at a mental, social and spiritual level. The third and last period, which goes from the middle of the 1960s to nowadays, has involved the move from the concept of 'overall care' to the concept of 'palliative care': the birth was witnessed of 'palliative medicine as a medical specialisation practiced by medical doctors, and with this was established the concept of palliative care as assistance offered by multidisciplinary teams made up of medical doctors, nurses, psychologists, therapists, social assistants, ministers of worship and volunteers'.[3] In 1987, with the recognition of palliative medicine as a medical specialisation, the season began when palliative care found positions with hospital departments: we are here talking about the first operational hospital units for palliative care.

Given the requirements of the time available, only some of the most interesting aspects that emerged during the course of the survey will be illustrated here.

Structure and Organisation

The structures that answered the survey were hospices (58.7%) and operational hospital units for palliative care (41.3%). Over 50% of the centres that were contacted work in advanced countries of the Western world. However, a series of differences connected with the local welfare systems and the different role played by the family group in accompanying the sick person during the terminal stage of his or her life were observed in relation to these centres. Palliative care remains a 'luxury' in these countries as well, where the health system is public and covers all citizens and where palliative care should belong to the sphere of public and social health care provisions. Unfortunately, palliative care still find difficulty in entering to the full into the world of hospital structures, not to speak of those countries where health care is guaranteed privately and where palliative care is a 'commodity' for those who can afford it. In developing countries, on the other hand, the situation is still critical: assistance is inadequate or too expensive, trained professional figures and volunteers at a local level do not exist, pain-killers are only administered in hospitals, and analgesics cost too much.[4]

In this general context, which is very variegated, are to be located the experiences of the centres that were reached by this survey. At least three structures out of four have a dispensary and beds, and one in every two had activated a service of home assistance. This is a very important statistic because the home of a patient, as a place of care, seems to respond better to the objective of improving the quality of life of the terminal patient. The model of home assistance involves the joint work of a multidisciplinary team to which belong various professional figures: from a medical doctor to a nurse, and on to a voluntary worker, a psychologist, and a social assistant. The patient and the family unit become the centre of the attention of different specialists who work together by coordinating their activities.

The centres reached by the survey are of very different sizes: from the small centre, which is usually a hospice, with about ten beds and an average of about a hundred and twenty admissions a year (2003) and able to provide dispensary and home assistance to a maximum of ten patients a day, to the centre of medium size, the hospital unit, with about thirty beds, about three hundred admissions a year (2003), and from twenty to thirty dispensary and home visits a day; and on to the largest centres which have over sixty beds, over five hundred admissions a year (2003), and two hundred or more dispensary and home visits a day.

Overall, the waiting times to obtain palliative care are not excessively long: lower for admissions and home assistance (from three to ten days); longer for the dispensary visits (from three to eighteen days). However, for the terminal patient time has a very special importance and only one hour's waiting time either way can make a difference.

The professional figures in the centres that were interviewed were the traditional figures: medical doctors, nurses and auxiliary technical operators. However, side by side with these figures voluntary workers and spiritual assistants who are Catholic or belong to other confessions also work. The presence of spiritual assistance in these structures is an important indicator of the closeness of these centres to all the needs of the patient: the physical needs, assured by the presence of a medical-scientific team that is specialised in palliative care, and the spiritual needs, assured by Catholic ministers of worship and ministers belonging to other confessions. Spirituality, therefore, understood in a broad sense because whoever belongs to a religious creed, whoever he or she may be, but also whoever is an atheist, has in most cases his or her own spirituality, and the person who provides palliative care must know how to interact with this spirituality.[5] As regards Catholicism, in nearly all of the centres that were surveyed the ministry of the sacraments (the Eucharist and the anointing of the sick) is assured, as well as pastoral visits (something that is the responsibility of priests and religious). 84% of the centres are also active in providing assistance during mourning – the funerals, in fact, often take place within the structure itself. In the largest centres as many as three thousand people a year are helped to die; 1,200 people a year are helped to die in their homes.

To return to the human resources that are available, it should be observed that a sizeable number of the centres that were questioned complained about the need to be able to rely upon a greater number of medical doctors, as well as psychologists, physiotherapists and voluntary workers. The shortage of human resources is also explained with reference to the sources of funding on which most of these centres are based: 33% of funds come from donations; 23.6% from individuals; but only 28.6% from state origins. To summarise: over 55% of the resources that finance hospices and operational hospital units in the Catholic world that provide palliative care come from private sources.

Activity Involving Assistance

A fifth of the medical services offered by the centres is made up of therapeutic assistance of a pharmacological kind or pain-killing treatment (*pain treatment*); a tenth is made up of nutritional therapies; a further 15% involves physiotherapy and rehabilitation; and finally another 20% involves the provision of psychological support to families in their management of mourning. For the most part, the patients have a clinical profile characterised by oncological illnesses or chronic-degenerative pathologies. The number of patients is distributed rather equally between adults and young people in the case of oncological illnesses, but the number of people over the age of sixty-six is higher amongst the patients who suffer from chronic-degenerative pathologies.

Therapeutic treatment involves a 40% pharmacological component, a 30% psychotherapeutic component, and a 20% rehabilitative component. Pharmacological treatment is prescribed in 40% of cases and by medical doctors who are specialists in anti-pain treatment and also belong to a team responsible for palliative care. The pharmacological protocol is in the main based upon weak painkillers (23.3% of the answers) or strong painkillers (21.9% of the answers) together with anti-depressives (20% of the answers) and general aids (15% of the answers). The protocols that are followed correspond to the second and third levels of the pharmacological approach envisaged by the World Health Organisation: respectively weak or strong painkillers together with non-steroid anti-inflammatory pharmaceuticals and other support pharmaceuticals. The protocol is communicated and explained to the patient in 44.3% of cases and in 36.8% of cases to the family leader.

However, activity involving assistance is not limited to an approach of the medical-therapeutic kind. The psycho-relational dimension, in fact, is an important component that is of fundamental importance in reducing and alleviating the pain and the overall suffering of the dying person. For this reason, side by side with the administration of painkillers (45.5% of cases), the staff (according to the specific character of their mission) also relies upon the support of the family and the faith of the patient (43.6%) during the course of the illness. The benefit for the patient is thus translated not only into a reduction in pain (54.4% of cases) but also in the recovery of his or her affective life (45.6% of cases). To support these measures, in 71% of the centres surveyed innovative therapeutic pathways are implemented, such as physiotherapy associated with music therapy (21.9%), reading (23.8%), and art workshops (21%).

Pastoral Activity and the Local Support Networks

76.7% of the centres that were surveyed complained about the lack of specific pastoral programmes on palliative care; 69% complained about the absence of bodies for the coordination of pastoral care; and 66.4% complained about the lack of an appropriate catechesis. However, when a pastoral programme had been drawn up, a priest or a religious with sound participation from lay collaborators was responsible for its creation. The main objectives of the pastoral programmes that exist relate to the overall accompanying of the patient both in hospital and in his or her home, with special attention being paid to his or her spiritual dimension, which in the case of Catholics takes the practical form in particular of prayer and the celebration of the Eucharist. In addition, pastoral care in directed towards the members of the specialist team so as to foster relationships and collaboration between its members and to support them at times that most run the risk of producing burn out.

In cases where forms of collaboration have been promoted with other realities in the local area, these have turned out to be very satisfactory (in over 70% of cases), above all in the case of health care structures, voluntary work and lay associations, as well as Catholic NGOs. The relationship with dioceses and parishes is more difficult. When a body engaged in the co-ordination of pastoral care exists, its work is directed towards the spiritual direction of workers through the fostering of periodic meetings with other realities in the local area, with chaplains, voluntary workers and with patients.

An analysis of the system of formal and informal help received by patients, and the level of satisfaction involved, bring out and emphasise the special efficacy of informal support as compared to formal support. The satisfaction of patients with the help that they have received from the family leader and other family relatives (over 80%) is to be found at average-high levels of satisfaction. The help and support of neighbours and friends is less widespread. However, when this does exist the benefits for the patient are very high. For this reason, the satisfaction of the patient and the utility that he or she receives from the system of informal help is decidedly highly than that produced by help offered by the formal support systems in the local area. This bears out the fact that a context that is as family-based as possible, or anyway that is able to involve the members of the family unit to which the patient belongs, is the best channel by which to provide support to a suffering person.

Training

Courses of pastoral training in this field are still at the initial stage (30% of centres). In general, they take the form of an internal seminar and last for one to three days at the most. During these courses in the main questions connected with the end of life (32.1%), the approach to the patient (32.7%) and the use of drugs and medicines (27.2%) are addressed and discussed.

Concluding Reflections

There can be no doubt that the realities investigated by this survey are experiences that are emblematic of the assistance that is provided to people who need palliative care. However, it is clear that much remains to be done and that the room for improvement is still very great.

According to those who were interviewed, more than 50% of people who need palliative care still today die in pain and with pain, at times alone, without affection at the moment of death, and without the warmth of the comfort of an at least known face. For this reason, it is my hope that this conference will open not only a debate on this subject, which is very sensitive as regards meanings and definitions that are not always agreed upon, but will also light a torch and direct attention to the need to strengthen the allocation of resources to palliative care so as to alleviate the suffering of those who suffer because of incurable illnesses. And, embracing the requests of the Active Citizenry Movement, I believe in the need to insert palliative care into the essential levels of assistance, in the need to certify those workers who show interest in and pay attention to such care, in the need to consider the structures and services of palliative care as a discriminating element as regards gaining access to accreditation in relation to the national health service, in the need to promote the training of workers, and in the need to establish information campaigns for citizens.

In an ageing society, in which life spans are growing but in which incapacitating chronic-degenerative pathologies or devastating oncological illnesses are also concomitantly present, in a country in which health care costs are increasingly unsustainable and the welfare state is in crisis, and in which the voice of the weakest runs the risk of losing in the face of the crushing logic of the economy and finance, we need to struggle to assure that the right to a dignified natural death is guaranteed, quite outside the logic of exaggerated treatment but also in opposition to every temptation to engage in 'euthanasia'.

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Notes

[1] For their help in the drawing up of the questionnaire I would like to thank Dr. M. Evangelista, tenured researcher of the Institute of Anaesthetics, Resuscitation and Pain Treatment of the Catholic University of the Sacred Heart A. Gemelli, Dr. V. Zagonel, specialist in oncology and haematology, the Director of the Oncology Unit. I would also like to express my gratitude to Miss Elisabetta Sezzatini, Official of the Pontifical Council for Health Pastoral Care, for her co-ordination of the carrying out of the survey.

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SIMONA CASTELLANO

2. Pain: the Scientific Data

For human beings pain is one of the most important sensorial experiences there is. For a clinical physician, it is one of the most frequent and indicative symptoms of illness because in almost all pathological conditions there are stages characterised by pain. Indeed, this is the case to such an extent that when pain is absent a diagnosis is uncertain. The International Association for the Study of Pain defines pain as an 'unpleasant sensorial and emotional experience that is associated with a real or potential tissue damage or described in terms related to this damage'.[1] This experience, because it is purely subjective, is difficult to define and it is often difficult to describe and interpret: it is, therefore, influenced by a multiplicity of factors of a cognitive, ethical, affective and environmental character.

The classification of pain involves an important distinction between acute pain and chronic pain. Acute pain is a biological symptom related to a manifest nociceptive stimulus, such as that constituted by tissue damage or a trauma or an illness. Pain can be localised or radiate out, it usually consists of pangs and its duration is closely bound up with the continuation of the pathological event that has given rise to it or to a failure to respond (for different reasons) in time spans that are considered arbitrarily short (three months) to the therapeutic treatment that has been engaged in. Thus acute pain limits itself with the diminution or ending of the nociceptive stimulus but it can evolve into clinical cases of chronic pain or pained behaviour.

By chronic pain is meant a complex pathological process that is much more long lasting than the evolution of acute pathologies or traumas. This symptom can be associated with a persistent illness or last after the healing of the damage which provoked its outbreak. When it is rooted in a physical pathology, its ending can also depend on the efficacy of the treatment for this pathology. Chronic pain is often deaf, persistent, not very localised; the associated signs of autonomic response (for example sweating or horripilation, which are frequently associated with acute pain) can be absent; and the emotional component of the perception and experience of chronic pain has in depression one of its principal constituents.

Pained behaviour involves a set of evident, oral or non-oral expressions manifested by a person that are interpreted by the individual who is observing that person as signs that that person is experiencing pain or suffering.

Acute pain and chronic pain can be schematised in two dimensions – time and physical damage – which, if represented abscissa or ordered respectively by a Cartesian graph, allow the tracing of a diagonal above which are located cases of acute pain (with grave or recently occurred physical damage) and below which are located causes of chronic pain (with light or long lasting physical damage).[2]

But 'how does pain function?' On this point we may refer to the physiology of nociception. An illness, an inflammation or a trauma (including that produced, for example, by a surgical operation) provoke a histio-prejudicing damage that activates the peripheral receptors. The tissue receptors involved are the following:

– In the skin and the dermis:

1. Low threshold mechanoceptors (LTM) innervated by fibre Aβ: they transmit tactile and pressure sensations;
2. High threshold mechanoceptors (HTM) innervated by fibre Aδ: for a swift pained response;
3. Polymodal nociceptors (PMR), or 'neuroeffectors', innervated by fibre C: for a slow pained response; these are also activated by heat.

– In the fascias, muscles, tendons and periosteum:

nociceptors and PMR innervated by fibres Aδ and C (which, in this case, because they come from deep tissues, are termed respectively group III and group IV).

– In the visceral sphere: polymodal nociceptive mechanisms innervated by fibre C.

Recent advances in knowledge[3] lead it to be believed that the fibres C belong to due different categories:

– Polymodal nociceptors, regulated by the nerve growth factor (NGF) and involved in tissue inflammation;

– Specific nociceptors, modulated by the neurotrophic factor derived from the glia and principally involved in cases of nerve damage.

The activity of the specific nociceptors has the biological meaning of revealing histological damage and generating a flight reflex in order to conserve the tissues and life. The polymodal nociceptive system, on the other hand, acts to monitor and regulate the local physiology and to modulate the neural system by promoting mechanisms of tissue repair, that is to say, in the final analysis, conditions of normal health. The reflex responses of the PMR to changed normal and pathological tissue biochemistry are very relevant in the genesis of neurogenic inflammation. The function of the PMR is to prevent and contain the damage and to facilitate the healing process ,but in particular cases they can, in contrary fashion, help to emphasise or prolong the pathological condition and support a profile of chronic pain. In the human skin most of the fibres C is made up of polymodal receptors; the presence of the PMR in various tissues attests to the various homeostatic requirements of the histological locations involved. But the alterations that are stimulated by the damaging event at a peripheral level are able to bring about the functional mutation of the locoregional PMR: from promoters of the tissue defence functions they become facilitators of a worsening paradoxic response.

All the tissues also have a widespread apparatus of silent nociceptors which, inactive in the normal tissues, respond in the case of inflammation. In this way, innervation informs the central nervous system (CNC) only in the case of pathology or phlogosis.

The ends of the afferent fibres have connections with the second-order neurons of the ventral and lateral horn, in the spinal segment itself and the adjacent segments. These connections have an important role in somatic and vegetative reflexes.

On the other hand, the second-order neurons involved in the ascendant transmission of pain sensations project, in their turn, contralaterally (but also ipsilaterally) to the higher levels of the central nervous system. Their axons, as has already been observed, originate practically at the level of all the medullary laminas, with the exception of the laminas occupied by the motoneurons. Obviously, the highest density of provenance is from laminas I, II, III, IV, V, VI and X of the medullary gelatinous substance. The axons that come from the laminas I and V, with the median line crossed at the anterior spinal commissural level, are the principal constituents of the lateral neo-spino-thalamic tract, which rises from the antero-lateral fasciculus. This pathway, which is direct and rapid, projects to the ventro-postero-lateral nucleus of the thalamus and from here to precise areas of the sensitive cortex: it is at the base of the sensitive-discriminative aspects of pain, that is to say of the processes that allow the localisation, identification and probably the recognition of the character and the intensity of the damaging stimulus.

The cells of the deepest laminas of the dorsal horn give rise to a slower pathway of ascendant transmission. This group of fibres form the paleo-spinothalamic tract (laid more medially always within the area of the antero-lateral fasciculus of the medulla: it makes synaptic contact in the bulbus with the neurons of the giganto-cellular nucleus and, higher up, with the reticular formation of the mesencephalon, with the periacqueductal gelatinous substance and with the hypothalamus, and projects to the medial/intralaminal nuclei of the thalamus (association and widespread activation of a reticular kind); from these last begin widespread projections to the cortex and the limbic system.

Two ascendant pathways, slow in speed and often shared, which from the spinal medulla lead to the reticular formation of the trunk and the mesenchaphalon, are the spinoreticular tract and the spinomesenchaphalic tract. These pathways reach the reticular substance of the trunk and the mesencephalus and from here go on to the posterior hypothalamus and the medial/intralaminary nuclei of the thalamus, from which they lead their projections to the sensitive cortex.

The commissural tract of the horn (fibe C – gr.IV, prevalently), starting from the medial position of the deepest laminas (X) of the posterior grey horns, is a propriospinal ascendant multisynaptic system that transmits signals from the deepest and visceral nociceptors; this also projects – rostrally – to the reticular formation of the encephalic trunk, and from this on to the medial) intralaminary nuclei of the thalamus.

It is important to consider the role of the slow ascendant pathways in the transmission of chronic pain. The transmission of widespread and not very localised pain that originates at the level of deep structures, such as the intestine and the periosteum, has been attributed to these pathways. Some authors[4] think, furthermore, that the system of fibres, with their widespread projections to the limbic and frontal lobes, through the encephalic trunk and the thalamus, is at the base of the emotional aspects of pain, that is to say of the unpleasant sensations associated with it, because it continues to evoke the mental experience of pain even when the transmission along the neo-spino-thalamic pathway has been extinguished.

To achieve a complete picture, it is advisable to refer to the post-synaptic nociceptive pathway of the spinal column. Differently to what was previously held to be the case, when the dorsal column of the medulla (posterior cordons) was thought to be made up of fibres activated by tactile and proprioceptive stimuli, it has been demonstrated that this column possesses a component of non-myelinic fibres that respond to nociceptive stimuli of visceral origins. These fibres reach the gracilis and cuneate nuclei of the bulbus; from here, starting from the medial lemniscus, they lead on to the ventro-postero-lateral thalamus (but also to the higher and superior colliculi and the mesenchaphalic reticular formation).

The data of neuroanatomy and neurophysiology, to which reference has been made, are of great use for our 'functional' understanding of pain.[5] But the studies carried out to clarify such aspects have also allowed the identification of some of the systems entrusted with nociceptive modulation.

At the level of the dorsal horn of the spinal medulla, the information that comes from the nociceptors is modulated by afferent inputs made up of influences: descendant, facilitating and inhibiting; local interneuronal; laminary neuronal and activity dependent influences. The fibres A-δ (myelinic) terminate in lamina I, and to a lesser extent, in lamina V, of the posterior grey horn of the medulla; the fibres C, which are non-myelinic, terminate in lamina II but also in lamina I and lamina V; other neurons, that respond to painful cutaneous stimulation, also reach the intermedial and ventral region of the grey horns. The aminoacid exciters, such as glutamate and aspartate, and the ATP, are the neurotransmitters of the fibres A-δ; substance P (a peptide with eleven amino acids) is involved as a transmitter in the slow communication along fibre C. Substance P excites the ganglion of dorsal roots and the nociceptive neurons of the dorsal horn; in contrary fashion, the destruction of the fibres containing substance P provokes analgesia. The meconics act as important modulators of the pain impulses that move through the dorsal horns and the bulbar and pontine centres. The meconics reduce the concentration of substance P; receptors for the meconics (of three types) are present both in the (pre-synaptic) afferent terminal axons and on the (post-synaptic) dendrites of the second-order neurons at the level of the lamina II of the posterior grey horn of the spinal medulla. When stimulated, the neutrons of the lamina II are able to free both enkephalin and dinorphin and other endorphins, that is to say morphine similar endogenous peptides that are connect themselves specifically to the receptors for the meconics and inhibit the transmission of pain at the level of the dorsal horns.[6]

Cholecystokonin (CCK) is a peptide made up of eight amino acids which, at a spinal level, are principally present at a interneuronal level and have a localisation similar to that of substance P. CCK attenuates the effect of many anti-nociceptive treatments, in particular the meconics, and its concentration increases notably after nerve damage.

One can at this point outline the mechanism of the spinal modulation of pain. In 1990 there was a scientific demonstration of inhibition at a segmentary level – gelatinous substance of Rolando, lamina II for the fibres C (group IV) and laminas I and V for the fibres A-δ (group III) – mediated by endophinergic interneurons (various endo-opioid mediators, connected with various types of peripheral receptors) which are activated by descendant reflex pathways and segmentary mechanisms (with presynaptic inhibition of the release of substance P) and intersegmentary interneurons (these last have not been completely clarified). One of the descendant systems for nociceptive regulation has its origins in the frontal cortex and the hypothalamus and projects to the neurons of the periacqueductal region of the mesencephalon. It then rises in the ventral and medial portion of the bulbus and descends along the dorsal portion of the lateral fasciculus of the medulla until the posterior grey horns (laminas I, II and V).

Of the levels of processing and convergence of the nociceptive information transmitted by the ascendant pathways, and which it touches on its pathway in the central nervous system, the one that has been most studied in detail (and the most interesting as regards the spinal reflex response that it is able to induce) is the mesencephalic level. The stimulation of the periacqueductal gelatinous substance produced by the nociceptive afferences transmitted to it involves the (enkephalin-mediated) activation of the large raphe (serotoninergic), patagigantocellular (noradrenergic) and locis coeruleus (noradrenergic) nuclei. From these nuclei begin descendant fibres which, rising in the dorsolateral funicle, go on to reach the endorphynergic interneurons of the medullary laminas I, II and V. Through them, both fibres A-δ and fibres C are inhibited by these descendant influences.[7]

The threshold for the perception of pain, that is to say the minimum intensity of stimulus to which the quality 'pain' is attributed, is approximately the same in all individuals in physiological conditions. In the presence of inflammation it falls: this process is defined as 'peripheral sensitisation' and is clinically rather significant because in sensitised tissues innocuous stimuli can provoke pain (allodinia). Indeed, when conditions are produced that support a repeated and protracted stimulation of PMR, the polymodal fibres C, at a high threshold, tend to respond to respond to lower thresholds of stimulus and to prolong and increase the posthumous charge (at the base of hyperalgesia) with a mechanism that has an adaptive meaning in the presence of the mediators of phlogosis with a 'sensitising' action. The 'central sensitisation' takes place in the same way but in response to a tissue damage or nervous activity-dependent damage. In other words, hyperalgesia and chronic pain are supported in many cases by an altered central mediation that takes place at a spinal level and modifies the primary nociceptive afference by emphasising it and prolonging it. Thus, in relation to the type of prevalent mechanism of sensitisation (peripheral or central), it is possible to classify pain as *inflammatory* (of which carcinomatosis and the chronic and ulcerating inflammatory processes in the visceral, articular, muscular/tendon and skeleton structures are frequent examples) when it is related to tissue damage. Vice versa, *neuopathic pain* is correlated with damage or dysfunction that is primarily the responsibility of the central nervous system. This is further separated into 'peripheral neurogenic pain' because this follows on from damage that is the responsibility of the peripheral nervous system (plexus, root, nervous trunk) and 'central pain', when the damage or dysfunction is in the central nervous system (medullary, troncoencephalic, thalamic and cerebral suffering). However, it should be made clear that the many interactions between the immunity system, which is the principal architect of the complex mechanisms of inflammation, and the nervous system, must lead us to think that this distinction is relatively arbitrary.

Conscious awareness of pain takes place only when the impulses reach the thalamic-cortical level but the role that these structures perform in relation to pain understood as a 'mental process' has not yet been clarified. At the present time, however, the separation between 'sensation' (that is to say awareness of pain, a function traditionally attributed to the thalamus) and 'perception' (the awareness of its nature and its characteristics, which it was thought was the responsibility of the cortex) does not appear to be feasible: this supports the approach that sees a close connection between sensation, perception and other (conscious and unconscious) components of nociception within the context of a response to pain, understood as a functional sensation.[8]

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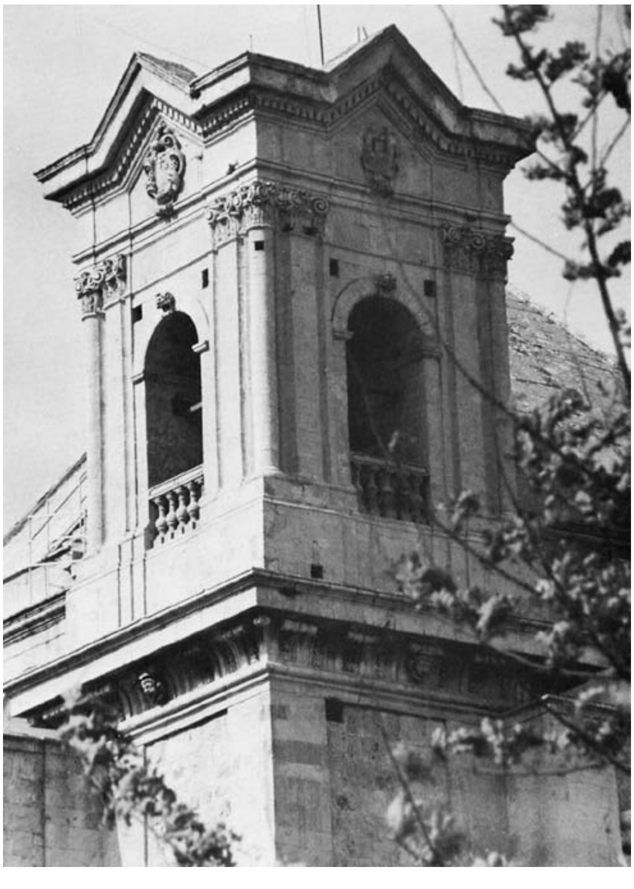

PIERLUIGI ZUCCHI

3. Pain Therapy

FROM TREATING TO TAKING CARE OF

Introduction

For man, pain is one of the most mysterious and disquieting realities that exists. It raises questions and involves disciplines that not only belong to the medical sciences but also to the humanities.

Indeed, we cannot have a reductive vision of man and confine pain to a parameter that is merely medical. We must necessarily locate pain within the field of philosophy, psychology and theology as well. This approach is present in the Algologic School of Florence which defines 'pain as a psychophysical entity of universal meaning, the perception of which involves different individual, cultural and religious factors, and in whose analysis participate not only the branches of medicine and biology but also those of the human sciences (philosophy and psychology) (Zucchi, P.L., 1983).

The Linguistic Meaning of Pain

From this definition one understands that in medicine, as a science and as an art, pain has a special linguistic meaning and creates a language that is shared but always new and renewable, uniting the sciences of nature with the sciences of transcendence and giving rise to an anthropological parameter that is in close dialogue with the metaphysical parameter.

To pain should not be given the semeiological meaning, which solely involves a pain-inducing stimulus for the individual, or the philogenetic meaning, which involves the moment of behavioural change of the individual in relation to nature, but above all the ontological meaning of a penetration of the person-man with God in a true, real and experienced participation in the passion of Christ.

In this metaphysical vision, medicine draws away from its exploitative schemata to create a new *culture of health*: the physiognomy of an anthropological medicine of such an approach provides a human meaning, which is really incisive, with transcendent meanings, to pain.

To come to the aid of the person who has the right not to suffer, the medical doctor can not employ solely the technical to combat suffering: he or she must establish and transmit a culture for suffering, also taking into account of the historical and ethical dimensions within which the medicine of pain has developed (Honings, B. and Zucchi, P.L., 2004).

The Relationship between the Medical Doctor and the Patient, Communication and Language

Pain manages to create conditions that are favourable to a form of special encounter and welcoming that lead to a profound *tension* in the Kierkegaardian sense of the term between two people, namely the medical doctor and the patient, who are distinct in their roles but not distant because both of them are united by the hope for a wished for improvement in the therapeutic result.

The seesawing eccentricity of these two physiognomies in the relationship between a medical doctor and a patient exists alternatively not only in terms of *communication*, that is to say an exchange of information, which is valuable for the therapy involved, but also in a linguistic reality that is very special, in which the tonalities of *language* bring out the delicate sensitivity of who is engaging in the dialogue and wishes to give a meaning to the symptom of pain.

Towards a Definition of Health and Pain

In order to make the term of the delicate subject that we are addressing comprehensible, it is advisable to offer the official definitions of health, of pain and of therapy that are adopted by all study groups at an international level.

The World Health Organisation (Alma-Ata, 1978) states that 'health must be a state of complete physical, mental and social well-being and not only the absence of affections and illness'.

The Pontifical Council for Health Pastoral Care defines 'health as a tension towards physical, mental, social and spiritual harmony and not only the absence of illness: it makes man able to carry out the mission that God has entrusted to him according to the moment in life in which he finds himself' (Lozano Barragán J., Message for the World Day of the Sick, 11 February of the Jubilee Year 2000).

The International Association for the Study of Pain (I.A.S.P., 1982) defines 'pain as an unpleasant sensorial and emotional experience associated with a real and potential damage to the tissue or described with terms that refer to such damage'

From the definition offered by the I.A.S.P. one understands that pain has two physiognomies: an objective physiognomy represented by *damage* (trauma, fracture, illness) and a subjective physiognomy identified with the *meaning* attributed to such an unpleasant event, which is differently interpreted and experienced according to the individual cultural and religious approaches involved.

The Christian experience explains pain within the dimension of Redemption, where damage as pain is experienced in a different way to that of the other religions because the experience of pain belongs to the close relationship between damage and meaning.

This is why, although it is characterised by universal meanings, pain remains an experience that is undergone in an individual way by each subject.

The Clinical Concept of Pain

However, pain must also be seen as the great friend of living beings because it provides, within the organism, a signal by which a man understands that he must engage in a therapy in order to improve a condition that could compromise his physical and mental safety.

On this point, biology itself brings out for us the positive value of pain in that very special syndrome known as 'congenital analgesia'. The individuals afflicted by this syndrome die young because they do not have the capacity to perceive pain in conditions in which normal subjects react to a pain-inducing stimulus (Sternbach, 1968).

In addition to this clinical picture, the opposite condition can also arise in which people feel intense pain in the absence of apparent pain-inducing stimuli; at times a slight contact or even a breath of air can provoke an algic crisis which in this case has a meaning that is totally without a purpose.

These two examples, namely *congenital analgesia* (where an individual displays an inability to perceive pain despite evident damage), on the one hand, and *hyperalgesia-hyperpathy* (where there is the presence of spontaneous pain in the absence of a damaging stimulus), on the other, are two opposing clinical extremities that are increasingly the subject of detailed and accurate studies by different research groups that deal with the physiopatholgy and the therapy of pain.

However, not only the mechanisms of the perception of pain but also the mechanisms involving the control of pain are today a field of research that is in constant evolution. It is known that men and animals have the possibility of eliminating or reducing pain, which, beginning with the periphery, reaches the encephalon, following behavioural factors that modify the electro-physiological and neurochemical responses of the organism.

From a clinical point of view, the subject of pain and suffering has been addressed in a special way by the Florentine School (Teodori, U., Neri-Serneri, G.G., Procacci, P., Galletti, R., 1973; Zucchi, P.L., and Duranti, R., 1979) which has made a distinction between pain as a symptom and pain as an illness.

Pain as a symptom is the symptom *par excellence* that arises very rapidly, a unique clinical sign, often for the purposes of defence, of the set of symptoms that are present (acute appendicitis, cluster headache, myocardial heart attack) that creates a reaction of alarm such as to induce a rapid therapeutic action; this clinical situation is to be identified *with acute pain* with its accompanying physical parameters.

Pain as illness is pain that emerges as a primary element of the situation of illness and loses its characteristic as a symptom, which is useful to the medical doctor and to the patient. This emergence is gradual and has a recurrent, subcontinuous development. Pain as illness is to be identified with *chronic pain* which lasts for months or years, gives the patient no respite, and often induces symptoms of anxiety and/or depression. Examples of this kind of pain are: rheumatic pain, post-herpes neuralgia, causalogical pain, arthrosis and osteoporosis pain, and the pain caused by cancer.

A clarification of these two important concepts helps us to understand that pain can characterise a clinical situation that involves a pathology that is very variegated from the physical, mental and social point of view and which the English language manages to explain very well with the word 'disease', which refers to the physical component of the illness (*algos*, acute pain), with the word 'illness', which refers to the mental and moral suffering (*pathos*, chronic pain) experienced by the patient and his or her family relatives, and with the word 'sickness', which refers to painful illness as socially perceived.

From this elaborate meaning that the English language offers us of the Italian word '*malattia*', one can understand that a patient afflicted by a painful pathology lives out his or her own state of total pain in all its three (physical, mental and social) expressions, involving in his or her own tragedy also family relatives, acquaintances, and the healthcare staff (Sindrome di Burn-Out, Mayou, 1987).

Anatomical Aspects of Pain

In order to achieve the best possible analysis of the clinical and therapeutic aspects of a specific painful illness, it is more than helpful to ask ourselves about the origins of pain.

Pain is due to the activation of receptors (nociceptors) and the peripheral and central afferent pathways that make up *pain perception*. At the level of the organism, the algic situation creates an anatomical damage to the tissues that involves the liberation of algogenous substances which then stimulate the apparatus of reception (*peripheral pain perception*), which in turn transforms the stimulus into a nociceptive input that reaches the spinal medulla through the order I neuron (*reflex pain perception*). At this level the order I neuron enters into synapsis with the order II neuron which then informs the thalamus (*unconscious pain perception*). From the thalamus the order II neuron projects the nociceptive input onto the somatoestesic cortex (*conscious pain perception*).

The Concept of Pain Therapy

This brief anatomical-physiological parenthesis helps us to understand better at which level the person who treats pain must effect a specific analgesic treatment (pharmacology, anaesthetics, surgery or physiatrics).

However, the meaning that we wish to give to the term ‘therapy’ is that equivalent to the ancient Greek term *therapeia*, by which was meant taking care of, or being totally ready to help somebody in a state of need. This concept of therapy does not refer only to physical illness in a clinical sense, and thus to biology and to medicine, as happens with the modern term ‘therapy’, but to the general condition of life, the aspect of the person in his or her totality, his or her well-being in a broad physical, mental and spiritual sense.

In this approach, therapeutic treatment acquires a new interpretation, which is more detailed and overall in character and which sees man in the real ontological meaning of the person.

It follows that the concept of pain therapy must therefore be examined both as etiological hermeneutics of the illness and in a broader sense as hermeneutics of the needs of man.

Pain therapy as *hermeneutics or etiological interpretation* of the algic set of symptoms of illness belongs to the clinical examination of a situation that is often highly problematic for the patient. The therapeutic moment takes on meaning only when the subject in his or her intimate being-man person relationship lives out his or her special moment of illness in all its wholeness.

The interpretation of noxa, at this point, can identify a therapeutic process operating at the level of knowledge but one that is not guaranteed, one open to success but depending on the illness involved at times risky and also threatened by possible failure, and to such an extent that it cannot be implemented except in a climate of fractures, of contradictions and even of anxiety.

Pain therapy as *interpretation of the needs* of man is a fundamental stage in the life of each suffering individual, not only in relating to what he or she should *do* but above all else in being educated in what he or she should *know what to do* to achieve the strengthening of his or her physical and mental being and thus the establishment of his or her *knowing how to do*, as the acquisition of a new personal culture.

From these premises one understands, first of all, how pain therapy, in trying to follow a personalised process for the patient, becomes a personalising element as regards the relationship between the medical doctor and the patient, taking on the most varying meanings: from a highly variegated art to an effective therapeutic method, from a technique that seeks to solve difficult pathogenetic interpretations of illness to a real and authentic philosophy of suffering man at special moments of the totality of his meaning.

Thus one deduces that it is not only the state of painful illness but also the human experience itself that requires an interpretation of one’s suffering, and this is because the being itself of man requires an answer at the human and biological level. Pain therapy must continually address the problem of the physical, moral and also spiritual suffering of man struck by illness, which must be treated well by the medical doctor but also accepted equally well by the patient.

In these terms the treatment of pain takes on the physiognomy of a useful instrument that must deal with intricate pathologies that are at times of extreme gravity. With its characteristics of a discipline that is also technical in character, anti-pain therapy tries to solve, or for the most part reduce, sets of problems which are at times of great clinical difficulty in which the algic condition tends to distort the meaning of the normal and also the meaning of being not only in its physical but also in its moral and spiritual terms.

At this point pain therapy establishes in the relationship between the medical doctor and the patient a new form of language that is individual and unifying in its uniqueness: this condition makes possible the acquisition and the interpretation of a special circumstance which is often of extreme gravity. In such situations the therapeutic treatment takes on not only the methodological meaning inserted at the most important moment of the protocol of a specific pathology but also seeks to favour the delicate ontological moment of the introjection of the ego in order to achieve a better understanding and acceptance of the person’s own physical and moral suffering.

Algology and Pain Treatment

The treatment of pain belongs to that branch of medicine – a real and authentic discipline that is relatively recent – known as ‘algology’. Thanks to this branch of medical science, preconceptions about the treatment of pain have been modified and it has been possible to adopt therapeutic criteria that are much less restrictive than was previously the case in the past.

Within the field of paint therapy directed above all else towards palliative care, on the one hand there has been the use and the spread of pain-killing pharmaceuticals, and on the other, in the countries of the European Community and in the United States of America, funds have been allocated for the creation of suitable hospital structures for the treatment of pain. Until a few years ago, the right not to suffer was discussed very little in Italy and the other industrialised countries. Yet it is specifically the facility of access to structures where forms of treatment involving pain relief are engaged in that constitutes the condition for a distancing of requests relating to euthanasia or assisted suicide from those who suffer from incurable pain.

One of the fundamental parameters, therefore, on which the model of assistance must be founded is made up of a diversified approach to the control of pain according to the actual needs that the patient generates, with the opposing of 'total care' to 'total pain' so as to deal in an adequate and appropriate way with the physical, mental and spiritual suffering of the person.

It should not be forgotten that the patient often tends to close in on himself or herself, to reject his or her condition, to isolate himself or herself from every communication with the outside world, and often to withdraw from his or her family context and to refuse contact with friends and acquaintances.

As regards the wonderful and fascinating relationship between the medical doctor and the patient, I would also like to emphasise that the patient who suffers from unbearable pain should totally entrust himself or herself to the medical doctor responsible for his or her case.

In such situations the medical doctor feels in a more incisive way the commitment to respond to this trust and these hopes. To this end, the medical doctor tries to use drugs and medicines that modern pharmacology places at his or her disposal in an attempt to distance the spectre of euthanasia which is increasingly present in a culture that seeks solely to achieve rapid solutions that involve criteria of 'efficiency' and forgets about the real needs of the patient in his or her totality.

The Principle of the Dual Effect

If we want to examine the obverse of the positive aspects of the coin of pain therapy we may observe that the crucial point of anti-pain therapy is at times made up of the lethal effects of a treatment involving the use of high levels of opiates that tend to hasten the death of the patient.

In this area, in order to free the medical doctor from ethical scruples about his or her professional conduct, appeal is made to the 'principle of the dual effect', on the basis of which consequences that would appear not morally unacceptable could be considered licit (and obtain free rein in practice) each time (beyond any assessment based upon probabilities) they are not assessed for what they really are (Rossi, L., 1961; Di Pietro, M.L.; Spagnolo, A.G., 1992; Honings, B., 2004).

It is obvious that the patient should be adequately informed about the risks that he or she could run and that he or she should give his or her informed consent, to the extent that this is possible, to what is done.

In referring to some important texts of the Church, we may observe that they refer in a clear manner to the practice of pain reducing or killing therapeutic activity in order to improve the conditions of suffering sick people. One need only think of the fundamental address of Pope Pius XII on the use of analgesics in order to reduce unbearable pain even when a shortening of the life of the patient in envisaged, or of the Apostolic Letter *Salvifici Doloris* (n. 5) of His Holiness John Paul II which emphasises that '*Medicine,* as the science and also the art of healing, discovers in the vast field of human sufferings *the best known area,* the one identified with greater precision and relatively more counterbalanced by the methods of 'reaction' (that is, the methods of therapy)'.

We know that every pharmaceutical involves, together with the hoped and wished for principal effect, at times also undesirable secondary effects whose appearance and scale are not always predictable. Precisely for this reason, rigorous and constant scientific study in a discipline such as the physiopathology and treatment of pain, which in the past was taught in very few universities, is important.

On this point I am happy to observe that the Faculty of Medicine of Florence has always had groups of researchers that are especially interested in algology because it has been demonstrated that in all the branches of medicine, but in pain therapy in particular, a half of the notions that have been acquired become obsolete within five years. This means that what a medical doctor learns during his or her university studies, has lost 75% of its validity ten years after his or her graduation.

Pain Perception and Anti-Pain Pharmaceuticals

For the student of pain, the discoveries made by neurochemistry in relation to pain perception have been of very great interest. From the discoveries of Hughes and Kosterlitz (1975) one understands very well that the first healer of the organism is the organism itself. This is because it is able, following a pain-inducing stimulus, to free substances that have a pain-reducing action. These substances are similar to morphine, they are the *endorphins*, and they create an endogenous analgesia.

In order to understand not only the mechanisms of pain and its control but also the mechanism of the action of anti-pain pharmaceuticals, we need to turn to the study of synapse. Monod defines synapse as 'the fundamental logical element of the nervous system', and it is precisely this element that allows the neurons to dialogue with each other.

Pain appears precisely when an alteration of the synaptic homeostasis creates an alteration in the communication between neurons. It is at this point that the therapeutic moment must take place in order to reestablish within the organism the balance that has been altered, and the anti-pain therapy will be that much more effective the more altered synapses it manages to place in harmony between the nociceptive system and the anti-nociceptive system.

Despite the advance in the knowledge of physiopathology and pain therapy, pain-killing pharmaceuticals in general, and the opiates in particular, even in the presence of unbearable pain, are rarely used by Italian health care workers (such that their administration in Italy is twelve times lower than is the case in Germany, thirty-two times lower than is the case in France, and one hundred and ten times lower than is the case in Denmark). The United States of America and Sweden are the first two countries as regards the use of pain-killing pharmaceuticals with a central action. Some medical doctors, even in the presence of pain that reaches the highest levels of intensity, tend not to administer opiates out of a fear of creating a *physical dependence (physical sub-*

ordination to the effect of the substance), which, in a patient subject to unbearable pain, can be due in part to the advance of the illness itself and in part to the appearance of the phenomenon of *pharmacological tolerance (habituation to the substance)*.

In the majority of cases there is a use of anti-pain therapies in an attempt to reduce pain, especially if it is very intense and prolonged, because this condition favours a positive acceptance of those special moments in illness that tend to foster an inner tranquillity and a trusting self-giving to God in prayer.

The data derived from the recent literature in the field are very comforting because they bring out that adequate pain therapy eliminates the requests for euthanasia on the part of patients: in Italy, in 2002, out of nine hundred cases of patients with severe pain because of cancer, only one asked to be helped to die, but this person banished this idea after suitable anti-pain treatment (Corradi, M., 2002).

When focusing attention on the therapeutic microcosm of our country, it emerges that in recent years the medical and political classes in Italy have wanted to eliminate this grave delay and have sought to make adequate use of anti-pain treatment along European lines.

This phenomenon should certainly be encouraged because there are no sustainable reasons to adopt an acquiescent approach to those who want their pain to be treated in a suitable way, not least because, unfortunately, we have to operate within a social reality strongly shaped by criteria of efficiency, which increasingly demands analgesic measures (the reduction of pain) if not, indeed, anaesthetic ones (the elimination of any feeling of pain).

The first element that the algologic medical doctor must take into consideration in appropriate pain therapy is the ability to be able to use methods for the *measurement of pain*, with which to assess the physical, mental and socio-environmental components of the experience of pain. The measurement of pain, assessed in a constant way during the anti-pain treatment, provides a measurement of the efficacy of the therapy that is engaged in and indicates any variations underway in the presence of the persistence of intensity levels (VAS) of very high pain (Scott-Huskisson,1976).

The treatment of pain in general, and within the framework of palliative care in particular, must bear in mind the possibility of using diversified approaches: the pharmacological, the cerebrally located, physiotherapy, and techniques involving a local anaesthetic block. Of all these aids, pharmacological therapy is the most common and the least aggressive, and is, therefore, the most suggested in cases of pain in many places of the body or generalised pain.

The Efficacy of Pain Therapy

At the present time medical doctors have instruments available, above all of a pharmacological kind, with which to address any kind of pain, even rebel pain, as long as in the anti-pain protocol certain inescapable rules are borne in mind. Such rules may be expressed with reference to the following parameters:

The administration of pharmaceuticals must be carried out in line with planned timetables and not according to immediate need, taking into account the fact that an organism can be compared to an electrochemical centre where nociceptive inputs arrive and leave and where algogenic and anti-pain substances are released that follow circadian rhythms that can bear upon the perception of pain, in a positive or negative way, according to the timetables of the administration of pharmacological treatment.

The doses of an analgesic pharmaceutical should be personalised because its efficacy varies from patient to patient. The optimal dose is the one that obtains identifiable clinical effects in an intermediary zone between obtaining adequate analgesia and not reaching high levels of toxicity.

The side effects and possible levels of toxicity should be treated systematically and immediately.

In the presence of pain at the highest levels of intensity a placebo should never be used because this is not right from a medical and ethical point of view.

The most correct and proven model of anti-pain therapy must be employed, which in the above all oncological field is the 'three level analgesic scale' proposed by the therapeutic protocols of the World Health Organisation (1986). In the first level, which corresponds to *light pain*, non-steroid anti-inflammatory (FANS) pharmaceuticals are used for a protracted period until such pharmaceuticals are effective in controlling the pain. In the second level, which corresponds to *moderate pain*, the therapist of pain uses FANS with so called weak narcotics (*codeine*). This treatment continues until unacceptably high levels of pain appear. The third level, which corresponds to *severe pain*, involves the use of strong narcotics, amongst which morphine, a pure agonist opiate, administered on its own or together with the FANS.

Non-Steroid and Opiate Anti-Inflammatory Pharmaceuticals

At this point, in order to understand more effectively the organisation of a correct anti-pain therapy, I would like to dwell briefly on the peculiarities of these two categories of pharmaceuticals – the FANS and the opiates.

The FANS are pharmaceuticals with an analgesic effect that is largely peripheral in its impact and connected with the well-known blocking action of the synthesis of prostaglandins. The identity of the mechanism of this action involves these pharmaceuticals being able to have collateral effects which are interchangeable at the level of quality and scale, such as gastric damage, the blood plaque anti-aggregation effect, the bronchial constriction effect, the possibility of causing diarrhoea, the possibility of bringing about sleepiness and phenomena connected with allergies.

The opiates, which are also called narcotics or drugs, produce analgesia by placing themselves on the receptor sites at the level of the central nervous system where endogenous opiate substances are also found (enkephalins, endorphins, dinorphins). Some opiates can act by activating this function (agonists) or blocking it (antagonists); others behave as agonists if used alone, or as antagonists if used with other opiates (agonists-antagonists). This last condition brings out that it is dangerous and useless to use more than one opiate in a therapeutic regime. The collateral effects of these substances are: sleepiness, nausea, vomiting, and constipation; in the case of an overdose there can be respiratory depression, dysphoria, and urine retention.

Another aspect that should be brought out in relation to pain therapy practiced with opiates is that of the phenomenon of dependency or tolerance. Dependency on opiates is a mental and physical phenomenon. The war now going on in Iraq has, unfortunately, brought out these two aspects very well. With some American soldiers, in fact, who habitually took opiates for psychological reasons (tension, fear of dying, being far away from family affection), it has been almost impossible to suspend the use of these substances because a *psychological dependence* had been established. Other American soldiers, who took morphine or other opiates because they were wounded or needed pain treatment, at the right moment could suspend the treatment without risking psychological dependence; at the most they risked incurring a slight *physical dependence*.

Patients with very intense pain are to be located in the second condition because the pain therapist can eliminate their taking of opiates in a gradual way when this is thought to be required by the clinical situation. This pharmacological explanation of opiates demonstrates that patients treated with such substances rarely end up with a psychological dependence. This condition, unfortunately, is the rule with drug addiction.

The other point that should be brought out as regards pain therapy is the phenomenon of tolerance. The *phenomenon of tolerance* takes place when an individual who has taken opiates constantly after a certain period of time enters into a kind of habituation as a result of which the same pharmaceuticals in the same doses are no longer effective and it is only possible to have the same initial results by increasing those doses. The mechanisms that lead to the establishment of such tolerance have still not yet been fully clarified and the same may be said of the way in which the speed with which this takes place varies from patient to patient.

Conclusions

In this study we have taken into consideration the fact that in pain therapy there is an *ab estrinseco* vision that is expressed in the treatment of illness and physical pain (*algos, to cure*), and an *ab intrinseco* vision which is expressed in taking care of the patient (*pathos, to care*).

In this move from immanent perception (*algos*) to transcendent reflection (*pathos*), each individual raises his or her own physiognomy from being *homo technologicus* to being a person who manages to live out his or her suffering in the dimension of hope.

In this sphere the reticent approach to the administration of pharmaceuticals by a medical doctor could be justified as long as such an approach is wanted by the patient alone. In this area we should allow the patient who wants to live out the moments of his or her suffering from a personal and Christian perspective the freedom to forgo the possibility of relieving his or her own suffering. This is because pain, in this case, takes on a valuable and salvific meaning as participation in the Cross of Christ, and thus can be freely welcomed (Congregazione per la Dottrina della Fede, 2001).

In conclusion, I would like to emphasise that beyond correct pain therapy each patient lives out his or her own experience of illness in a totally personal way in which that person's ethical and spiritual formation has a major influence on the result of the anti-pain treatment. This is because, as His Eminence Cardinal José Saraiva Martins says, 'the spiritual life places the believer in a continual situation of divine empathy' fostered by valuable instruments such as prayer (*Dolentium Hominum*, 2004).

As a proof of this, recently, in fact, clinical studies carried out in a rigorous way from a scientific point of view (with the recruitment of subjects according the random criterion; the blind study of subjects; and the assessment of data by statistical calculation), have emphasised how faith and prayer manage to strengthen the effects of pharmacological therapy by raising the pain threshold (Zucchi, P.L. and Honings, B., 1996; Zucchi, P.L., Honings, B., and Voegelin, M.R., 2001; 2003).

Given that the person-patient is a unity made up of *soma*, *psiche* and *pneuma*, the improvement in pain is obtained at all three levels – the physical, the mental and the spiritual. Our research group, in fact, managed to demonstrate that 1) patients who were believers had a higher pain threshold than patients who were agnostics, that is to say they perceive pain less (the faith effect), and have a better response to pharmacological treatment; and 2) patients treated with ethical treatment (prayer) had a better response to pharmacological treatment compared to those not so treated, whether believers or agnostics (the prayer effect).

From this study it was shown how the condition of faith (believers) and the instrument of prayer manage to modulate the perception of the stimulus of pain by positively influencing the effects of anti-pain treatment.

The physiopathological interpretation of this phenomenon lies, from a *neurophysiological* point of view, in the well-known theory of 'gate control' Melzack and Wall (*Science*, 1965).

Indeed, the condition of faith and the instrument of prayer are thought to foster the activation of descendant inhibitory fascias that modulate the condition of the nociceptive stimulus, thereby bringing about a lower perception of pain. From a *neuropharmacological* point of view, in a clinical state of severe pain, it is argued that the condition of faith in believers and prayer in believers and agnostics (who have *freely* accepted to follow ethical therapy *as well* (Zucchi, P.L. and Honings, B., 1996; Zucchi, P.L., Honings, B., and Voegelin, M.R., 2001; 2003) facilitate the release of endorphins – endogenous substances of an opiate nature with an analgesic action – that block the algogenic receptors at both a central and peripheral level (Hughes *et al.*, 1975).

From the study that has been carried out one can infer that a suffering patient can be helped in a *medical sense* (pharmaceuticals) and in an *ethical sense* (prayer) in eliminating, or at the least in reducing, the symptom of pain.

In subsequent research (Zucchi, P.L., Honings, B., and Voegelin, B., in press), our study group examined whether music could induce a strengthening of the pharmacological effects of anti-pain treatment in algologic patients. The results were positive and really encouraging (*Dolentium Hominum*, in press).

It is thus from this intersection and penetration between immanence (*soma* and *psiche*) and Trascendence (*pneuma*), present in the nature of man, whether a believer or an agnostic, that pain therapy, both pharmacological and ethical, can give an optimal result in each subject, as a person, precisely because he or she is a mysterious and fascinating creature made in the image and likeness of God.

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MAURIZIO EVANGELISTA

4. Palliative Care

Premise

Sensu strictu, palliative care is a subject that is not only medical in nature but is also, and above all else, a discipline that in its very implementation encounters man in his totality and thus acquires a philosophical, spiritual and anthropological character. Even more, palliative care is directed not only towards the individual as such but forms a part of a familial, professional and social whole.

Palliative care is thus a discipline with intrinsic and structural characteristics of a complexity that derives from the factorial multiplicity of all the components that determine is character. In this sense, this paper is a good opportunity to expound – in a way that is integrated with the other papers of this volume published by the Pontifical Council for Health Pastoral Care – certain basic concepts about palliative care.

Where the reader thinks this is opportune, he or she will have a possibility to explore in greater detail the aspects that he or she thinks are worthy of greater development and analysis by consulting the bibliography that is given at the end of this paper.

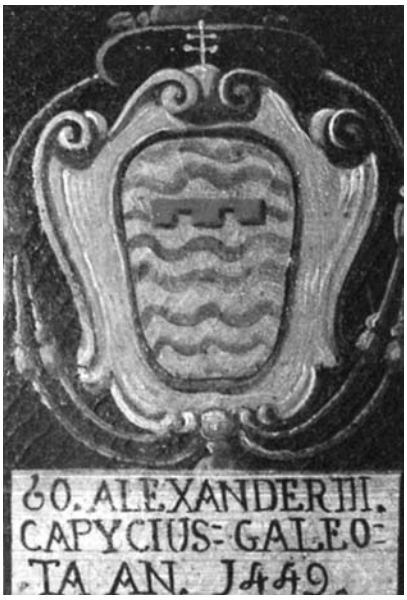
Palliative care is a potential instrument by which to implement important forms of synergy through which – seeing the encounter between Hippocratic humanism and Christian humanism as a decisive factor in achieving progress towards a civilisation increasingly worthy of the name – it becomes possible to apply this anthropological vision, where this is possible, to people of different cultures and religions and to find a moment of synthesis and practical sharing. From this base, through an increase in the already rigorous attention that is paid to this grave and urgent problem that calls upon medical research and science, there can derive that inspiration and that motivation that can lead to a better expression of service to the person through caring for suffering and commitment to an emphasis on the centrality of man, respect for life and its unconditional defence, in each person's specific context and daily life.

Above all else during that stage of an illness when it is no longer possible to practice proportionate and effective forms of therapy, and when there is an obligation to avoid all forms of therapeutic stubbornness or exaggerated treatment, that we encounter the need for methods of palliative care which, as the encyclical *Evangelium Vitae* observes, 'seek to make suffering more bearable in the final stages of illness and to ensure that the patient is supported and accompanied in his or her ordeal' (65).

Historical testimony attributes the birth of palliative care to 238 BC when the Emperor Asoka built a refuge for the dying in Varansai near to the Ganges. In Western culture the specific concept of a 'hospice' advanced during the Medieval period because of the work of the Fatabenefratteli who were moved by the need to offer a place where adequate spiritual assistance was provided together with medical care and treatment.

In 1960 Lady Cecily Saunders, observing, interpreting and addressing this need, renewed these principles and in 1967 she inaugurated the St. Christopher's Hospice in London. This occasion was a propitious and practical opportunity to emphasis the treatment of pain during the final stage of life and to stress the need, within a hospice organised along modern lines but going far back in history, *to link medical technology and science with compassion and the humanisation* of a form of medicine whose approach must be focused on the patient. The highest merit that can be ascribed to this action of Cecily Saunders is to be identified in the fact that she encouraged research directed towards the understanding of the basic mechanisms of the physiopathology of pain and as a result secured the achievement of specific advances in the treatment of pain as well. From this important focus of the scientific community, there derived the famous and widely read book entitled 'Cancer Pain Relief' which was published by the World Health Organisation (WHO) in 1986, and the organisation of the therapeutic scale of the WHO, an instrument that is universally known and still today unsurpassed because of its ability to be applied in all types of health care situation.

Despite the exponential growth in palliative care that has taken place over the last thirty years, the discrepancy between what is avail-



able and what is needed remains, unfortunately, a dramatic and current reality.

According to the definition of the National Council for Hospice and Palliative Care Services WHO-OMS 1990, which was subsequently modified by the Ministerial Committee on Palliative Care of 1999, palliative care is still that care that is intended to improve quality of life rather than to control the course of the illness. In addition, palliative care upholds life and sees dying as a natural event; neither accelerates nor delays death; provides for the relief of pain and other disturbances; integrates the psychological and spiritual aspects of assistance; helps patients to live in an active way until their deaths; and supports the family during the illness and during mourning. Furthermore, palliative care is characterised by the overall character of the intervention which, because its objective is the quality of life that remains, is not confined to the control of physical symptoms but also extends to psychological, relational, social and spiritual support; a positive appreciation of the resources of the patient and his or her family in addition to those of the social context to which they belong; the multiplicity of the professional and non-professional figures that are involved in the plan of care; full respect for the autonomy and values of the sick person; a strong integration into, and full membership of, the network of health care and social services; the intensity of the forms of care, which, indeed, must be able to provide rapid and effective answers to the changing needs of the patient; continuity in care until the last moment of the sick person's life; and the high quality of the services that are provided.

One of the subjects that is most discussed within the scientific community relates to the identification of the most suitable moment to begin forms of palliative care. According to a strictly medical point of view, such forms of care should be begun when the therapies designed to control the course of the illness are no longer effective and it is no longer realistic to prolong the life of the patient: such forms of care have the principal task of improving quality of life. This means the control of pain in its various aspects, of the physical disturbances that accompany the advance of the illness, and the offer of psychological support to the sick person and to his or her family relatives, with the aim of avoiding their isolation and loneliness and reducing their spiritual suffering.

Another point of view in this field is directly derived from observations and calculations that have an epidemiological origin: beginning with the assumption of a hypothesis as to the future that can be generally shared and which envisages that for the period 1990-2020 there will be a progressive increase in the proportion of the population that will be over sixty-five years of age, it may be estimated that there will be a proportionate increase in the number of chronic-degenerative pathologies that will affect the *quoad valetudinem* rather than the *quoad vitam* of a large part of the world's population. In other terms, it is plausible that an increasingly large number of people will be affected by chronic pathologies whose epiphenomena could compromise their quality of life. On the one hand, these considerations require, at the level of health care policy, the drawing up of new strategies directed towards provide new and suitable responses to new emerging needs; on the other, they justify a return (which is already underway) to the original philosophy and the initial impulse of palliative care, which is beginning to be applied not, as was previously the case, only to terminal cancer patients or cancer patients who are about to be terminal, but also to those patients affected by grave pathologies that involve a current and future decline in the quality of life that remains to them.

Palliative care, therefore, is addressed in an active and total way to patients afflicted by an illness that is not necessarily or exclusively oncological in character, which does not respond in a total way to specific forms of treatment, and whose direct and ultimate consequence is death. The control of pain, of other symptoms and of psychological, social and spiritual aspects, is acknowledged as being of fundamental importance and the fundamental purpose of palliative care lies in achieving the best possible quality of life for patients and their families. Quality of life is a concept that is directly derived from that definition of health which holds that health must be understood not only and no longer as the mere absence of illness but as a state of complete physical, mental and social well-being. Supplementing the definition of the World Health Organisation with a holistic vision of man, one can state that to these aspects should be added the spiritual dimension, adding the conclusion that quality of life is a subjective perception that an individual has of his or her own position in life, within the context of a culture and a set of values within which he or she lives, in relation as well to his or her own goals, hopes and concerns. Quality of life thus involves a homeostatic and dynamic concept with a broad spectrum of meaning that can be modified in an overall way by the subjective and contingent perception of one's own physical and psychological-emotional health, by one's level of independence, by one's social relations and interactions with one's specific environmental context, including the capacity of the patient to attend to his or her normal daily activities, the management of his or her own social roles, alteration in cognitive capacities, the psychological symptoms connected to his or state of illness, social and familial support and the socio-economic consequences of his or her illness. It is thus possible to state that the concept of quality of life is a highly individual concept. Indeed, if on the one hand some patients are more worried about physical symptoms such as pain, in others greater attention is focused on the specific impact of their illness on their daily lives. Yet others may be worried by the uncertainty of their situation because of religious or spiritual beliefs of because of the impact of their illness on their family relatives. The point of view of the patient is of fundamental importance and can differ from the point of view of the medical doctor or of the family relatives who are looking after him or her. A large number of scientific studies have identified a minimum common denominator in oncological patients: the need for communication with their families and medical doctors in order to address the disability, the pain, the worry and the depression that are connected with their illness. Very recent research has shown that such worries and needs are even greater in chronic patients during a specific stage of their illness, and this confirms the previous point. For this reason as well, at the present time there is agreement on the need to begin certain palliative measures earlier on in the course of the illness and at the same time as the etiological treatment that is administered.

From this point of view, the home of the patient as a place of care seems to correspond best to this objective, as also emerges from inquiries carried out into the sick people themselves. Indeed, hospitals are increasingly directed towards taking care of acute cases in order to up-date forms of treatment that have already been applied and towards the return of the patient and his or her circle to their most normal context. It is interesting to observe here that this concept is described in a complete and clear way with other words in the *Charter for Health Care Workers*: ‘A terminally ill person should be given whatever medical assistance helps us to alleviate the pain accompanying death. This would include the so-called palliative or symptomatic treatment… In this way human dying is withdrawn from the phenomenon of “being overtly medicalized”, in which the terminal phase of life “takes place in crowded and activity-dominated environments, controlled by medical health personnel whose principal concern is the biophysical aspect of the illness”. All of this “is being seen increasingly as disrespectful to the complex human state of the suffering person”’ (n. 117).

A personal alternative to being admitted to hospital is the hospice, a structure that is in general of small dimensions, which is able to accommodate about ten patients, in which the human relationship and psychological support are emphasised and health care action is in large measure directed towards the adaptation of the therapeutic protocols. But to a large extent this is an option that is limited. A hospice has structural characteristics and organisational forms that are specific to it and are different from those of hospital wards. It also has certain requirements that are held to be fundamental: it should be located in a protected area, be easy to get to and accessible, assure respect for the dignity of the patient through comfortable areas with special purposes, together with a personalisation of the rooms and the creation of living conditions that are similar to those of the patients’ homes, engage in a search for solutions that facilitate surrounding comfort and psychological well-being with shared areas for socialisation, have the possibility of accommodating family relatives, assure spiritual assistance where this is requested, care for the person, and promote activities involving entertainment and the provision of company. The philosophy of assistance of the hospice has remained coherent over the years: ‘the hospice believes in the importance of offering individual assistance, human contact and an interdisciplinary and multidisciplinary approach by a group of dedicated *ad hoc* workers. The hospice did not arise to meet all the requests for assistance and sees its goal in the implementation of a model of accompanying that is increasingly suitable and able to sensitise society and other health care institutions to the needs of these patients with the purpose of drawing up responses that are increasingly appropriate’.

In palliative care, reference is made to ‘total pain’ in order to emphasise its multidimensional character and to stress that pain cannot be treated without reference to its many aspects – the physical, the social, the psychological and the spiritual. The schema of total pain underscores the need for a multidisciplinary team that is well suited to meet a spectrum of extremely broad and variegated needs. Amongst these, stress should be laid on the need for spiritual assistance. Depending on the response on the person involved, this could become a pathway of faith: ‘the wounds of the spirit must be cared for, the patient must be accompanied in the search for the meaning of what he or she is experiencing, he or she must be helped to take appropriate ethical decisions, and in a way that respects his or her own way of living, his or her religious beliefs, and makes possible the practical expression of his or her faith’.

However, and the point should be stressed again, the home context should be favoured. Because the needs of this context are of a different nature, it is advisable to address them by using the specific skills and instruments of various professional figures: a multidisciplinary team should carry out periodic or urgent visits according to the requirements that arise. In addition, the team should seek to help in the control of physical disturbances through the work of people who are experts in palliative medicine, supplemented by those who are entrusted with psychological, social and spiritual support for the patient and his or her family. At a more detailed level, the medical doctor should install, identify and maintain communication with the family leader; in addition to engaging in nursing tasks, the nurse should control the efficacy of the therapies that have been prescribed, detect the presence of new symptoms or needs felt by the patient, support the family relatives, and assess the need to involve voluntary workers (voluntary workers have an important role through their collaboration with the team in giving the sick person and his or her family not only psychological help but also concrete and practical help. The Holy Father, at the time of the audience granted to those taking part on the nineteenth international conference of the Pontifical Council for Health Pastoral Care, defined their action in the following way: 'a valuable contribution through which, with their service, they give life to that creativity of charity that infuses hope in the bitter experience of suffering as well'); the voluntary worker has the task of keeping the patient company and replacing the family relatives for a few hours each day, and he or she is trained in active listening to the patient and the use of techniques of distraction and entertainment – the voluntary worker is also involved in the provision of support to the family relative during the period of mourning; the co-ordinator of the voluntary workers should organise the selection and the training of those who aspire to such responsibilities and allocates patients to them; the psychologist should support the team and train and supervise the voluntary workers; the social worker should identify and act in relation to the needs of assistance that may arise in relation to the patient and his or her family. The consultation of specialists in nutrition and rehabilitation is also envisaged on request.

In this way, the sick person and his or her family become the centre of attention of the various specialists who work together in a co-ordinated way.

One of the more relevant contemporary problems in the field of palliative care is the inability to provide adequate care even though such care is available. The genesis of this modern paradox is to be found in a series of cultural and ideological barriers that, when we look at them closely, obstruct, and often in an insurmountable way, the achievement of the primary objective of palliative medicine and hinder the patient and his or her family relatives from living out this period of their lives with dignity and quality. Of emblematic relevance here is the prejudice against the employment of oppioids. This is to be attributed to a series of barriers and beliefs that are very often based upon incomplete and out of date scientific and ethical knowledge. In daily professional life, one often encounters objections to the use of morphine and oppioids that are motivated by the erroneous belief that some religions prohibit the treatment of pain. Here we should remember what the *Charter for Health Workers*, published by the Pontifical Council for Health Care Workers, says on the subject in its section entitled 'The Use of Painkillers for the Terminally Ill': 'Among the medicines administered to terminally ill patients are painkillers. These, which help to make the course of the illness less dramatic, contribute to the humanisation and acceptance of death. This, however, does not constitute a general norm of behaviour. "Heroic behaviour" cannot be imposed on everyone. And, very often, "pain diminishes the moral strength of the person: sufferings "aggravate the state of weakness and physical exhaustion, impending the impulse of the spirit and debilitation the moral powers instead of supporting them. The suppression of pain, instead, brings organic and psychic relief making prayer easier and enabling one to give oneself more generously". "Human and Christian prudence suggests the use for most patients of medicines which alleviate or suppress pain, even if this causes torpor or reduced lucidity. With regard to those who are unable to express their wishes, one can reasonably suppose that they wish to take painkillers and these can be administered according to medical advice"… First, their use might have the effect of not only alleviating pain, but also of *hastening death*. When "proportionate reasons" so require, "it is permitted to use with moderation narcotics which alleviate suffering, but which also hasten death." In this case "death is not intended or sought in any way, although there is a risk of it for a reasonable cause: what is intended is simply the alleviation of pain in an effective way, using for that purpose those painkillers available to medicine"… The right to life is specified in the terminally ill person as "a right to die in total serenity, with human and Christian dignity."' These principles and notions were proclaimed by two Popes: Pius XII and John Paul II, in 1957 (Pius XII, 'To an International Assembly of Doctors and Surgeons, Feb. 24 1957', in *AAS* 49 (1957), pp. 144-147; 'To the Participants at a Congress on Neurophyschopharmacology, Sept. 9, 1958', in *AAS* 50 (1958), p. 694) and 1984 (John Paul II, 'To the Participants at the Congress of the Italian Association of Anesthesiology, Oct. 4 1984', in *Insegnamenti* VII/2 (1984) p. 749, n. 2; 'To Two Work Groups Set up by the Pontifical Academy of Sciences, Oct. 21 1985', in *Insegnamenti* VIII/2 (1985) pp. 1082-1084, n. 4).

In the encyclical *Evangelium Vitae*, lastly, there is a summary of the traditional doctrine on the licit and at times incumbent use of painkillers in a way that respects the freedom of patients who must be placed in the position, to the extent that this is possible, to 'satisfy their moral and family duties, and above all they ought to be able to prepare in a fully conscious way for their definitive meeting with God' (n. 65). On the other hand, whereas one should not deprive patients who so need it of the relief produced by painkillers, their use must be effectively proportionate to the intensity and the treatment of pain, with the avoidance of every form of euthanasia through the administration of large doses of painkillers with the specific aim of bringing about death.

It should be said that a good palliative care doctor must also be well informed about, and a good disseminator of, knowledge of this kind which at times is as useful as, and even more useful than, many laws which, on the basis of these beliefs, remain dead letters and do not combat a great deal of useless and unwanted pain. It is advisable to remember that pain not only decreases quality of life but also provokes further physical harm to the patient because of the immobility, insomnia and worry that it generates. In contrary fashion, the effective control of pain can lengthen life expectancy, even though this is not a specific objective of palliative care.

A hypothesis that is shared but difficult to apply involves palliative care beginning on the basis of needs and before the clinical situation becomes difficult to manage. The hope is that palliative care will be applied more broadly and also outside specialised teams, palliative care services and hospices. What, then, should be done? An ageing population displays new needs and requires a health service that is equally flexible in its monitoring and its responses. Traditionally, palliative care has been directed towards, and associated with, cancer patients, and this has induced the perception that its sphere of action covers only the last weeks of life, that it is the exclusive responsibility of specialist teams, and that it is engaged in when aetiological forms of treatment are no longer effective. In reality, patients and their families encounter a large number of problems during the course of many years of illness and require assistance well before the period of time that is usually indicated. In an approach that is consistent with current and future scenarios, the concept of the location in time of the forms of palliative care that are provided only during the final stage is no longer consistent with what is proposed by the large number of situations where patients need care immediately after the diagnosis until the final moment of their lives. Seen in such terms, it is evident that forms of palliative care should go side by side with potentially aetiological therapies and are more suited to the needs of the elderly population but also those of the younger population affected by chronic advancing pathologies. If it is true, as indeed it is true, that every individual has the right to receive the best forms of care and treatment possible during his or her illness and to die with dignity, free from pain and in harmony with his or her religious and spiritual beliefs, then it is right to posit, following the ethical principles of justice, equality and fairness, that palliative care should be extended to all those people who have the same needs, even though they are not suffering from cancer. Other important ethical principles are those connected with the form of supply, choice and implementation of care by the sick person. A very sick person or a person afflicted by a grave chronic pathology should be respected in relation to his or her beliefs and his or her values. Such people vary greatly both as regards their readiness and their capacity and will to speak openly about their illness and its prognosis, about the needs that they would like to see satisfied, about the level of the control of symptoms that is thought to be adequate, about the measures that they would like to see implemented, and about who they would like to be treated by. Health care workers should take these aspects of the individual and his or her family very much into account and should involve patients in the decision-making process. This requires sensitivity to the person and his or her values, empathy, the capacity to communicate with people, and to involve people, where they so wish it, in choices about their forms of care and treatment. In this area, an increasing amount of research demonstrates that patients prefer to share in the decisions about the palliative care they receive. Most studies have shown that about 75% of those interviewed would prefer to die in their own homes, whilst amongst the chronically ill a percentage of between 50% and 75% expressed a preference for home-based care. Their family relatives and friends, with much lower percentages, prefer hospital-based care and treatment.

It is known to everyone that the structural development of contemporary society involves the presence of some groups of so-called vulnerable people who do not find, among other things, suitable responses to their needs or equal access to palliative care. In this field, the paradox of elderly people who do not have access to hospices or services of palliative care to the extent that they would want is typical. In addition, there is considerable evidence of an underestimation and inadequate treatment of *symptoms* such as pain in hospitals and health care structures, which, indeed, constitute the principal context of care for elderly people during the last years and months of their lives. Children and adolescents are a special group because of the devastating and debilitating impact of their deaths on families. In this case, the role of those providing palliative care is central in the attempt to avoid useless suffering, in sensitive communication and in the avoidance of future remorse on the part of relatives about the choice of forms of care, which, in itself, can cause suffering.

This is another one of the primary tasks of modern palliative care, together with the need to know about the cultural diversities of contemporary society which involve major variables between and within cultural groups: the level of autonomy that is desired, the wish to know the truth, and the way in which death and the rituals that accompany death are perceived.

Conclusion

A resolution of a legal committee of the European Parliament that was adopted in 1992 contains the following words: ‘many decisive advances have been made in this field. But a great deal still remains to be done, especially as regards spreading and extending methods that have already been effectively tried and tested. The task is great because many obstacles remain: the absence of a health care policy towards pain, the shortage of training in relation to health care personnel and those that deal with public health care, the fear that the medical use of morphine and other oppioids can be in opposition to the laws on drugs, the lack of the availability of anti-pain pharmacies, the low professional level of medical doctors in prescribing painkillers, the lack of economic resources for research and development in the field of palliative care, and a widespread cultural attitude that rejects death as a taboo and thus neglects to engage in efforts to address death and to humanise it’.

In other terms, as a form of respect for the individual and his or her dignity, the reduction of, or at least the making bearable of, his or her suffering is indispensable. It should be understood first and foremost to what kind of suffering reference is being made: the suffering of the sick person or the suffering of the people near to him or her or his or her family relatives. A gravely ill person changes the lives, the careers and the work of the people that in various ways are connected to that patient. In addition, it should be remembered that those who feel that they are near death experience suffering that is not only physical in character: they feel the loneliness of being without company during a difficult journey towards the unknown, and it is then, like no other time, that they would like to hold the hand of a friend, that they would like to hear the affectionate words of people they love, that they would like the comfort of a religious promise. Instead, they often become a number in a room in a hospital – those who really care for them should not leave them on their own.

And to support this I would like to conclude with the words of the Holy Father to be found in his apostolic letter *Salvifici Doloris* (8): ‘In itself human suffering constitutes as it were a specific “world” which exists together with man, which appears to him and passes, and sometimes does not pass, but which consolidates itself and becomes deeply rooted in him. This world of suffering, divided into many, very many parts, exists *as it were “in dispersion”*. Every individual, through personal suffering, constitutes not only a small part of that “world”, but at the same time that “world” is present to him as a finite and unrepeatable entity. Parallel with this, however, is the interhuman and social dimension. The world of suffering possesses as it were its *own solidarity*. People who suffer become similar to one another through the analogy of their situation, the trial of their destiny, or through their need for understanding and care, and perhaps above all through the persistent question of the meaning of suffering. Thus, although the world of suffering exists “in dispersion”, at the same time it contains within itself a *singular challenge to communion and solidarity*’.

Independently of his or her race, culture or religion, every suffering individual who makes this request is deserving of our engaging together with him or her in this challenge in the name of the centrality of man, for the defence of his dignity and his life, as, indeed, the Holy Father emphasised on the occasion of the audience granted to the participants at the nineteenth international conference of the Pontifical Council for Health Pastoral Care, 12 November 2004: suffering, old age, the state of being unconscious, and the imminence of death do not diminish the intrinsic dignity of the person, who is created in the image of God. Medicine is always at the service of life. Even when it is not able to combat a grave pathology, it devotes its energies to reducing suffering. To work with passion to help patients in all situations means to be aware of the inalienable dignity of each and every human being, even in the extreme conditions of terminal health.

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STEIN BØRGE HUSEBØ

5. Palliative Care: Dignity for the Dying

In the last century modern medicine made it possible to prevent and treat illness. Nevertheless, since the beginning of human existence people are born and people will die. A hundred years ago mean European longevity was 49 years. More than 50% of the population died before the age of 20. Today, in the industrialised world, more than half of us will reach the age of 80 years or more, and children account for fewer than 1% of all deaths.

During the last century birth and death became institutionalised. In all previous epochs, the home was the major arena of birth and death. In the 20th century, in all developed industrial nations, these events underwent a radical transfer to health-care institutions.

These changes have yet to reach most of Africa, Asia and Latin America, where the situation is still similar to that in Europe 100 years ago.

These demographic and social changes have had, and will increasingly have, a radical influence on all parts of society and on individual lives. Fewer children are being born. Mankind is getting radically older. In the year 2050 in many European countries, more than 35% of the population will have reached age 65, compared with 20% today. The number of persons aged 80 years or more will have increased by more than 100%. The number of persons over 90 years old will increase by more than 1,000%. In Italy, for example, it is estimated that the population will be 25% smaller in 2050, 50% smaller in 2100.

The transfer of death from the family to institutions is in my opinion the most radical social change of the last 100 years. Why? Previously, all families – children, adults or the old – had personal experience of birth, dying and death. Through this experience they knew that life is transitory, and that death is a central part of life. The presence of death at home and in everyday life was also a major reason for personal involvement in religion, art and philosophy. Today death is present in the minds and everyday life of our children, but in a different way. Through the media and television they will experience death and dying thousands of times in their childhood, but only the dramatic death: accidents, catastrophes, violence, murder, terror and war. On the other hand, hardly any of our children have experienced grandmother peacefully dying at home, with sufficient care from her closest, loving family, as in earlier times.

Modern medicine is a consequence of the modern society. The main goal of modern medicine is to use the knowledge won from medical experience and research to prevent illness and restore health. Progress has been enormous, but has had its cost. One obvious cost is the explosion of the healthcare budget. Equally obvious are the problems facing end-of-life situations, where continuation of life-prolonging treatment is connected with exploding costs and prolonged suffering of the patients. Several publications indicate that more than half of the costs of healthcare service in a person's lifetime are spent in the final 6 months of their life.

Like birth, dying means a struggle with major distress, pain and other troublesome symptoms. The difference is the duration and the motivation. Birth lasts hours and is connected with the strongest positive motivation of all: to give life to a child. The mother knows that her suffering will end with the birth. Dying lasts hours, days, months or years, and is often connected with fear, isolation, existential and spiritual crises, lack of communication, denial, grief and prolonged, unrelieved suffering.

This is the genesis of the modern hospice movement and of palliative care. During the middle of the last century Dame Cicely Saunders and other pioneers like Balfour Mount and Elisabeth Kübler-Ross increasingly focused and published on 'dignity for the dying'. The central message of this development has been acceptance of death as a part of life, availability of sufficient pain and symptom control when the patient needs it, open

and skilled communication with patients and relatives concerning the impending death, psychosocial and spiritual support for patients and relatives.

The central message from palliative care is: *When nothing more can be done, there is enormously much to offer.*

1968 Dame Cicely Saunders opened the first modern hospice, St. Christopher's Hospice in London, following the first palliative care unit, in Montreal 1972 (Balfour Mount). In 1989 the European Association for Palliative Care – EAPC – was founded in Milan. Today all European countries have hospice and palliative care programs, and they are increasingly spreading to all parts of the world.

The lesson learned from palliative care is that pain and suffering is a central challenge to the dying and their caregivers. More than 60% of cancer patients and 50% of patients with other diagnoses will face severe suffering in their last days, weeks or months of life. In most situations this suffering was ignored or insufficiently treated.

There are four main reasons for this malpractice:

– The fear and denial of death.

– Lack of competence – and the fear and myths regarding use of morphine.

– Lack of resources.

– The legalisation of euthanasia.

The fear and denial of death

Since the beginning of human existence man has feared the end of life. Today this fear is connected with denial. In the industrialised world many, if not the majority, live as if death and dying did not exist. This development is strongly supported by the institutionalisation of death and a belief, almost a new religion, that modern medicine and science can answer all questions. Medical schools hardly mention dying and death. Doctors learn to identify illness and promote health. Most of them feel more than helpless when their patients are dying. How can the dying receive palliative care when the healthcare system denies death's very existence?

Lack of competence, and the myths about morphine

Palliative care can provide proper pain and symptom control, skills in communication and ethics, psychosocial and spiritual support to the dying. But this competence and these skills must be taught to, learned by and examined in students in medicine, nursing and other healthcare professions. Even now, only a small minority of the universities and medicine faculties teach, practice and examine in palliative care.

A key question is the myths about morphine. Morphine has been described as: *God's gift to mankind.* Good palliative care is unthinkable without the skilled use of morphine, allowing the dying to go on living with good pain and symptom relief in their remaining days. The suffering terminal patient will not experience the problems of addiction. In these situations morphine will not shorten life, *au contraire* it will give the patient strength to live. When it is used with skill, the patient's quality of life will improve without negative influences on the mind.

Lack of resources

In the industrialised countries the majority of the dying will be 80 years or older. These old patients will at the end of their lives face denial of death and aggressive medical treatment in the hospitals, the only consequence being prolonged suffering before death at high personal and healthcare cost. They would have the best quality of life in their final years in their homes or in nursing institutions, but these options are more than often poorly organised or not available. This development is strongly aggravated by the facts that families are choosing to live apart and the birthrate is rapidly falling.

Mercy killing - Euthanasia

A major challenge in the well-developed industrial countries is the rapid development of legalisation of mercy killing or euthanasia. Today euthanasia, or physician-assisted suicide, is legalised in the Netherlands, Belgium and Switzerland, and in Oregon in the United States. More nations are expected to follow. The number of persons receiving euthanasia in the Netherlands each year is estimated to be 4,000, 3,000 of them on request. About 1,000 persons receive euthanasia without request. If all European countries developed the same practice as in the Netherlands, 250,000 persons in Europe would receive euthanasia each year, among them 60,000 without request. These figures are especially worrying because in the coming decades all European countries will face rapid ageing, with exploding costs of acute health care, and very limited resources for proper care for the weakest old people. The majority of persons receiving euthanasia without request are elderly patients, who, because of unconsciousness, illness or dementia, are unable to speak for themselves.

The postponement of human aging raises difficult questions for public funding and social ethics. Is it immoral for the old to want to go on living? Is euthanasia, as practiced in the Netherlands, Belgium and Switzerland, an act of mercy or simply society's answer to the burden of getting ill, frail and old?

And what about the severely ill, starving or dying in the third world? In most countries in Africa, Asia and Latin-America hospitals and acute wards are rare. The suffering and severely ill are cared for in their homes, and access to professional care, nurses, doctors, food and the relieving drugs is often non-existent or extremely limited. On the other hand, in these cultures birth, life, dying and death are totally integrated into the family, where they share what they have and give care and love to their frail or dying.

Palliative care, with its physical, psychosocial, spiritual and ethical perspectives should be offered to all of us, when our time has come, for aging, terminal illness, frailty and death, when we face suffering, loneliness or lack of care, whether we have families or not. The central question for all societies is how the weakest should be cared for.

Birth, life, dying, grief, love, afterlife and religion are not only connected, they are the key questions of our existence.

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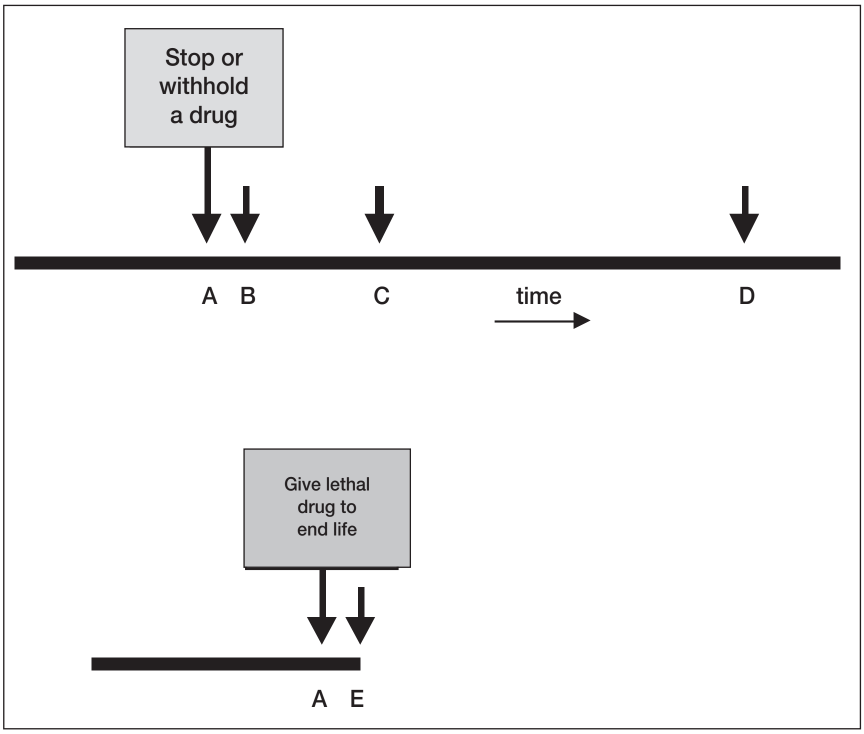
6. Euthanasia – What it is and What it is not

Euthanasia is the deliberate administration of a drug with the purpose (intention) of bringing about the death of a patient at his/her competent and persistent request. When the patient takes the prescribed lethal medication without help, the term 'physician assisted suicide' is used. However, this is inextricably linked to euthanasia because, if the patient for some reason cannot take the drug unaided, then they will request assistance. Additionally if the attempt to kill oneself through swallowing a lethal dose of drug, usually barbiturate, fails, then the patient is killed with a lethal injection.

Other terms, such as non-voluntary, involuntary and passive euthanasia, are used to describe the process of end of life decisions making, but the term voluntary euthanasia should be strictly reserved for the deliberate needing of a life at a specified and predicted time according to the definition above. It is misleading to attach the word euthanasia to these other situations. Involuntary euthanasia is the killing of a patient without their request – it is murder or manslaughter depending on the circumstances; it was practiced by the Nazis in the early 1930s when those with mental illness and disability were 'relieved of a life not worth living'. Non-voluntary euthanasia is the ending of a life at the explicit request of another – usually a close relative – but without the explicit request of the patient because they lack competence; again this is manslaughter.

Passive euthanasia is the most misleading of all the terms as it implies that the withdrawing or withholding of treatment always has the intention to cause death. However, this is a very different scenario when a patient is gravely ill; the disease process is taking them inexorably towards death. The stopping of medication may not bring about their death – indeed it may surprisingly result in a clinical improvement. It its worth remembering that during the doctors' strike in Israel, the death rate went down! Every clinician will recall patients who were thought to be imminently dying and surprisingly rallied the following day, just as there are many who seem to have a life expectancy of some weeks and suddenly die. The decision to withhold medication is taken on the balance of harms – if the considered intervention is predicted to be more burdensome or risky than it predicted benefits, then it should not be given. Such predicted balancing of benefits against risks and burdens requires consideration of the principle of justice, since with limited resources the use of an intervention on one patient may deprive another who has a greater chance of benefiting. Such is the decision that clinicians face when there are limited numbers of ventilators or other high technology or expensive intentions and brings the debate over end of life decision making into the arena of rationing. Although the outcome may be the same as in euthanasia – the patient's death – the fundamental intention is different and the decision making process is very different. However, even ceasing ventilation can sometimes result in the patient surprisingly starting to breathe spontaneously.

Some philosophers and ethicists disagree with this analysis, but theory and practice are differentiated by the subtleties of the clinical decision making process, not only the outcome. It can be useful to think about a patient as travelling down a path towards death. If treatment is withheld or withdrawn at point A the patient is predicted to die but the time is uncertain – it may occur at point B, C or D in the diagram below. So, the true prognosis cannot be accurately predicted, the disease is progressing and intervention may (or may not) alter course towards death. However if euthanasia is practiced the patient will certainly be dead within the time from giving the drug at time A and the predictable end-point of death at E. The sole purpose of the euthanasia is to kill the patient at their competent and persistent request; there is no room for life to continue.



So, euthanasia is not the withdrawing or withholding of treatment that has no purpose and affords no benefit to the patient as a person. The patient may live for a long or a short time after the decision, until natural death occurs, due to the underlying disease process. But, euthanasia is the deliberate administration of a lethal dose to cause certain death at a set time.

Different phrases have been used by advocates of euthanasia, as euphemisms for the process. 'Death with dignity' implies that the only way a person can die with dignity is to have euthanasia, yet the palliative care movement has been striving to try to ensure that everyone has a dignified natural death. The term 'right to die' has been used to describe the demand for a change in the law to permit euthanasia – however everyone will die inevitably so this is a universal 'right' – the advocates of euthanasia are asking for the right to be killed.

The term 'assistance in dying' has been used to describe the process – indeed it is in the title of the Bill – The Assisted Dying of the Terminally Ill Bill – currently before the UK Parliament at present. But, as the Royal College of Nursing have pointed out in their oral evidence to the House of Lords Select Committee that has been set up to examine this Bill, those in palliative care are like midwives. A midwife is present at birth to assist the natural process. Similarly at death the palliative care team are there to ease the natural process, not hasten it or defer it.

Prognosis prediction is notoriously difficult. All doctors have had patients under their care who look as if they are dying soon, but make a dramatic recovery, sometimes to live for months or years. Others who look as if they will live for months are dead in days or weeks. Any prognosis prediction based on probabilities is just that – it is a best guess from the data available but there is no accurate way of predicting the prognosis of a patient, even those with advanced cancer. In those with neurological disease or cardiac disease, it is even harder to even hazard a guess at life expectancy. Work by Paul Glare in Australia has demonstrated just how inaccurate prognosis prediction can be, even in advanced cancer.

When a euthanasia request is made it is crucial to be certain that the patient is not under duress and therefore that they are competent to make such a request. For consent to any intervention to be valid, it must be voluntary. The patient must be fully informed of the process and possible outcomes, including complications and must be able to understand the implications for him/herself and for others. There must be no distortion of thinking through depression, drugs etc. and the patient must be able to communicate the request.

Thus the very people that may be considered to be the most likely to 'warrant' euthanasia in society's eyes are the very people who are not eligible as they cannot make a valid, competent request. How often does one hear it said 'you would not let a dog be like that' of a patient who is demented or profoundly psychiatrically disturbed. But people are not dogs and those with impaired competence are the most vulnerable in our society and need to be protected form harm inflicted by self or others.

The way that a clinician, be it the doctor or nurse, communicates with a patient gives a very powerful message about the future for that patient. The patient is extremely dependent on the clinical team: they are the source of most information about the disease, are the ones who can provide adequate symptom relief if they have the knowledge and can be the access to all sorts of treatment. So the unequal position of power should not be underestimated. Unfortunately many clinicians have not had adequate communication skills training and are not as skilled as they should be at entering into two way dialogue with patients. Many spend far to much of the time in a consolation talking to the patient rather than listening to the patient's concerns; as a rule of thumb it is worth remembering that whoever provides a support service should listen for about 80% of the time and speak for only about 20% of the time on average in a consultation – the commonest complaint of patients is that they were not listened to. The culture of an institution also alters communication. In those teams where there is open communication, then communication with patients seems to be better. Those health care professionals who are able to talk about their own death are more comfortable talking with patients about death and dying – they are more able to allay fears and address concerns.

Patients who desire death often cite fear of being a burden to others as their main reason. This concern was exemplified by a group of patient in a study discussing issues of spirituality in advanced disease. They did not want to be a burden to their family. As one woman said: 'They have to live with it after you have gone and that's the hardest, what you have burdened them with is what they will remember'.

This concept of the family having to live with the memories they have of person as a patient, rather than when they were fit and healthy, is also very strong and motivates many to struggle on, not disclosing that they need additional help and support. Another woman described: 'My boy said – Why are you always laughing, why are you always smiling? – I said – Because I don't want you to remember me as miserable. I want you to remember me laughing and smiling'.

The burden of being ill weighs heavily on some patients, creating a sense of isolation: 'You find you can't talk to your family about your illness because they can't handle it. It becomes a burden that presses you down sometimes that you just want to scream and shout and tell them how you really feel. But you can't because they just can't cope with it. They are just about hanging on as it is'.

Dignity has been defined, by the founder of the modern hospice movement Cicely Saunders, as having a sense of personal worth. A perception of loss of dignity has been associated with desire for death as demonstrated by the work of Harvey Chochinov. Those patients reporting moderate or severe loss of dignity were more likely to desire death, had higher sense of being a burden and higher levels of anxiety. Their sense of dignity was highly dependent on the time of care given. Thus, again, the power of the professionals to influence how the patient views their life cannot be underestimated. Indeed, Chochinov has suggested that: 'Care that confers honour, recognised the deservedness of respect and esteem of every individual – despite their dependency, infirmity and fragility – could lie at the heart of care that conserves dignity'.

Amongst those who desire death to be brought forward, a few key characteristics emerge: these patients experience a sense of loss of connectedness to the world around them – they have experienced social death, where the roles they once had are taken by others and they feel society behaves as if they were already dead. They often fear the future, viewing it as holding more horrors than the present. They are profoundly influenced by bad past experiences, particularly if they have seen a loved one die badly even many years ago. Pain and other symptoms do not seem to be a major issue although profound weakness and fatigue are demoralising. Such patients often have great fear of being a burden; they may view the process of needing care as humiliating and may be experiencing poor care.

Interviews with patients who request physician assisted suicide in Oregon reveal the same picture as in Europe. Linda Ganzini reports such patients as being people who value control, dread dependence, and assess their current quality of life as poor. They have often been high achievers in life and find palliative care difficult as they deplore needing care. Additionally: 'Many tell of childhood experiences with unempathic and over controlling adult figures where they learned that receiving care from others is humiliating.'

These patients report higher levels of physical symptoms and psychological suffering than those not requesting death. The fear of being a burden and of care-giving needs is coupled with a sense of being demoralised by the process of being ill, by depression or both. They report less confidence in symptom control, fewer social supports and overall less satisfaction with life experiences. Those over 65 years of age are more likely to feel unappreciated than those who do not express a desire for death.

Kissane and other researchers have found that those desiring death are often depressed, demoralized or both. They seem to also have doctors who are demoralized by the process of giving care and are somewhat worn down by it, suggesting that the doctor's mood may be a powerful influence on the patient's perception.

Those who advocate euthanasia are often motivated by their own experiences in the past of seeing someone they love die in pain or in distress. Sometimes the pain and suffering in the observer are very great as the strength of their love makes the loss harder to bear. Indeed, it seems that suffering and love are intricately intertwined and perhaps 'suffering' in all domains outside the purely physical is in some way part of the human condition associated with feeling love.

It is worth considering what happens when euthanasia is legalised and how this alters medical care. It is legal and therefore deemed by society to be a potential good – so, when it is legal it becomes a therapeutic option. And as an option there is an ethical obligation on the clinician to consider offering it to every patient who is 'eligible'. We would not withhold antibiotics for an infection if the drug is available and the patient is suffering from an infection for which that treatment may be of use. The clinician looking after a patient with intractable symptoms may then be offered euthanasia as the physician is ignorant of alternative strategies for relieving the distress, rather than that the distress is truly resistant to all possible interventions.

In Australia in 1998 the Northern Territories introduced the 'Right of the Terminally Ill' Act, later to be repealed by the Federal Parliament in Canberra. During the time the Act was in existence, seven patients were considered as eligible for a life ending intervention and four of these had their lives ended by Dr. Nitschke under the legislation. One of the patients who life was ended believed she was dying of terminal cancer, but after death was found to have been effectively treated. Dr. Nitschke comment to the press, the *Sun Herald newspaper,* four years later is interesting – he considered that it was irrelevant whether she had cancer because 'the quality of her life was such that she thought death was preferable.' This describes a new form of honesty developing in society, where the patients wish to die becomes the pre-determinant of their eligibility to be killed as their continued living is causing to great a degree of suffering for them. It would appear illogical to therefore restrict euthanasia to the terminally ill who are going to die imminently anyway and to deny it to those who have made a rational suicide decision for whatever reason. At present in our society there are those who desire death and attempt to take their own life but are not suffering from a terminal illness and they are subject to psychiatric treatment, sometimes under compulsion.

In Oregon the law allows physician assisted suicide. Patients should have a prognosis of less than six months, although in fact only ¾ of those considered for physician assisted suicide fulfill this criterion. About one in six of those requesting physician assisted suicide receive a prescription for a lethal overdose and one tenth take the drugs. It is worth noting that significantly more of those who receive palliative care interventions change their minds than those who do not access such care.

Overall the evidence is that requests for physician assisted suicide or euthanasia are often not persistently sustained over time. Patients who request euthanasia are more likely than others to feel they have been poorly investigated, have poor symptom control, and/or lack of confidence in their doctors' ability and knowledge.

Evidence from the Dutch experience shows that there are complications associated with the process of ending life. Physician assisted suicide is usually by a massive barbiturate overdose, but some patients are unable to swallow the medication or vomit it back; there are also descriptions in the scientific literature of the drugs failing to induce coma and of patients awaking again after coma. When euthanasia is resorted to there can be difficulties accessing a vein.

There is also an impact on professionals involved in euthanasia. About ¾ of those involved in euthanasia report feelings of discomfort, described as feeling the process was burdensome, emotional and a heavy responsibility. One in twenty report subsequent doubts or regrets after the event. When life had been ended without an explicit request the proportion feeling doubts or regret rose to 11%.

In Holland there does seem to be an effect on society of the change. Despite the claim that legalisation would result in accurate reporting of such life ending events, it seems that still only about half all euthanasia/physician assisted suicides are reported. Some doctors have called for the duty to report to be removed as it is administratively burdensome on the doctor. It seems that the bias in thinking towards euthanasia and physician assisted suicide distract from other options in care, but as doctors learn more about palliative care they feel less need to resort to these life ending measures.

Different parts of the world have looked at the law in different ways. In Belgium the recently introduced legalisation of euthanasia has introduced the concept of a palliative care filter into the process. In France the debate in public reflected confusion between euthanasia and palliative care, but a committee of the French Government is due to report shortly.

It is of note that in the UK where palliative care is probably the most developed, over 95% of palliative medicine specialists do not want a change in the law to allow euthanasia/physician assisted suicide.

Some have described the principle of double effect as a covert form of life ending. This is untrue and those working in palliative care are clear that the evidence supports the view that giving morphine and other powerful drugs correctly does not shorten life – in fact it may prolong life as the patient is not exhausted through poor symptom control. With the concept of double effect, a predictable but unwanted effect of a drug occurs and results in the patient's death. Chemotherapy can be seen to have a double effect at times – it is given to destroy a malignancy but in some patients the fall in white count is so great that they develop neutropaenic sepsis and die from it much earlier than they would have done if treatment had not been given. However, in the context of symptom control, drugs such as morphine are titrated up to find the minimum effective dose to achieve therapeutic benefit – by contrast when the intention is euthanasia the drug is given in a massive and purposefully lethal overdose.

So to conclude, euthanasia is a seductively simple solution to the complex problem of suffering, illness, vulnerability and the way that a society responds to those requiring care. This is a complex issue for society. It is easy to make the case for the individual, but very difficult to establish the impact on (potentially) vulnerable people in the community of a change in the law to allow a doctor to kill a patient on the patient's persistent, voluntary, competent request. Perhaps it is worth remembering that no-one is isolated in their autonomy. Society is made up of people who all interact in one way or another.

Our living and our dying have an effect on those around us.

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FERNANDO ANTEZANA ARANIBAR

7. Legal Aspects of Forms of Palliative Care for Pain

In general, forms of palliative care are programmes for the treatment of patients at the terminal stage of their lives, programmes that have the goal of improving the condition of these patients through the overall control of their physical, psychological and social disturbances and the provision of support to their family contexts.

Forms of palliative care are active and total forms of care for those patients who are not responsive to curative forms of treatment. These are interdisciplinary forms of care that include the work of specialist medical doctors, nurses, social assistants, pharmacists and pastoral workers, amongst others. In addition to treating pain and symptoms, forms of palliative fare increase the scientific precision and the most valuable traditions of medicine: goodness, respect, enthusiasm, understanding and sympathy. Their goal is to obtain the best possible quality of life for the patient and his or her family.

The medical personnel that work in this field strive to control the set of symptoms of the patient, and in particular pain. In definitive terms, the intention is to avoid or at least to alleviate suffering so that these patients can live out their last days in the best way possible and when the moment arrives so that they can have a worthy death.

In some countries, patients with grave symptoms related to advanced cancer cannot be denied access to specialised and high quality care. For such care to be effective, however, certain conditions are required, and these include information on the time that remains to the patient, the certification of the medical doctor dealing with the case, and the wishes of the patient and/or his or her family regarding the state of the patient.

All of this is only possible if, in providing forms of care to the patient, attention is paid to all the details involved, which principally involves the application of the advances that are offered by technology and pharmacology for the treatment of pain and the other symptoms that accompany the terminal stage of life.

At times this requires a multidisciplinary treatment that includes not only various medical specialists but also a nursing staff and replacement and non-medical personnel. In the final analysis, it is the family, the medical doctor and other personnel who can have an effect comparable to that of a positive substance that has an immediate effect on the quality of life and the relief of the suffering of the incurably ill.

Forms of palliative care are increasingly becoming an option of medical treatment as well as a right of patients who are at the terminal stage of their lives. In this approach, medicine sees such forms of palliative care as intended to serve the patient and not the illness and it is advancing its required knowledge and skills in the field in order to provide the patient with professional and compassionate care until the end of his or her life.

The end of a patient's life is a natural and unalterable fact and must not be seen as a failure on the part of medicine; the end of a person's life, too, can be endowed with meaning and dignity.

In general, there are juridical frameworks that govern the clinical management of pain and as a result the administration of palliative cures as well. However, in many countries, and especially in developing countries, the legal aspects of these procedures are inexistent or rudimentary. Whatever the case, the ethical and moral concepts are those that allow the provision of legal aspects to the management of forms of palliative care that should always favour a better life for those people who are being subjected to intensive care or are at the terminal stage of their lives.

The government of conduct in this situation has always been a matter of belief or of law. Those people who believe in a god or share deep beliefs about the ends and means of human life obey the directives of inspired books or leaders who represent their beliefs. Those who refer to secular rules trust in law, in the traditional or written norms that envisage, declare or judge acts or intentions.

Between belief and norms, between faith and law, there exists a space that can be agreed upon through dialogue and a wise consideration of the circumstantial act or intention. This is a space of social relations and interests that exists between people and their worlds, an open space in which day after day new challenges arise and new dilemmas emerge, that is to say problems that create other problems. In this space, which is not three dimensional like the human body and things but multidimensional like the spirit, are created and recreated those social phenomena that we call life, illness and death. Each community creates, destroys and recreates these in a complex set of beliefs, norms, customs, habits, expectations, ideals and myths.

The medical doctor who is responsible for the incurably ill is not obliged to use extraordinary means for the artificial preservation of life. In these cases, whenever this is possible, he or she will listen to the views of other professionals in the medical field. The way things are managed will develop the contents of this dialogue.

In the same way, it is of fundamental importance to realise that the entrance and stay of patients in intensive care units must be subjected to rigid of norms of assessment so as to avoid the unjustified, useless and wasteful use of these services for pathologies that do not need them and the provision of assistance to the incurably ill during the final stage of their suffering. For this reason, the terminal patient must be received and treated in the most suitable place possible and by those people who can offer him or her the greatest benefit during the last part of his or her life. An intensive care unit is probably the place that is the most unsuitable for this.

The most important criteria as regards priorities for the entrance of patients into intensive care units can be summarised as follows:

Patients who have chances of a definite recovery; critical patients who cannot be treated by a service other than an intensive care unit because of the condition they are in; an urgent need for life-support systems; and an adequate level of intellectual cognition.

There should be an absence of the establishment of priorities on the basis of sex, race, nationality, ideology, or social or economic position.

As regards the rights of the patient and his or her relationship with forms of treatment, the following two categories may be referred to:

Ordinary forms: all the drugs and medicines, forms of treatment and operations that offer a reasonable hope of benefit for the patient and which can be obtained and used without excessive expenditure, pain or other factors of inconvenience.

Extraordinary forms: the drugs and medicines, forms of treatment and operations that cannot be obtained without excessive expenditure, pain or other factors of inconvenience, and whose use does not provide a reasonable hope of benefit for the patient.

Admission to an intensive care unit involves the control of arrhythmias, the use of tubes, mechanical ventilation, the use of artificial organs, transplants, the monitoring of the invasive, artificial feeding, and the introduction through the veins of vessel-modifying substances.

In the same way, there are factors that notably influence the condition of the patient in relation to the professional team that is looking after him or her, amongst which may be listed: professional skill and expertise, the humanistic grounding of the medical doctor, ‘human’ relationships, a positive appreciation of the person and his or her dignity, the differences between a person and an individual, the ability to decide (responsibility), rational and appreciative judgements, a consideration of the family environment, conduct that is in line with ethical norms and principles, ‘the golden rule’, the trends towards privatisation, the limitation of economic resources, and the dehumanising effects of technology.

To a certain extent the following considerations form a part of the juridical frameworks, or in some case laws, that govern the management of the provision of forms of palliative care to people, taking into account that the right to life and health are fundamental aspects of any political constitution of a State:

The patient is the reason for the existence of health care institution and the provision of health care.

One of the worst forms of suffering that a terminal patient can endure is loneliness. The company of his or her family and of the medical team has an immense value.

Telling the truth to the patient is something that depends on his or her psychology.

Delaying the right of a person to die in peace and with dignity is to be seen as a counter-value and an aggravating factor if we thereby prolong his or her suffering and that of his or her family relatives and an increase in expenditure because of his or her illness.

The information that is provided to the family relatives of a terminal patient must be clear and suitable.

When an ethical and moral assessment of the foundations of palliative care with special reference to its general objectives is carried out, the following elements must be carefully considered:

The medical assessment of the patient, which should include the bases for an improvement in the condition of the terminal patient, the needs of the patient and the general forms of care that are offered.

The control of the patient’s symptoms, both those that are general and those that are specific: his or her gastrointestinal, respiratory, dermatological and edema symptoms, and his or her neurological and psychiatric set of symptoms.

As regards the management of

pain: the ascertaining of the fundamental origins of most of the problems of these patients that will be addressed through pharmacological treatment, the treatment of pain with neurological origins in babies or children afflicted with cancer, the treatment of pain in patients with AIDS and the management of pain in situations that do not involve usual forms of treatment.

Everything connected with care for the family both from the medical point of view and the psychosocial and human point of view should be analysed.

Taking all of this into account and bearing in mind the condition of the vulnerability of patients undergoing palliative treatment (principally for pain), as well as the condition of other terminal patients tormented by various forms of suffering, one can see the importance of the presence of a juridical-normative framework that addresses all the rights of these human beings and their access to various procedures and measures that allow them a more bearable life and lower levels of suffering, as well as a worthy death when the moment arrives.

It has to be recognised that the technologies in this field are advancing in a more dynamic and dominating way than the normative and juridical requirements, which, indeed, are often absent, in particular in developing countries. It is for this reason that ethical and moral principles are becoming increasingly relevant and necessary in relation to everything connected with palliative care.

Respect for the life and the well-being of all individuals, and even more of the terminally ill, are universal principles of humanistic and spiritual co-existence. It is in these circumstances that a definition of health that goes beyond the mere absence of illness becomes more real, just as life clearly reflects the concepts of the psyche and the body and the spiritual dimension of life itself.

As a corollary that offers a human vision with ethical and moral considerations that rise above the legal frameworks that exist in various societies, I would like to quote what Pius XII had to say, namely that 'human life exists as long as the vital functions – which are distinct from the mere life of organs – can express themselves spontaneously, without the help of measures that support it. Medical doctors are not obliged to continue in the use of extraordinary measures to keep a person who cannot be saved alive'.

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II Section

Illumination

JESÚS CONDE HERRANZ

1. Palliative Care: Origins, Precedents and the History of a Christian Approach

I. INTRODUCTION

1. Preamble

I would like first of all to make clear that I am not a historian but a minister of pastoral care in health. This is because I was the first Catholic chaplain of a large hospital in Madrid, Spain, a hospital that belonged to the National Health Service of that country. Over the last twenty-five years, as an episcopal delegate of the Archdiocese of Madrid, I have been the director and coordinator of the sector of ecclesial pastoral care. You will thus understand that history as such is not the direct subject of my vocation or my work. However, I can and must add that history has always interested me a great deal, in particular the part that refers to the various questions and issues connected with pastoral care in health. This is because I believe that this history is one of the inescapable enlightening keys by which to understand and direct in a correct way my Christian, ecclesial, presbyter and pastoral responsibilities in the fields in which the Church asks me to reflect and act in her name.

With respect to palliative care, my interest in its history reflects both my direct pastoral work for over twenty years with the terminally ill, with their family relatives and with the personnel that look after them, and my personal contribution to the birth and first steps of the *Sociedad Española de Cuidados Paliativos*[1] (Spanish Society for Pastoral Care), of whose managing committee I was a member from 1992 to 1995.

2. The history of palliative care: lights and shadows today

As far as we know, palliative care has had a very brief historical existence, about thirty-seven years, but during this very brief period it has been acknowledged as the most thoughtful, complete and effective response that can be given at the beginning of the third millennium to the needs of assistance required by the *moment of death* or, in other words, the *terminal stage* of the life of a patient and the people looking after him or her during this period.

Specifically because of this short chronological age, the history of palliative care has not been sufficiently investigated or written about, as far as I know, from an overall perspective in relation to its birth and development in the various countries and regions of the world where it has been introduced. Nor has it been investigated or written about from an all-embracing point of view, that is to say in a way that includes all the aspects of assistance that are involved – at the level of practice and law – in this form of care.[2] And lastly, there has not even been a coherent and detailed investigation of its origins and its precedents, which are very important, in my opinion, if we want to understand the usefulness and necessity of its emergence during the 1960s and its subsequent evolution until the present day.

These are my general views after finding and reading the literature that I managed to gather on the subject under question. My aim, as a person who looks at history from the point of view of the pastoral work of the Church, is only to call attention to one of these views, which I will refer to below, so that other people, who are certainly more expert than I am, will feel led to address the question in greater depth if, as I hope, they think that it is sufficiently interesting.

3. The history of palliative cure, the Christian tradition, and pastoral care in health

I will seek to demonstrate the close connection that exists between many of the special forms of assistance that bear the ‘classic’ definition of palliative care accepted in Europe today, and the very many developments that, from its origins, have characterised the sphere of the Christian tradition that we today call pastoral care in health.[3] As I believe I can demonstrate, the history of palliative care has a great deal to do with pastoral care in health and this is one of the aspects that, in my opinion, has been only slightly analysed and emphasised by historians, even within the contours of the Catholic Church. My thesis is that in having to explain the origins and contemporary development of palliative care, reference to the history of pastoral care in health is decisive and inescapable, even though, obviously enough, it is not the only reference that should be made.

Before entering in detail into the question, I think that it is advisable to recall the above-mentioned 'classic' definition of palliative care. This was given in 1991 by the Sub-committee on Palliative Care of the Europe Against Cancer programme, which was based upon a document of the previous year of the World Health Organisation whose title was 'Cancer Pain Relief and Palliative Care'.[4] That definition reads: 'total, active and continual forms of care for patients and their family relatives, provided by a multidisciplinary team when the medical expectation is not a cure. The aim of the treatment is not to prolong life but to improve as far as this is possible the conditions of the patient and his or her family relatives, meeting physical, mental, social and spiritual needs, and, where necessary, the extension of support to the period of mourning'.

II. THE ORIGINS AND HISTORICAL PRECEDENTS OF PALLIATIVE CARE

1. In the ancient Greek-Roman world

a. *The forgoing by Hippocratic medicine of any curative treatment for patients held to be incurably ill*

In the Hippocratic work *De arte* we find illustrated in an eloquent way the refusal by the first form of scientific medicine in the West of what we now call *exaggerated treatment*. This is what this work says on the subject: 'medicine has as its goal freeing sick people from their pains, alleviating the grave attacks of illness, and abstaining from treating those who are already dominated by illness, given that in this case it is known that the art is unable to do anything'.[5] This 'abstaining' was based upon the net distinction between illnesses that were *tiquéticas*[6], or produced by the case, and *ananquéticas*[7] illnesses or inevitable death. The first could be treated by the *l'ars medicina*, or τεχνη ιατρικη *(tekne iatriké),* whereas the application of treatment to the second, as well as being useless was also a sin against nature.[8] The idea of not prolonging life at any cost expressed by the definition of palliative care here encounters its clear and first antecedent.

However, there is no element that can allow us to affirm that within Hippocratic medicine there was a kind of specific and specialised form of assistance for the incurably ill and the dying. This kind of assistance would begin to be thought of and promoted within early Christianity.

b. *The beginning of thinking about forms of care, beginning with the myth of Cura*

This myth, the story of which displays historical echoes and contains a number of coincidences with that of the creation of the world that is to be found in Genesis 2:1-7, appears in the *Book of Fables (Fabulae)* of Iginus[9] and today is seen as one of the historical roots of the anthropology of *care* and its subsequent practical translation into forms of assistance. The following is the text of that fable: 'When crossing a river Cura saw claylike mud, picked it up in a thoughtful way and began to shape a man. While observing what she had done, Jove arrived. Cura asked him to bestow life upon the statue and Jove carried out her wishes without any difficulty. But when Cura wanted to give him her own name Jove prohibited this and said that his name should have been given. While Cura and Jove were discussing the question of the name Telos also intervened and said that the creature should bear his name because he had provided the body. Saturn was chosen as judge, who it appears gave a just judgement: 'You, Jove, because you gave him life will have his body! Because you shaped him to begin with, Cura, you will have him as long as he is alive; but given that a controversy arose about the name to be given him he will be called man, because he is made of humus, which means fertile soil'.

The important thing about this mythological figure as regards the subject that I am addressing in this paper is that it presents Cura as a reality who originates the human being and accompanies him throughout his life.[10]

2. In the vision that Holy Scripture offers on the process of death[11]

a. *The book of Qoelet*

The observation of this wise man of Israel who states that there is 'a time to die' (Eccl 3:2) is a milestone in the human and Christian awareness that dying is not a mere inescapable prelude to death but a real *time* or stage in the life of men, indeed the last time: a time when men need assistance directed not only towards care of the body but also overall and integral help *in dying well.*

b. In the Gospel accounts of the death of the Lord

Both in foreseeing his death and during its immediate approach, the Gospels attribute to the Lord the same words, words that would constitute a theological illumination and a stimulus for pastoral action directed towards the promotion of a *good death* for the Christian tradition that would come afterwards. I will briefly choose those phrases of Jesus whose contents reflect in an incipient way the approaches and developments that are also present in contemporary palliative care.

What does it profit a man if he gains the whole world but loses his soul? (Mt 16:26) This phrase, which is part of a declaration when Jesus for the first time announces his passion and death, indicates, among other things, that dying is a *kairós,* a suitable time for human life to achieve completion, which is favourable or unfavourable, humanising or dehumanising, with fullness or marked by degradation. Two thousand years later, Dr. Kübler-Ross, one of the two pioneers of palliative care, significantly entitled one of her books 'Dying, the Final Stage of Growth'.[12]

My soul is very sorrowful, even to death; remain here, and watch with me (Mt 26:38). The request for company and support that Jesus made to his disciples at Gethsemane clearly had an influence on the awareness on the part of the first Christian communities of the need *to assist*, that is to say *to be near* to those who are drawing near to death and to assist them with a series of forms of *care* that I will list in the next sections of this paper.

Here I would only like to add that the Gospel according to St. John,[13] the tangible depictions of 'Pity' in Christian art, and musical compositions such as the *Stabat Mater*, have been, and are, portrayals of the important function of accompanying that Christianity attributes to the family and relatives of the terminally ill patient in the process that will bring him or her to death.

My Father, if it be possible, let this cup pass from me (Mt 26:39). The state of mind of Jesus is that of a person who is drawing near to his death and who asks God for a *palliative* in order to overcome this critical moment. St. Luke, in one passage (22:43ss) that parallels another passage to be found in Matthew, refers to an angel who *comforts* Jesus as he is *deep in agony* and sweating thick drops of blood.

It is finished! (Jn 19:30). In my view, with these words Jesus expresses the deepest purpose of forms of palliative care: to help those who are entering the final stage of their lives to reach the apex of their process of spiritual growth.

Father, into thy hands I commit my spirit! (Lk 23:46). With these final words, Jesus is he who teaches us how to die by completing his own life through the conversion of a feeling of being abandoned (cf. Mt 27:46) into one of unlimited trust (Lk 23:46), of the greatest injustice (Mt 27:23) into the greatest love (cf. Lk 23:34), of immense torture into immense tenderness (cf. Lk 23:43), and of the imminence of the end (cf. Lk 22:53) into hope in resurrection. A reference to the psychological stages described by Dr. Kübler-Ross,[14] and culmination in the stage of the serene acceptance of detachment from one's own life, here, in my view, emerge in a spontaneous way.

3. In Christianity during the first three centuries of its existence

It was during the first period of the history of Christianity that the ways of being and living in a Christian way that constitute the real seeds and roots of palliative care were most abundant. At a general level, and by way of comment, they seem to me to be the following:

a. *The Pauline idea of dying with Christ*[15] which led Christians to see death as a move with Christ towards Life, through his resurrection, and which led the Christian communities to provide forms of care so that the faithful were assured this paschal experience at the end of their lives. Since that time for a real Christian it is unthinkable to see the moment of death as a situation of forced loneliness; on the contrary, dying can and must always be, according to St. Paul, *dying in the company of Christ*.

b. *The vision of dying as a time of especial need for spiritual assistance.* This need was perceived very early on in terms of prayer, sacramental help in the form of the eucharistic Viaticum, or sacramental nourishment for the last period of one's life on this earth, reconciliation and the anointing of the sick, and what the historian Laín Entralgo defined as a sort of oral or psychological psychotherapy of a moral and religious character.[16]

c. *The explicit mandate to assist the incurably ill and the dying* faced with the technical and moral abstention of Greek medicine in such cases,[17] as I have already pointed out (cf. II.1. a).

4. In Christianity from the fourth century until the early Middle Ages

The initiatives to do with pastoral care and assistance that the Christian tradition engaged in during this long historical period and which form the basis of contemporary palliative care are (at the least) the following:

a. *The creation of hospices and hospitals*. I do not need to dwell for too long on this point because most of the historical studies on the origins and roots of contemporary palliative care have recognised this fact.[18] The ξενοδοκοι or hospices created by the Church from a very early date[19] to assist the sick and the poor and the subsequent appearance of hospitals (νοσοκομιοι), nosocomia[20] and monastic infirmaries,[21] are a clear prefiguring of the hospices that would be established in France, England and other countries during the nineteenth and twentieth centuries with the aim of specifically assisting patients with no hope of a cure and the dying, as I will demonstrate later in this paper (cf. II. 5).

For the moment it is to sufficient to add here that although the Medieval hospitals did not have a purpose that was directly clinical, being more of a charitable character, they were directed to all kinds of people in need (orphans, travellers, pilgrims, the sick and the poor) and everyone was provided with food and lodging. The first goal as regards the sick people who were admitted to these hospitals was, logically enough, that of treating them as best as possible, but given that unfortunately the therapeutic resources were not abundant many of these people inevitably died, even though they were cared for until their deaths and special emphasis was placed upon their spiritual recovery.[22]

b. The Christian tradition of cura animarum (care of souls), which received its first impulse with the *Regula Pastoralis* of Pope St. Gregory the Great.[23] This aimed at the spiritual care of people and especially of those who found themselves in grave situations, such as incurable or terminal illnesses. During its history within the framework of pastoral care provided by the Church, the tradition of *cura animarum* has promoted various kinds of care directed towards spiritual healing, such as compassionate consolation,[24] the sacramental celebrations of reconciliation, the anointing of the sick and Viaticum for the dying, and assuring personalised pastoral and moral guidance. Today, on the secular side of medical thought, the Christian tradition of *cura animarum* has begun to be appreciated once again as one of the most solid and inspiring historical foundations of the contemporary philosophy of assistance at the level of care and treatment.[25]

From the pastoral tradition of *cura animarum* derived two other characteristics of the Medieval period which predate contemporary forms of palliative care:

c. The task that Medieval physicians had of informing sick people, and not only incurable patients, about their clinical diagnosis and prognosis when a situation of pathological gravity was evident, and of inviting them to receive adequate spiritual assistance.[26] The prescribing of legal and economic sanctions for medical doctors who did not carry out this task is a clear sign of the very great importance that was given at the time to forms of spiritual care, which were seen as required and relevant in the case of gravely ill people.

d. The appearance and the spread of the *Ars moriendi*. Between 1403 and 1408, Jean de Gerson, a priest, professor and Chancellor of the Sorbonne,[27] published his work *Opus tripartitum* whose third and last part is given the title '*De arte moriendi*'. This is a text in which the process of death is described from the perspective of Christian spirituality. This work spread rapidly in France and was then translated into a number of languages; it was the first of many tracts on this subject that were published until the end of the sixteenth century.[28] From that period onwards, instructions for a Christian preparation for death continued to be listed as chapters in broader-based theological and pastoral textbooks or, to a lesser extent, as separate tracts.[29]

Beginning with the approach of this work, the pastoral literature on the *Ars moriendi* bears eloquent witness to the profound belief of the Church that *dying* and *helping to die* constituted a real art whose realisation was based upon intelligence and feeling helped by the grace of faith and the sacraments, which, together with the interpersonal pastoral relationship, made up the fundamental integrating elements of this art.

The influence of the *Ars moriendi* spread in the Catholic world in various literary and practical variations until the whole of the nineteenth century, an age when its purpose in terms of assistance, spiritual care and pastoral care crystallised in the practice of the hospice.

5. The establishment of hospices for the dying in the nineteenth and twentieth centuries

At this point we already find ourselves on the threshold of the history, in the strict sense, of palliative care, which was begun by Dr. Cicely Saunders who in 1967 founded the *St. Christopher's Hospice* in Sydenham, a district of London. This foundation marked the end of a stage that had begun over a century before and more specifically in 1842 in the French city of Lyons, when Madame Jeanne Garnier, with the help of two friends of hers who were widows, created[30] the *Association des Dames du Calvaire* (Association of the Dames of Calvary) whose aim was *to provide comfort and consolation to the incurably ill*. It was here, or so it appears, that the word 'hospice' was used for the first time to refer to taking care of the dying.[31]

This fact was not a chance event because in France ever since the high Middle Ages the *Confreries de la Bonne Mort* (Brothers of the Good Death) had existed, that is to say associations of volunteers charged with helping the dying at the moment of death as well as assisting their family relatives during the celebration of the funeral rites and the process of mourning. For their part, St. Vincent de Paul and St. Luisa de Marillas, as early as the first half of the seventeenth century, had promoted the creation of numerous hospices for poor people throughout France. The Daughters of Charity continue to engage in such work for the poor and the sick.[32]

Starting in 1843, the Association of Madame Garnier established hospice-type buildings in various cities of France (Lyons, Bordeaux, Marseilles, Saint Etienne, Paris) which were called di *Maison des*

Dames du Calvaire (Home of the Dames of Calvary). In Paris a home of this kind was established in 1874, in rue de Lourmel.[33] In 1899, basing herself on the work of Jeanne Garnier, Anne Blunt Storrs opened the Calvary Hospital in New York. It should be pointed out that these homes were established as institutions that provided care that was an alternative to that provided to poor patients in hospitals whose very bad conditions of hygiene and treatment meant that there was a real reluctance to die in such structures.

Without having a direct link with Madame Garnier and her *Dames du Calvaire*, but within the context of the tradition begun by the *Ars moriendi*, the Irish Sisters of Charity in 1879, in Dublin, founded Our Lady's Hospice, and later, in 1905, founded the St. Joseph's Hospice of London, the institution where Cicely Saunders worked and carried out research between 1958 and 1967, before, that is to say, she founded the St. Christopher's Hospice. The word 'hospice', both in French and in English, came to refer in a specific way to a structure for the care of the dying.

Following the approach and the intention of my paper, I think that it is advisable to emphasise the fact that during the last sixty years of the nineteenth century and during the first half of the twentieth century, a period when scientific medicine began and the then consolidated the bases of the great advances that it would achieve until the present time, it was above all Catholic people and institutions who were responsible for promoting initiatives involving the receiving, the accompanying and the care of the dying.

In 1948, once again in the United Kingdom, a charitable organisation, the *Marie Curie Memorial Foundation*, was created whose aim was to assist incurabile cancer patients in their own homes. In 1952, after the experience of following more than seven thousand patients in their own homes, a programme of continual nursing care at home and in nursing homes was adopted in an official capacity. This programme received the name of 'Marie Curie Cancer Care'. This programme began with the observation that the assistance provided to patients at an advanced stage of their illness did not meet the need to control pain and other symptoms, just as it did not meet their need for psycho-social, spiritual needs, and needs to do with information and other kinds of communication, not to speak of the help that was requested by families.

6. Other factors that influenced the origins of palliative care during this period

The first factor is related to the concept of the purpose of medicine and the second is connected with the figure of the sick person within the context of this approach.

a. In the middle of the nineteenth century, at a time of scientific-positivistic euphoria, two French medical doctors, Berard and Glüber, defined the fundamental mission of medicine with a phrase that would become famous a century later: '*Guerir parfois, soulager souvant, consoler toujours*' ('at times treat, often alleviate, always console').[34] This formula came to relativise and to limit the aspects that were purely curative of medical assistance and to open the door in a decisive way to forms of care.

b. During the second decade of the twentieth century so-called anthropological medicine emerged in Germany. This proclaimed, using the phrase of Viktor von Weizsäcker, 'the introduction of the sick person as a subject into medicine' and thus *produced the drawing up of a pathology that was clearly anthropological or biographical in character*. This was the work of von Weizsäcker and his collaborators and disciples.[35] This was another initiative – in this case within the field of scientific and academic medicine – that prefigured the inclusion of mental and spiritual aspects in the provision of assistance to sick people and of the forms of care required for such activity.

III. A BRIEF HISTORY OF PALLIATIVE CARE

1. The work of Cicely Saunders and E. Kübler-Ross

During the 1960s and the 1970s these two women, who both engaged in research and led a Christian life, attracted the attention of the health care world and public opinion generally to the importance of assisting the dying and stressed the placing of spiritual and religious care within that care.

a. In 1967 Cicely Saunders founded the St. Christopher's Hospice in London and this became the centre of promotion of a new form of understanding and assisting the terminally ill, namely 'palliative care'.[36] Cicely Saunders had begun to be in contact with the terminally ill during the years 1941-1958, a period when she worked as a volunteer at the St Luke's Home for the Dying Poor, a home for the dying run by female religious in Bayswater, London, and from there, between 1958 and 1967, she went on to work at the St. Joseph's Hospice of Irish nuns, which was also located in London.

Cicely Saunders decided to give this direction to her life because of her Christian faith. She felt that this was a way of thanking God for her conversion which, in 1945, had led her to draw near to the Gospel. In addition, her meeting and conversations with David Tasma, a Polish Jew from the Warsaw ghetto who was afflicted with incurable cancer, and whom she begin to assist in a professional sense as a social worker in 1947, influenced her in a decisive way when she conceived what would soon become her hospice, an intermediate structure between a hospital and a home. David died in 1948 and at that time Cicely Sauders already knew what she would dedicate her life to from that moment onwards. In the statutes of the St. Christopher's Hospice we read: 'The St. Christopher's Hospice is based upon Christian faith in God through Christ. Its aim is to express the love of God in everything it touches and in every possible way: with the efficiency of medical and nursing care, the use of all scientific knowledge to alleviate suffering and discomfort, sympathy and personal common sense, with respect for the dignity of every person just as he or she is appreciated by God and men, without barriers of race, colour, class or creed.[37]

The book 'Caring for the Terminally Ill' was published in the late 1960s and was edited by Cicely Saunders herself,[38] who also published an article entitled 'Hospice Care' in the *American Journal of Medicine* in 1978. Lastly, we should also refer to the contribution of Cicely Saunders to pathological and clinical medicine's approach to the concept of 'total pain', and within the concept of total pain, the concept of 'spiritual pain' as well.[39]

b. In 1969 E. Kübler-Ross[40] published the first and most famous of her books: *On Death and Dying*.[41] This publication was the result of the assistance she had provided to the dying (direct assistance carried out at her level of work) and the research she had carried out on the basis of the thousands of interviews she had conducted with the dying in hospitals in New York, Colorado and Chicago. E. Kübler-Ross was born in Zurich in 1926 and she had always been interested in the spiritual world. Starting in 1945, her work focused on death and dying after she became a member of the International Voluntary Service for Peace, a body that provided help to communities that had been destroyed during the Second World War. In the concentration camp of Maidanek she discovered carved into the walls of the place where prisoners spent the last hours of their lives the butterflies that would later become the symbol of transformation into beauty that arrived at the moment of death.

After graduating in medicine at the University of Zurich in 1958, she went to the United States of America. Observing the forms of treatment that were employed for the terminally ill in hospitals in that country she declared: 'they were avoided and used – nobody was sincere with them'. Differently from many of her colleagues, she sat next to the terminally ill and listened to them. Gradually she began to hold conferences on the terminally ill and to explain that they talked to her about their most private experiences during this final stage of life. Later she would write: 'my aim was to break the professional habit of preventing the patients from expressing their most private problems'.

When she wrote *On Death and Dying* in 1969, her readers thought that her conclusions were totally revolutionary. Her sister, Eva Bacher, declared that 'Elizabeth was very proud of the fact that her work had helped to establish the bases of the Hospice Movement in the United States'. In the 1960s she ran thousands of seminars and gave a large number of lectures to small groups of people throughout the world. In addition, the five psychological stages of dying described in her book were accepted at an international level. As her influence grew, she linked teaching with periods of training in hospitals and medical institutions.

At the end of the 1960s she became the President of the Elizabeth Kübler-Ross Center and of the Shanti Nilaya Growth and Healing Center. In the 1980s she bought a farm of three hundred acres in Head Waters, Virginia, and transformed it into a centre for care and seminars which she then called Healing Waters. At the same time she turned her attention to helping children born with AIDS at a time when nobody was concerned about them.

She officially retired in 1995 and went to live in Arizona where, despite a body that was becoming increasingly weak because of grave disturbances and a fire that destroyed her home, she continued to receive hundred of vistors from all over the world. On 29 March 1999 *Time Magazine* named her as one of the greatest minds of the century and chose her from over a hundred personalities. She received more than a hundred *honoris causa* degrees from faculties and universities of the United States of America. With her lecturers and her writings she gave an impulse to change and progress in areas of such importance as living testaments, home care, and above all else helping the dying to die with dignity and respect.

At the end of her life she, too, looked at death in the face without fear, wanting to be faithful to her beliefs and declaring: when you die, life does not end, it begins. She died in the evening of Tuesday 24 August in Scottsdale, Arizona, surrounded by her family and relatives. She was seventy-eight years old.

She ensured that her own Christian roots were very evident in her constant striving to inculcate in patoral ministers her vision of dying and the importance of the provision of good spiritual assistance to the dying, as well as her positive view of prayer in the whole of this process.[42]

2. Groups of home assistance and the hospital departments for palliative care

a. Since 1970, in England, groups of home assistance called 'home care teams' have been making progress and have spread. This development is due to two cancer charities: the MacMillan Cancer Relief Foundation and Marie Curie Cancer Care. In 1997 the first had over 1,500 nurses and 160 medical doctors who were taking care of about 16,000 cancer patients in palliative care groups. In the same year, the female nurses of the Marie Curie Cancer Care were taking care of about 20,000 cancer patients, a number that constituted 40% of this category within the whole of the United Kingdom. In addition, this organisation had over 5,000 beds in hospices. Day-hospital centres and hospital supports have also began to develop rapidly.

In 1974 the Connecticut Hospice was opened in the United States of America and in 1984 the hospice model was introduced into the national health service of America (Medicare) which in ten years, prior to 1993, had grown to have 1,290 structures throughout the country. In 1994 the hospice-style services were looking after over 340,000 patients. However, the greatest development in palliative care in the United States of America has been expressed at a practical level in programmes of home care.[43]

b. In 1974 the Royal Victoria Hospital in Montreal opened the first service of palliative care which employed the term 'palliative' for the first time to refer to non-curative forms of treatment for patients with an advanced, progressive and incurable illness. Since that time, various countries have begun to develop palliative care units, and I will now give some examples of these.

In 1982 the first palliative care unit in Spain began its operations. It was located in the Marqués de Valdecilla Hospital of Santander and was the result of an initiative by Dr. Jaime Sanz Ortiz. The unit was recognised as such by the Ministry of Health of Spain in 1987. In the same year the second palliative care unit came into existence, this time at the Santa Creu Hospital of Vic,[44] Barcelona. Almost in the same period another palliative care unit was opened – in the El Sabinal Hospital of the Canary Islands, directed by Dr. Marcos Gómez, who was also the first great champion of the training of health care workers in palliative care in Spain.

Once again in 1987, the first palliative care unit in France was opened, at the Saint-Michel Hospital (Institute Mutualiste de Montsouris). Twelve years later, in 1999, a law of 9 June gave an official character to palliative care and established that '*toute personne malade dont l'état le requiert a le droit d'accéder à des soins palliatifs et à un accompagnement*' ('every sick person whose condition so requires it has the right to accede to palliative care and to accompanying').

3. Institutional recognition and support for palliative care

a. In 1973 the International Association for the Study of Pain (IASP) was created with the aim of encouraging research into pain and to improve the treatment of patients with grave problems connected with physical suffering. The association is open to researchers, medical doctors, dentists, psychologists, nurses, physiotherapists and other health care workers who are involved in research into pain or its diagnosis and treatment. At the present time this association has over 6,500 members in 170 countries.[45] The control of the symptoms of malign chronic pain in terminal patients received a major impulse from the creation of the IASP.

b. In 1986 the World Health Organisation published a document entitled 'Cancer Pain Relief'. This was intended to be a manual for the pain-killing treatment of cancer patients and laid stress in a particular way on the use of pharmacies, and more specifically opioids, in alleviating or eliminating pain.[46]

c. In 1987, in the United Kingdom, palliative medicine was established as an academic specialisation and an obligatory discipline in medical schools. Subsequently it was established as a subject of specialisation in Canada, Australia and Poland.

d. In 1988 the European Association for Palliative Care (EAPC) was established and in Paris, in1990, it held its first congress. The chief animator of this association was Dr. Vittorio Ventafrida who since the end of the 1960s had developed forms of treatment for pain in Milan even though the creation of the association involved professionals from all over Europe.[47] The European Council recognised this association as a non-governmental organisation in 1998. Today, the EAPC has members from forty countries in the world and is connnected with twenty national associations of European countries which represent about 50,000 professionals and voluntary workers who are involved in the field of palliative care.[48]

e. In 1991 the World Health Organisation published its document 'Pain Relief and Palliative Care' and on the basis of this publication the Sub-Committee on Palliative care, which is a part of the Europe against Cancer Programme promoted by the European commission, drew up the definition of palliative care which is quoted above (cf. I. 3).

f. In 1992 the National Council for Hospice and Palliative Care was created in the United Kingdom.

g. In December 2000 the national health service of Spain approved the *Plan Nacional de Cuidados Paliativos* (National Plan for Palliative Care). At the present time, Spain is the country with the most advanced development of palliative care in Europe after the United Kingdom.[48]

4. Other events and developments that have influenced the origins and the development of palliative care

a. In 1976 Ivan Illich published his book 'Limits to Medicine. Medical Nemesis: The Expropriation of Health.[50] It included two chapters, 'The Killing of Pain' and 'Death against Death', which greatly contributed to a humanising of the vision of clinical pain and dying in medical circles.

b. In 1982 the book by Carol Gilligan 'In a Different Voice: Psychological Theory and Women's Development'[51] was published. This addressed palliative care beginning with the perspective of the moral development of women, and during the 1980s and 1990s ethics directed towards caring and care developed under the influence of this work.

c. In 1992 the first edition of the *Catechism of the Catholic Church* was published and article 2279 of this work declares: 'Palliative care is a special form of disinterested charity. As such it should be encouraged'.

d. In 1993 the first edition of the *Oxford Textbook of Palliative Medicine* was published and this was the first academic and interdisciplinary textbook of this new discipline and branch of assistance.[52]

e. In 1993 as well Dr. Sherwin B. Nuland, professor of surgery and the history of the medicine at the University of Yale, published his book *How We Die: Reflections on Life's Final Chapter*[53] in which he describes, through a series of clinical accounts of various patients, the biological, mental, social and spiritual aspect connected with them as they gradually enter the process of death. The influence of this work has been very great.

5. The Catholic Church and palliative care

Here I will confine myself to the work of the Church in Spain which, obviously enough, is the work with which I am most familiar.

a. In September 1989 the Bishops' Conference of Spain approved the *Plan de acción sobre la Eutanasia y la ayuda a Bien Morir*, a plan which had been presented by the Department for Pastoral Care in Health.[54] In this document emphasis was placed upon 'providing information about palliative care' (1.2.3); upon 'the development of programmes of overall assistance for the terminally ill at home' (4.1.3); upon 'the drawing up of a protocol for the provision of assistance to the terminally ill' (4.1.5); upon the 'conversion of ecclesial centres so as to care for the terminally ill' (4.2.1.); upon 'promoting pilot schemes in relation to assistance for the terminally ill '(4.2.3); and upon 'supporting and stimulating the creation of associations of palliative medicine or palliative care' (4.3). In addition, emphasis was placed upon the dissemination of the '*Testamento Vitale*' as an instrument of evangelisation to promote the reality of good death amongst Christians.[55]

b. In 1991 the Pastoral Commission for Palliative Care was set up within the Department for Pastoral Care in Health of the Bishops' Conference of Spain. The commission has organised various national days directed towards health care workers and pastoral ministers in order to spread knowledge about palliative care and the encouragement of spiritual and religious assistance that should form a part of such care.

c. In 1991 as well the first programme of home assistance for the termimally ill was launched. This programme was based upon the philosophy and practice of palliative care and was promoted by the delegation of pastoral care in health of Madrid with the help of the association PROSAC (Christian Health Care Professionals) which is linked to that delegation.[56]

d. In April 2002, the St. John of God Hospital in Pamplona, Navarre, Spain, was entrusted by the autonomous government of the region to be a consultant in this field to the Autonomous Community. In the 1990s, the Hospital Order of St. John of God created a network of palliative care units, amongst which was the first such unit in Spain dedicated to pediatric palliative care. This unit was located at the *Hospital Sant Joan de Deu* in Espluges (Barcelona). To a lesser extent, such units have also been developed by religious of the Camillians.

IV. CONCLUSION

In this paper I have tried to show that it is not possibile to explain the origins and the development of palliative care without taking the historical tradition of the Catholic Church as a decisive and inescapable point of reference, and within that tradition pastoral care in health as well. I have sought to show that the roots and the historical antecedents of palliative care must be looked for above all else but not exclusively within the framework of Christianity and more specifically within Catholicism. At the conclusion of my paper I believe that I have provided arguments that have been sufficient to sustain my opening thesis.

I would like to add only that the history of care within Christianity has its specific point of departure in the figure of the Good Samaritan, the highest expression of practical charity towards the sick and those in need. Jesus described the Good Samaritan in the Gospel According to St. Luke (Lk 10:29-37) as a man who took care of[57] and promoted care,[58] and in this description the Christian tradition has also seen very clearly that epimeleia *(epiméleia), concerned care*, is the practical translation of curative love that alleviates and consoles, and which God wants to gives to all people who are wounded along the journey of life and are at its end. Returning to the historical account that I have provided, Jesus Christ, like the Good Samaritan, emerges as the *corner stone* of the history of health care. Down the centuries the Christian tradition of assistance has constructed the various stages of a journey that gave rise to the palliative care of today's world.

For me the conclusion is clear: out of faithfulness to God, who was revealed in Jesus Christ and manifested through his Spirit in the Christian history of assisting people to die well; because of faithfulness to those who have preceded us, until our days, in the contribution of pastoral care in health and thus that of all Catholics to the development of the art of dying well and helping people to die well; and because of the scale of the needs that this great undertaking presents us with at the beginning of the third millennium, we have to deduce that this is one of the greatest challenges that face us.

In addition, in my opinion at the present time a discipline or a branch of health care assistance does not exist that is so close to the thought and the sensibility of Catholicism, or so in line with its creed and its living tradition, as palliative medicine and care. To go on contributing to its roots and its young trunk those wise contents of the theological and pastoral tradition of the Church in relation to dying through that form of communion at the level of discussion and assistance that is constituted by an interdisciplinary approach involves nothing else but continuing to transmit, and to open up practical roads to, the assurance of St. Paul: 'If we have died with him, we shall also live with him' (2 Tim 2, 11).

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Notes

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[1] For greater information on the subject link see the web site: www.secpal.com.

[2] It should be said that numerous substantial and precise monographs exist on the appearance and subsequent development of palliative care in a growing number of countries in the world. In order to gain access to them it is sufficient to go to the bibliographies of the specialised works in the field or to the large number of web sites offered to us by cyberspace.

[3] I present a brief historical study that may clarify what pastoral care in health during the whole of the Christian tradition has been in the following works: 'La aportación de la Iglesia a la Sanidad desde el Evangelio y su propia Tradición', *Labor Hospitalaria*, 223, January-March 1992, pp. 69-77; 'Pastoral de la Salud', in *Nuevo Diccionario de Pastoral* (San Pablo, 2002), pp. 1084-1096; 'La Pastoral y la Pastoral de la Salud', in J. CONDE HERRANZ, *Introducción a la Pastoral de la Salud* (San Pablo, 2004), pp. 7-40.

[4] *Technical Report Series 804. World Health Organization, 1990.* I take the reference from D. DOYLE *et al.*, *Oxford Textbook of Palliative Medicine* (Oxford University Press, Oxford, 1993), p. 3, where the two paragraphs from the document that in its time had inspired this definition are quoted. The World Health Organisation gave a more detailed definition of palliative care and this can be found on the web page: www.who.int/cancer/palliative/definition/en.

[5] Cf. *De arte,* L. VI, 4-6.

[6] From the Greek noun τυχη *(tijé), case, fortune, good luck or bad luck ...*

[7] From the Greek noun αναγκη *(anánke), strength, need, coercion, violence, fatality, destiny...*

[8] An excellent exposition of this point can be found in PEDRO LAÍN ENTRALGO, 'La relación médico-enfermo en la Grecia clásica', in *La relación médico-enfermo* (Alianza, Madrid, 1983), pp. 58s, 70s, 83, 155-158.

[9] Caius Giulius Iginus was a Latin writer of Spanish origins who came to Rome as a slave. Augustus freed him and made him a librarian. Amongst other works he wrote the *Book of Fables*, which contains the fable of Cura (n. 202). He died in 17 AD.

[10] Subsequent philosophers of the history of the West such as Sören Kierkegaard and Martín Heidegger, and writers such as J. W. Goethe, explored this insight of the myth of Cura and bestowed upon it a fundamental existential and ontological status.

[11] The observations contained in this section are taken from my work 'El proceso de morir en la interculturalidad: el punto de vista católico', *Labor Hospitalaria*, 268, April-June 2003, pp. 15-20.

[12] *Death, the Final Stage of Growth* (Prentice-Hall, Englewod Cliffs, N.J., 1975).

[13] In concrete terms, the reference is to the close presence to the dying Jesus on the cross of the Virgin Mary, Mary of Clopas and Mary Magdalen: John 19: 25-27.

[14] Cf. *On Death and Dying* (MacMillan, Toronto, 1969).

[15] This is born witness to in a large number of passages in his letters, for example 2 Tim 2, 11: 'If we have lived in him we shall also die with him' (also Rom 6: 4s; 8:17; Phil 3, 10.).

[16] Cf. P. LAÍN ENTRALGO, 'El cristianismo primitivo y la relación médica', in *op. cit.*, p. 129.

[17] LAÍN, *op. cit.*, p. 132.

[18] By way of an example of numerous bibliographical references to this fact we may cite those given by the *Oxford Textbook of Palliative Medicine* (see the foreword written by C. Saunders and the corresponding references), pp. v-viii, and cited in 'Historia de los Cuidados Paliativos' provided by the web page of the *Sociedad Española de Cuidados Paliativos* (cf. note 2).

[19] The first about which we have documentary evidence was founded by Pope Cletus, the third successor of St. Peter, in 73 AD. On the birth and the development of the Christian *xenodochi* see J. ÁLVAREZ GÓMEZ, *Y ÉL LOS CURÓ* ... (Mt 15, 30). *Historia e identidad evangélica de la acción sanitaria de la Iglesia* (Publicaciones Claretianas, Madrid, 1996), pp. 27-40; D. CASERA, *Chiesa e Salute. L'azione della Chiesa in favore della salute* (Ancora, Milan, 1991), pp. 25-43; and J. CONDE, the three works cited in note 4.

[20] The first and the most emblematic of antiquity was the hospital city founded roundabout the year 370 by St. Basil of Cesarea of Cappadocia. With respect to Rome, it is thought that the first large-scale hospital was founded in the city in the year 400 AD by Fabiola, a disciple of St. Girolamus.

[21] Within Western monasticism, beginning with St. Benedict of Nursia. It should be said, by way of example, that the architectonic project of the monastery of St. Gallo, which is conserved in Switzerland, has a section clearly allocated to the *infirmarium.*

[22] Cf. C. CENTENO and P. ARNILLAS, 'Historia de los Cuidados Paliativos y del Movimiento Hospice', on the web page www.secpal.com.

[23] His papacy lasted from 590 to 604. In the *Regula Pastoralis* he taught that a guide of souls must be a compassionate neighbour towards everyone, a perceptive observer, careful, and capable of discerning, like a phsyician, the state of a body.

[24] On the biblical, theological pastoral and therapeutic character of consolation in a Christian approach see the pages of the subject in my 'Sufrimiento', published in *10 Palabras clave en Humanizar la Sanidad* (Verbo Divino, Estella, 2002), pp. 312-316, 330-333, 336s.

[25] As an example I will quote the following words of W. T. Reich: 'care for souls is the healing treatment of people as regards those aspects that go well beyond the needs of physical life, towards the achievement of the health of the personality. Thus when we speak today about care for the whole person we are talking about something that can be compared to the ancient idea of *cura animarum*...The first message transmitted by *cura animarum* is that there is an unvarying hierarchy of values according to which human beings choose to care and amongst these values caring fo the spirit must be a pre-eminent value' ('History of the Notion of Care', in *Encyclopedia of Bioethics* (Digital, 1995).

[26] LAÍN, *Historia de la Medicina* (Salvat, Barcelona, 1978), p. 239s.

[27] On Jean de Gerson see, for example, E. VILANOVA, *Historia de la Teología Cristiana,* I, (Herder, Barcelona 1987), pp. 997-1004.

[28] Today about three hundred manuscripts on the *Ars moriendi* survive, together with about a hundred incunabuli which, in their turn, include books, wooden engravings and printed editions with certain kinds of movable letters. The first edition in wood appeared in 1465 and the fact that about 20% of all books of this kind deal with the *Ars moriendi* is a sufficient demonstration of the extraordinary importance of this literary sub-genre at the end of the Medieval period and the beginning of modern thought. Both in wooden form and in printed form, some of these examples are written in Latin and others in one of seven vernacular languages. Their illustrations of the bed of a dying person surrounded by celestial and infernal beings extended the impact of these small popular works well beyond literary circles: cf. MARY CATHARINE O'CONNOR, *The Art of Dying Well: The Development of the Ars Moriendi.* (Columbia University Press, New York, 1942).

[29] On the survival of the *Artes moriendi* in Spain during the sixteenth century see the anonymous *Arte de bien morir y Breve confesionario* edited by F. GAGO JOVER (Medio Maravedí, 1999); *Artes de bien morir. Ars moriendi de la Edad Media y del Siglo de Oro,* edited by A. REY HAZAS (Lengua de Trapo, Madrid, 2003).

[30] In realty, the association was founded in 1843.

[31] Cf. C. Centeno and P. Arnillas, 'Historia de los Cuidados Paliativos' (www.secpal.com).

[32] 'His example of love for the sick was imitated by Protestants a century later when in Prussia the Foundation Kaiserwerth was created, which is considered the first Protestant hospice' (C. Centeno and P. Arnillas, '*Historia'*).

[33] Since 1971 it has been called *Maison Medicale Jeanne Garnier* and today it continues to be a prestigious institution dedicated to palliative care for cancer patients at an advanced stage of their illness. At the present time its address is n. 106, Avenue Emil Zola (75015-Paris). For more information on the *Maison Medicale* and *Association des Dames du Calvaire,* consult the web page www.jeanne-garnier.org.

[34] Cf. P. Laín, '*La relación'*, p. 197. This phrase is usually attributed to the Hippocratic period but there is no clear evidence that can corroborate this. Or at least I have not found any.

[35] In 1928, Ludwig von Krehl, in a lecture entitled 'Form of Illness and Personality' championed the need to move towards a medicine based at one and the same time on the natual sciences *(Naturwissenchaften)* and on the sciences of the spirit *(Geistwissenchaften).* Krehl was the founder of the so-named Heidelberg School to which Rudolf Siebeck and von Weizsäcker himself also belonged. For these references see P. Laín, 'Historia' pp. 636.658s; 'La relación', p. 231.

[36] Although at that time they were still not known by this name. To be precise, the hospice movement began with the foundation of St. Christopher's. The term 'palliative care', as will be seen below, appeared with the Royal Victoria Hospital of Montreal, Canada, seven years later (Cf. III, 2, b).

[37] Quoted by C. Centeno and P. Arnillas, 'Historia de los Cuidados' (l. c.). Cicely Saunders expressed her Christian beliefs and convictions in many other places and on many other occasions, for example in an interview published by *Diario Médico* on 18 Novembre 2002.

[38] Cf. C.M. Saunders (ed.), *Cuidados de la enfermedad terminal maligna* (Salvat, Barcelona, 1980). This book contains an article by Saunders entitled 'La filosofía del cuidado terminal' (pp. 259-272).

[39] Cf. C. Saunders: 'The Hospice Movement. Providing Compassionate and Competent Care for the Dying*',* in *Contact,* n. 122, October 1991.

[40] The information on E. Kübler-Ross is taken from the web page www.elisabethkublerross.com, and from two interviews carried out by the journal *Labor Hospitalaria* (n. 212, April-June 1989, pp. 106-111; n. 225-26, July-December 1992, pp. 258-261.

[41] Cf. the bibliographical reference in note 12. The translation into Spanish is entitled *Sobre la muerte y los moribundos* and is in its eighth edition (Martínez Roca, 1976). This book has been translated into twenty-eight languages. E. Kübler-Ross was the author of over twenty books, all of them on death and dying.

[42] See *Prayer for Healers,* a version adapated from the prayer for peace of St. Francis of Assisi that E. Kübler-Ross published at the beginning of the book referred to above: *Death, the Final Stage.*

[43] At the present time there are about 2,400 of these programmes in the United States of America.

[44] Within the framework of the programme '*Vida als anys'* promoted by Dr. X. Gómez i Batiste and his collaborators.

[45] For more information consult the web page www.iasp–pain.org.

[46] In 1996 a second edition was published which contained 'a guide to opioid availability'.

[47] Another figure of importance in the development of palliative care in Italy is Dr. Franco de Conno, a speaker at this international conference.

[48] For more information on the EAPC see the web page www.eapcnet.org.

[49] At that time 208 specific programmes of palliative care were identified in Spain. In 2004 over 17,000 terminally ill patients were cared for in their homes by palliative care teams during the last weeks of their lives and over 20,000 such patients a year are treated by a hospital unit.

[50] I refer to the paperback edition published by Penguin Books/Pelican Books in 1976.

[51] Harvard University Press, Cambridge, Massachusset.

[52] With an introduction by Cicely Saunders, this is a work that contains the work of 103 specialists, co-edited by D. Doyle, G. W. C. Hanks and N. MacDonald (Oxford Medical Publications, 2nd. ed., 1995).

[53] The edition in Spanish has the tile 'Cómo morimos. Reflexiones sobre el último capítulo de la vida' (Alianza, Madrid, 1995).

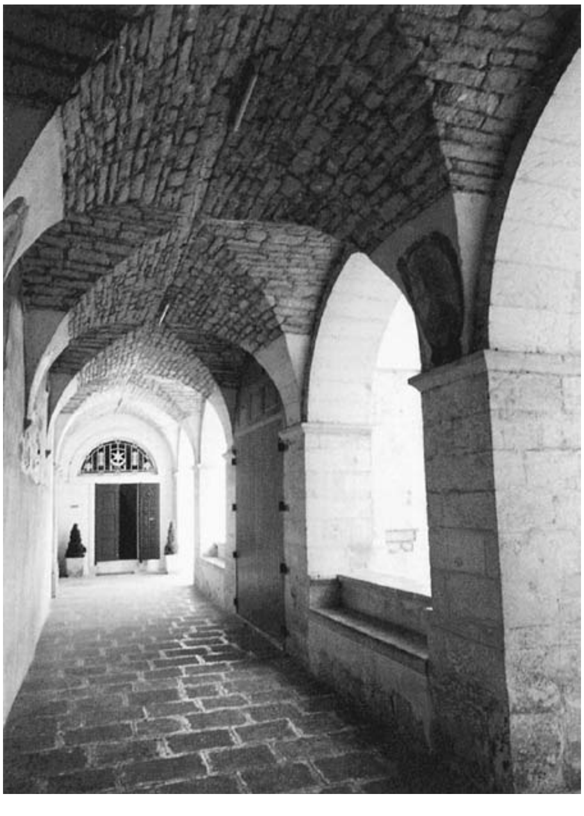
[54] Cf. The Department of Pastoral Care in Health, 25 años de Pastoral de la Salud en España. Memoria de un largo camino (Edice, 1999), pp. 75-80.

[55] *Testamento Vitale* was published by the Bishops' Conference in March 1990 and since then almost a million copies have been distributed.

[56] Its *modus operandi* was indicated in a book published by the promoters of the programme entitled ASISTENCIA A DOMICILIO DE ENFERMOS TERMINALES. Manual para el voluntariado y los familiares (PPC, 1992).

[57] Cf. v. 34: 'and he took care of him' (curam eius egit; epemelhqh autou).

[58] Cf. v. 35.37: 'take care of him' (Curam illius habe, Επιμεληθητι αυτου). 'Go and do likewise' (Vade, et tu fac similiter; Πορευο και συ ποιει ομοιως).



RODOLFO QUEZADA TORUÑO

2. Palliative Care in the Light of the Death and Resurrection of the Lord

The subject that I intend to address is that of 'palliative care in the light of the death and resurrection of the Lord'. It offers me an opportunity to show that solely in the light of the Christian meaning of pain, of suffering and of death is it possible to understand and accept a human reality that for many of our contemporaries is not only an experience without meaning but also an enigma or a labyrinth in the full sense of these terms.

From the point of view of Christian revelation, the Church has the responsibility of making her own contribution to a suitable understanding of all human realities and especially those which, because they are 'limit situations', challenge the notions proposed by the emergent anthropologies of the new millennium which are based solely on concepts of efficiency and productivity. The culture of death, which the Holy Father John Paul II has described in so many ways over the last decade, sees sick people, and especially those who have no hope of recovering from the infirmity or illness to which they are subject, as an encumbrance and a useless burden for society. Christians, in contrary fashion, must proclaim the Gospel of life, and especially in those situations where the very weak are incapable of defending, on their own, their own rights and can become authentic victims of other human beings. I hope that I will be able to demonstrate with these reflections that I will share with you that the light that springs from the paschal mystery of Christ the Lord can illuminate in an appropriate way the existential situation of so many of our brothers and sisters who, faced with illness, await those actions that will allow them to live out the last days of their lives with that dignity that is specific to them as persons and as children of God.

The Light Radiated by the Paschal Mystery of the Lord

Those who have the immediate gift of Christian faith know with certainty that the culminating point of divine revelation and God's infinite love for men is to be found in the paschal mystery of Jesus Christ our Lord. Christ offered his own life and his own death (paradoxically on the scaffold of the cross) for the salvation of the whole of mankind. His sacrifice is an eternal sacrifice. From that moment onwards, Christ who died on the cross would be, according to the forceful phrase of St. Paul, a stumbling block and folly for those who do not believe but the power and the wisdom of God for the believer.[1]

Like the disciples of Emmaus we, too, must open ourselves to the word of God in order to understand the meaning of the death of the Lord. In his dialogue with Nicodemus, Christ says these words, which the Teacher of Israel would certainly develop later: 'For God so loved the world that he gave his only Son, that whoever believes in him should not perish but have eternal life'.[2] The Lord himself, after rising from the dead, explained to his disciples of Emmaus: 'Was it not necessary that the Christ should suffer these things and enter into his glory?'[3] And before the men and women of all times the meaning of the oblation of Christ to the Father would be expressed in concise form by the Apostle: 'Christ died for our sins in accordance with the scriptures',[4] and as the beloved disciple, the only one of the disciples present at the foot of the Christ, would say: 'By this we know love, that he laid down his life for us; and we ought to lay down our lives for the brethren'. 'Greater love has no man than this', he would write in his gospel when transcribing the words of the Lord, 'that a man lay down his own life for his friends'.[5]

These texts place us before the reality of the fact that the real cause of the passion and death of Christ was love for all of us – sinners. For this reason in the Christian catechesis – especially when faced with the mystery of physical and spiritual suffering and death – we must preach 'Christ crucified'[6] and with the words of the prophet Isaiah teach people to turn their gaze to Christ who was 'wounded for our transgressions, he was bruised for our inequities'.[7] This truth is the central point of what we could call *drawing near in dialogue to, and the real accompanying of*, sick people and all those who suffer (and in a special way the dying), aware that only in the passion and death of Christ, and as we will see below in his glorious resurrection, is it possible to discover a 'why' for these dramatic companions of the human condition from which, indeed, they cannot be separated.

'For Christ and in Christ', the fathers of Vatican Council II would declare in *Gaudium et Spes,* 'is illuminated the riddle of pain and death, which outside his gospel oppress us,' in total darkness and even desperation, as the Council text adds: 'when a divine instruction and the hope of life eternal are wanting, man's dignity is most grievously lacerated… riddles of life and death, of guilt and of grief go unsolved with the frequent result that men succumb to despair.'[8]

In other terms, the full and ultimate meaning of pain and death can be found only in the light of faith since, as St. Peter attests to before being confirmed in his faith, human reason is scandalised when faced with the possibility in the plans of God of suffering and death, and because of this deserves the grave rebuke of our Lord, indeed perhaps the strongest rebuke that we find in the gospels: ‘Get behind me, Satan!… for you are not on the side of God, but of men’.[9]

His Holiness John Paul II gathered together the Christian wisdom of centuries – the wisdom of the cross – in his encyclical *Fides et Ratio* where he declares: ‘In the New Testament, especially in the Letters of Saint Paul, one thing emerges with great clarity: the opposition between “the wisdom of this world” and the wisdom of God revealed in Jesus Christ… The crucified Son of God is the historic event upon which every attempt of the mind to construct an adequate explanation of the meaning of existence upon merely human argumentation comes to grief. The true key-point, which challenges every philosophy, is Jesus Christ’s death on the Cross. It is here that every attempt to reduce the Father’s saving plan to purely human logic is doomed to failure. “Where is the one who is wise? Where is the learned? Where is the debater of this age? Has not God made foolish the wisdom of this world? (1 Cor 1:20) the Apostle asks emphatically… Man cannot grasp how death could be the source of life and love; yet to reveal the mystery of his saving plan God has chosen precisely that which reason considers “foolishness” and a “scandal”… The wisdom of the Cross, therefore, breaks free of all cultural limitations which seek to contain it and insists upon an openness to the universality of the truth which it bears’.[10]

In caring for the sick and those who suffer, as is the case with any other human reality, we cannot forget that the purpose of our lives as Christians is to identify with Christ, and that all of us, in one way or another, are or will be participants in his passion and death, and also in his resurrection. From the opened rib of the crucified Christ, repeated the teachers of old, spring the Church and the sacraments and as a result channels of grace by which to address – with serenity – any circumstance of our lives, however difficult and painful it may be. For this reason, in one way or another, the Christian – knowing that the ways of the Lord are inscrutable – ends up by making the words of St. Paul his own: ‘I have been crucified with Christ; it is no longer I who live, but Christ who lives in me’.[11]

We thus encounter this other transcendent dimension of pain and death. Christ, in taking on (except in sin) human nature, wanted to experience pains in his own body and soul – tiredness, fatigue, weeping, pain – and he transformed them into a valuable way of expressing obedience to, and love for, the will of the Father. The Lord did not want to remove pain from the horizon of human life, but he eliminated its poison, which was infinitely lethal and corrosive and which made it really to be feared, and transformed it into an incredible instrument that allows us to suffer with him and to say with St. Paul: ‘Now I rejoice in my sufferings for your sake, and in my flesh I complete what is lacking in Christ’s afflictions for the sake of his body, that is, the church’.[12]

We thus come to *Salvifici Doloris*, about which the Holy Father has spoken to us widely with his Magisterium and his life: ‘But in order to perceive the true answer to the “why” of suffering, we must look to the revelation of divine love, the ultimate source of the meaning of everything that exists. Love is also the richest source of the meaning of suffering, which always remains a mystery’.[13]

But we should never forget that our faith does not believe solely in the passion and death of the Lord, as if everything finished there. Christ rose from the dead. From that moment Jesus Christ has been alive: he is *yesterday, today and for always*. The truth of the fact that Christ lives is what transforms human existence. Without this truth any human project of service to others, however noble it may be, is shipwrecked. And this is not to speak about caring for the sick who, indeed, require so much love and self-denial.

The resurrection of the Lord is, as the *Catechism of the Catholic Church* puts it, ‘the crowning truth of our faith in Christ, a faith believed and lived as the central truth by the first Christian community; handed on as fundamental by Tradition; established by the documents of the New Testament; and preached as an essential part of the Paschal mystery along with the cross’.[14] But ‘if Christ has not been raised, then our preaching is in vain and your faith is in vain’, St. Paul would declare.[15] In relation to the subject being addressed in this paper, our attempts to give a meaning to illness, death and every kind of suffering would also be in vain.

For a man who suffers, this truth – if accepted and lived with profound belief – is more radiant than the light of the sun. The resurrection of Christ is the foundation of our faith and our hope, which even in the most difficult situations illuminates our existence with light and warmth that are always new.

If we ask ourselves what sick people most need, the answer is not difficult – it is hope. We must know with certainty that life – however compromised it may be – deserves to be lived, that human beings cannot be classified according to greater or lesser quality of life, that everyone has a sacred value, and that all suffering has a meaning. This is not a fatalistic solution in the face of the inevitable, as indeed John Paul II has also pointed out: ‘authentic Christian hope has nothing to do with fatalism or fleeing from history. On the contrary, it is a stimulus to concrete commitment, looking at Christ, God made man, which opens up to us the way of heaven’.[16]

We Christians know with certainty that ‘here we have no lasting city, but we seek the city which is to come’,[17] because ‘we are made for heaven’.[18] If one lives by faith everything has meaning. Naturally, the fact that we are made for heaven cannot, for the Christian, be a pretext for forgoing noble earthly tasks and the efforts to improve them. On the contrary: a very concrete expression of this undertaking lies specifically in palliative care, which is, indeed, the subject of this international conference.

If we live and transmit these truths we will ensure that illness, and specifically terminal illness, is not only a challenge but in a certain way also an encounter with God and a divine adventure for he or she who is suffering such illness and those that are responsible for helping him or her at that difficult moment.

Spiritual Care: an Essential Component of Palliative Care

The sick person, although at a terminal stage of life, in an absolute ways keeps his or her sacred dignity as a human person. For this reason, he or she requires careful attention at all levels: the medical, the social, the psychological and so on. His or her family requires special care. I will not dwell upon this aspect, which will be addressed elsewhere during this international conference.

I would like, instead, to refer, at least briefly, to forms of palliative care of a spiritual character. The spiritual care that can be offered to a sick person is not only a need that is felt but also a fundamental right of every sick person, with the existence of a consequent responsibility on the part of those who are looking after that person and in particular those whom we know as workers in the sphere of pastoral care in health. Emphasis should be laid on the fact that we are not dealing here solely with helping the chaplains of a hospital, or of a centre that provides assistance, in performing their tasks, or other Catholic priests or ministers of other confessions who work with them, but rather with active co-operation through the formation of a real palliative care team in which spiritual care constitutes a priority.

As an international authority in the field of nursing has written: ‘respect for the spiritual needs of the patient and help in satisfying them form a part of the basic forms of nursing care, in every circumstance. Although essential for the well-being of people who are in a state of good health, religious practices are even more indispensable in the case of illness. The concept of doing everything possible to ensure that the patient can practice his or her religion pre-supposes a series of specific activities that cannot be listed here. However, I will refer to some of the most evident: helping the patient to go to a chapel or a place of worship, working to ensure that the patient can be visited by a minister of his or her religion, giving him or her the opportunity to speak with that minister and allowing him or her to receive the sacraments that are a part of his or her religious life.’[19]

These recommendations directed towards nursing staff must be suggested to all the staff of the various medical teams that engage in palliative care. They should also be a concrete objective for the members of the patient’s family and all those who accompany the sick person. A common objection may be made which argues that medicine can no longer do anything for a patient at the terminal stage and that because death is near greater care is not required. But specifically for this reason it is the duty of everyone to accompany the sick person until the end, providing that person with company, helping him or her to pray, and above all else using all the means that are available to ensure that he or she grasps the supernatural meaning of his or her pains and suffering. This kind of support, and in a special way in the case of believers, with the presence of a priest or a minister of their religion, is, without any doubt, a priority and of fundamental importance, not only as regards the efficacy of the sacraments that are received, in the case of Catholics as we will see below, but also, at the level of principle, because of the inestimable human support that they imply not only for the sick person but also for his or her family.

I cannot but also mention, as regards spiritual care for sick Catholics, the very important Marian dimension. Such a simple, brief and beautiful prayer as the ‘Hail Mary!’ is of great comfort and if the patient can do this without too much discomfort it would be advisable to help him or her to recite the Holy Rosary or at least to do so in his or her mind. This paper of mine does not have the purpose of analysing the Marian dimension in pastoral care for the sick or the importance at all levels of the Rosary, which is a centuries-old prayer recommended by the Supreme Pontiffs and in a special way by His Holiness John Paul II.[20] As regards the subject that is being addressed here, it is sufficient to observe that since time immemorial we have called on Mary to pray for us *now and at the time of our deaths*.

It may be equally very useful in relation to spiritual care and as an integral and essential part of palliative care that at a national level, and in all countries, certain concrete objectives and tasks suggested by bishops’ conferences are proposed. First of all, there should be implemented a profound, and as far as possible an attractive, catechesis on death, pain, suffering, and so forth. Then there should be a rediscovery of Anointing as a sacrament for the sick, and viaticum as Eucharist for the passing over from this life. Lastly, centres that provide overall help to terminal patients should also be promoted and developed.[21]

To conclude, I would like to return to the perspective offered to us by the paschal mystery of our Lord Jesus Christ as regards the place the sacraments occupy in care for sick people at the terminal stage of their lives. We well know that the sacraments can be sub-divided into the sacraments of Christian initiation, the sacraments of healing, and the sacraments that are at the service of the communion and the mission of the faithful,[22] and that each one of these sacraments makes us participants in the death and resurrection of the Lord, and as a result, of the intimate life of the Trinity. All seven sacraments, therefore, must be part of a form of pastoral care for the sick that may be termed adequate. Yet I would like to refer here, because of the special importance of palliative care, to the sacraments of penance, the holy Eucharist and Anointing of the Sick.

The sacrament of penance was instituted by Christ 'for all sinful members of the Church: above all for those who, since Baptism, have fallen into grave sin, and have thus lost their baptismal grace and wounded ecclesial communion'.[23] The most important of the effects that this sacrament produces is reconciliation with God. When receiving this sacrament with a contrite heart and in the due conditions, one obtains as a consequence 'peace and serenity of conscience with strong spiritual consolation'.[24] The believer receives the passion and death of the Lord as his or hers, and this is a 'true spiritual resurrection' that identifies him or her with Christ. Although one cannot argue that all terminally ill people have been distanced from God, could we not affirm, were this their condition, that the most important thing for a sick person to whom medicine can offer no prospect of a cure is specifically that of receiving through the ministers of the Church a sacrament that makes him or her pass over – spiritually – from death to Life? In this sense, the importance of receiving this sacrament often during the course of the illness should also be emphasised and appreciated.

With regard to the Eucharist, in addition to it being frequently received during the various stages of illness, the Church has also established, at the least since the Council of Nicea, that nobody who is about to leave this world should be deprived of the last and necessary Viaticum. This communion *per modum viatici* is prescribed by the Code of Church Law[25] and also expressed in the Ritual of Anointing and Pastoral Care of the Sick. At the time of the Year of the Eucharist, the Holy Father recommended that parishes should dedicate themselves regularly and worthily to bringing Holy Communion to the sick and that all pastoral workers should be concerned to make the doctrine of Viaticum widely known about.

As regards the need, which has already been mentioned in this paper, to rediscover Anointing as a sacrament for the sick, it is advisable to remember that Anointing is the specific sacrament of 'illness and not only of the last moments of life, to help the Christian patient live this situation in conformity to the meaning of his or her faith'.[26] It is evident that in illness a Christian man or woman calls on God for special help that reaches him or her specifically through this sacrament whose effects could not be more comforting. As a part of palliative care, this sacrament 'gives the grace of the Holy Spirit to those who are sick: by this grace the whole person is helped and saved, sustained by trust in God, and strengthened against the temptations of the Evil One and against anxiety over death. Thus the sick person is able not only to bear suffering bravely, but also to fight against it. A return to physical health may follow the reception of the sacrament if it will be beneficial to the sick person's salvation'.[27]

I would like once again to quote from the *Catechism of the Catholic Church* because it presents a part of that light, beginning with the death and resurrection of the Lord, that fills us with its splendour: 'In addition to the Anointing of the Sick, the Church offers to those who are about to leave this life the Eucharist as viaticum. Communion in the body and blood of Christ, received at this moment of 'passing over' to the Father, has a particular significance and importance. It is the seed of eternal life and the power of resurrection, according to the words of the Lord: 'He who eats my flesh and drinks my blood has eternal life, and I will raise him up at the last day' (Jn 6:54). The sacrament of Christ once dead and now risen, the Eucharist is here the sacrament of passing over from death to life, from this world to the Father' (cf. Jn 13:1).[28]

'It can be said that Penance, the Anointing of the Sick and the Eucharist as viaticum constitute at the end of Christian life 'the sacraments that prepare for our heavenly homeland' or the sacraments that complete the earthly pilgrimage''.[29] And is not the central goal that we must achieve in all our efforts in the field of palliative care that of ending the pilgrimage of our dear patients at the terminal stage of their lives in a luminous way? I believe, in the light of the love that is expressed to us in the death and resurrection of the Lord, that this is specifically what we should do and ensure that many people do.

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Notes

[1] 1 Cor 1:23.

[2] Jn 3:16.

[3] Lk 24:26.

[4] 1 Cor 15: 3.

[5] 1 Jn 3:16 and Jn 15:13.

[6] 1 Cor 1:23.

[7] Is 53:5.

[8] Vatican Council II, Const. *Gaudium et Spes*, n. 21.

[9] Mt 16: 23.

[10] John Paul II, Encyclical *Fides et ratio*, n. 23.

[11] Gal 2: 19-20.

[12] Col 1:24 (cf. 2 Cor 1:5).

[13] John Paul II, Apostolic Letter *Salvifici doloris*, 11-II-1984, n. 13.

[14] Catechism of the Catholic Church, n. 638.

[15] 1 Cor 15:14.

[16] John Paul II, Speech of 1 November 2000.

[17] Heb, 13:14.

[18] John Paul II, Speech of 1 November 2000.

[19] Victoria Sanders, *Principios Básicos de los cuidados de Enfermería*, Consejo Internacional de Enfermeras, Geneva, 1971, p. 53.

[20] John Paul II, C. Apost. *Rosarium Virginis Mariæ,* 16-X-2002.

[21] The Bishops' Conference of Spain, 'Sobre la Eutanasia y la asistencia al bien morir', *Ecclesia*, 2444 (1989), 1438-1440. Of great relevance here is also the Declaration of the Permanent Council of the Bishops' Conference of France of 23 September 1991: 'Respeto al hombre próximo a la muerte', *Ecclesia*, 2567 (1992) 246-250.

[22] *Catechism of the Catholic Church*, n. 1210.

[23] *Catechism of the Catholic Church*, n. 1446.

[24] *Catechism of the Catholic Church*, n. 1468.

[25] CIC, c. 921. 'Faithful who are in danger of dying from any cause receive the comfort of holy communion as viaticum. Even if they have received holy communion the same day, it is nonetheless strongly suggested that when they are in danger of dying they receive holy communion once again'.

[26] Cf. The Ritual of the Anointing of the Sick, nn. 47, 65, 68.

[27] *Ibid.*, n. 6.

[28] *Catechism of the Catholic Church*, n. 1524.

[29] *Catechism of the Catholic Church*, n.

EUGENIO SAPORI

3. The Anointing of the Sick and Viaticum

Introduction

Faced with the responses as to how many sacraments there are, we would not be mistaken if we stated that for many of the faithful the number varies according to the information they have and their beliefs. If we then ask what the sacraments of the Anointing of the Sick and Viaticum mean, we realise that it is often the case that many of the faithful do not know how to answer or have confused if not indeed mistaken ideas about the meaning and the importance of these instruments of grace.

The Sacrament of the Anointing of the Sick

As the Fathers have taught ever since the beginning of the Church, a fundamental testimony to this sacrament is to be found in the letter of St. James (5:14-16).[1] But even more significant is what we find in the history of charity towards the sick, even though different forms of celebration down the centuries should be registered. Indeed, there have been two kinds of practice that have led the Church to celebrate this sacrament for the sick and for the dying. In the second case one can state that there has been an idea that is not completely correct of the various rubrics. Hence the tradition, which was developed above all between the Council of Trent and the Second Vatican Council, of giving this sacrament (the anointing of the Sick) only to those who were about to die, thereby creating the idea that when the priest came… there was nothing else that could be done.

Although the Council of Trent clarified important points of doctrine as regards this sacrament, it is nonetheless the case that the Ritual of Paul V, which was promulgated in 1614, was not fully appreciated despite its pastoral-theological and charitable richness as regards the sick and the dying, for whom it established different rites, namely: visiting the sick, the sacrament of anointing and prayer for the dying, and Viaticum and prayer for the sick person who had just died.[2]

When we read with care the whole of the liturgical patrimony of prayers in the ancient sacramentaries, we realise that in such prayers the physical recovery of the sick, and thus their health, is prayed for, with the expression of joy and thanks to God for the healing obtained thanks to His goodness and fullness of mercy.

The liturgical movement that arose at the beginning of the twentieth century involved the rediscovery of the importance and the distinction of the sacrament of the Anointing of the Sick as compared to Viaticum. Subsequently, it was the debates of the Bishops during the Second Vatican Council that promoted a reform of liturgy in this area that was more suited to making the faithful more aware of the meaning of these sacraments. Of fundamental importance was the question of the denomination ‘extreme unction’ (for the end of life) or ‘the anointing of the sick’ (for cases of illness). The various Fathers of the Second Vatican Council who expressed an opinion on the subject strongly defended their positions by presenting reasons of a dogmatic or pastoral character, referring to Scholastic theology or their experience at the side of sick people, or alluding to Church law or the liturgical sources.[3] In the liturgical Constitution *Sacrosanctum Concilium* (SC) there are three sections that deal with different subjects. One of these, for example, is the *name* of the sacrament. This Constitution declares that ‘the Anointing of the Sick’ is preferable because it brings out more effectively the peculiarities that are involved. As the *subjects* of the sacrament, the Constitution indicates those who are gravely ill and thus not only the dying (*SC*, 73). With reference to the *order* of sacraments to which this sacrament belongs, the traditional order of Penance, Anointing and Viaticum is retrieved (*SC*, 74), an order that in a certain sense reproduces the category of sacraments of Christian initiation, namely Baptism, Confirmation and the Eucharist, as the *Catechism of the Catholic Church* would subsequently declare (*CCC*, 1212). The Constitution also observes that the rite of *celebration* should be reviewed both as regards the number of anointings to be administered and the texts of the prayers so as to express the meaning of this sacrament in a better way (*SC*, 75).

In *Lumen Gentium*[4] emphasis is placed on the ecclesiological dimension, and also on the Christological and anthropological dimensions, whereas in *Orientalium Ecclesiarum*[5] sacramental intercommunion is also accepted in the case of anointing. It should, however, also be pointed out that in the documents of the Second Vatican Council that were promulgated after *Sacrosanctum Concilium* this sacrament is referred to with the denomination ‘the Anointing of the Sick’, in the same way as the new Ritual of 1972 had the title *Ordo unctionis infirmorum eorumque pastoralis curae*[6], (that is to say ‘the sacrament of the anointing of the sick and their pastoral care’), which came to be expressed by the acronym ‘OUI’.[7] Thus, whereas the typical edition of the Latin Ritual comes from the year 1972, the various translations into contemporary languages can be traced back to the years that come immediately afterwards.

We may now dwell upon this ritual and above all on its theological, liturgical and pastoral premises, given that the *Praenotanda* are to be located within the continuity of tradition and at the same time have further theological-pastoral innovations in relation to *Sacrosanctum Concilium*.

The Apostolic Constitution *Sacram unctionem infirmorum* of Paul IV, put before the Ritual, gives its approval to the changes introduced into the rite, and in particular to the words of the new sacramental formula and to the number of anointings and the use of another oil (as long as it comes from a plant). Lastly, this Apostolic Constitution introduces innovations into the discipline of repeatability: the sacrament of the anointing of the sick can be given to a sick person who has already received it not only if he or she falls sick again, as contemplated by the Code of Church Law, but also if during the course of the same illness the danger to the patient becomes more serious.[8]

With respect to the Anointing of the Sick, in the above-mentioned premises this is presented as a moment of the therapeutic activity of Christ and is the principal sign of his care. Indeed, we read of the 'sacrament of anointing, which he instituted and which is made known in the Letter of St. James. Since then the Church has never ceased to celebrate this sacrament for its members by the anointing and the prayer of its priests, commending those who are ill to the suffering and glorified Lord, that he may raise them up and save them (see James 5:14-16). Moreover the Church exhorts them to associate themselves willingly with the passion and death of Christ (cf. Romans 8:17), and thus contribute to the welfare of the people of God' (*OUI*, n. 5). It should also be borne in mind that 'those who are seriously ill need the special help of God's grace in this time of anxiety, lest they be broken in spirit and, under the pressure of temptation, perhaps weakened in their faith. This is why, through the sacrament of anointing, Christ strengthens the faithful who are afflicted by illness, providing them with the strongest means of support' (*OUI*, n. 5).

If we look at the structure of the celebration of this sacrament, we can see that substantially it involves 'the laying on of hands by the priests of the Church, the offering of the prayer of faith, and the anointing of the sick with oil made holy by God's blessing' (*OUI*, n. 5).

It is affirmed that through grace the whole of a man receives help for his salvation, he feels heartened by trust in God and he obtains new strength against the temptations of evil and worry about death (cf. *OUI*, n. 6). There is also emphasis on the importance of prayer said with faith, both of the Church (through the minister) and above all else of the sick person who receives the sacrament (cf. *OUI*, n. 7).

The *subjects* of this sacrament who may receive through it relief and salvation are 'those of the faithful whose health is seriously impaired by sickness or old age' (*OUI*, n. 8). It is also specified, however, that 'a prudent or reasonably sure judgement, without scruple, is sufficient for deciding on the seriousness of an illness' (*OUI*, n. 8). In addition to the possibility of repeating the sacrament, it is observed that it can be administered in the case of an operation 'whenever a serious illness is the reason for the surgery' (*OUI*, n. 10).

The sacred anointing can be given to elderly people 'if they have become notably weakened even though no serious illness is present' (*OUI*, n. 11). Children can be given the anointing 'if they have sufficient use of reason to be strengthened by this sacrament' (*OUI*, n. 12).

As was done on a number of occasions by the Fathers of the Second Vatican Council, the Ritual also refers to the catechesis and states that 'in public and private catechesis care, the faithful should be educated to ask for the sacrament of anointing and, as soon as the right time comes, to receive it with full faith and devotion. They should not allow the wrongful practice of delaying the reception of the sacrament. All who care for the sick should be taught the meaning and purpose of the sacrament' (*OUI*, n. 13).

It is stressed that the minister of the sacrament is a priest (cf. *OUI*, n. 16),[9] and that the anointing is carried out by spreading oil on the forehead and the hands of the sick person, but nothing forbids (taking traditions into account) the number of anointings being increased or the place where it is carried out changed. However, where this is necessary a single anointing can be made (cf. *OUI*, n. 23), with the complete formula: through this holy anointing may the Lord in his love and mercy help you with the grace of the Holy Spirit. May the Lord who frees you from sin save you and raise you up' (*OUI*, n. 25).

If we try to ascertain how the application of the norms established by the Ritual (subsequently also sanctioned by the norms of the Code of Church Law of 1983) has become increasingly concrete, we may evaluate some documents issued by Bishops' Conferences, by diocesan synods or by individual Bishops, especially in relation to Europe.[10]

We can immediately observe, for example, how the French Ritual, 'Sacraments for the Sick, Pastoral Care and Celebration' (1977) already has outwardly a different approach to that of the *Editio Typica*. This document is divided into two parts that correspond to the following criteria: 1) pastoral care for the sick (visits, the Eucharist, the Anointing of the Sick); 2) care for the dying (Viaticum, the continual rite, confirmation, commending of the dying). The Ritual also proposes four *forms of celebration* that take into account the physical and spiritual conditions of the sick person and of those that are looking after him or her.[11]

As regards the Ritual issued by the Spanish Bishops' Conference,[12] emphasis should be laid on the premises made by the Bishops in this document who observe that pastoral care for the sick has its culminating point in the celebration of the sacraments, as a result of which 'it should be emphasised that a good celebration in which there is the active participation of the presbyter, of the sick person, of his or her family and the Christian community, will always be the best catechesis for the people of God and will always be above any other activity in this field'.[13]

In relation to the Anointing of the Sick, they declare that 'it is a specific sacrament of life and not of death. This is shown through the new sacramental formula and all the prayers orientated towards the most genuine Tradition for the health and recovery of the sick person. The net distinction from Viaticum as the sacrament of the passage from this life, helps to locate the Anointing of the Sick in its proper place'.[14]

The anointing, they continue, 'is the sacrament of the sick and the sacrament of life, a ritual expression of the freeing action of Christ who invites and at the same time helps the sick person to take part in it. The catechesis will be not very effective or it will even be useless if sacramental practice contradicts it by leaving its celebration to the last moment of life'.[15]

'The Anointing of the Sick, as a sacrament of life, must help a person to live out his or her illness with a sense of faith, and this is very different from helping a person to die well; the sick person must see in the anointing not the guarantee of a miracle but a source of hope'.[16]

As a sacrament of recovery, pastoral care must prepare the sick person for his or her reintegration into ordinary life when returning to his or her normal activity after experiencing a special encounter with Christ. A 'post-sacrament' pastoral care will enable him or her to discover the urgent need to live out his or her relationship with God and with his or her brethren in a more Gospel-based way, and he or she will be linked in a deeper way to that Christian community to which he or she will now give witness of his or her faith, after receiving from that community the gift of consolation during illness.[17]

It is also observed that 'the celebrations presided over by the Bishop with sick people from various places are very important. With a suitable catechesis such celebrations can enable people to rediscover the importance of the sacrament and the role of every member of the Christian community in the pastoral care of illness'.[18]

In 1975 the Austrian Episcopate issued its document on pastoral care for the sick and the sacrament of the Anointing of the Sick and observed in the first instance the example of Christ, and then the action of the Church which has also been concerned about our sick brethren. Indeed, the document states: 'the goal at which the renewal of pastoral care for the sick aims is to offer valid help so that the sick person accepts his or her state of illness, which often involves his or her soul and religiosity. This sacrament is made up above all else of anointing, which as a new rite has lost the function of the sacrament of death'.[19]

It is made clear once again that the sacrament is for the sick and not for the dead: 'the Anointing of the Sick can only be administered to the living. No sacrament exists for the dead, and thus a dead person cannot receive the sacrament of anointing… Thus the sacrament can be administered to unconscious people only if it is assumed that the sick person, if he or she were fully conscious, would have wanted to receive it. Thus the priest, in order to avoid any misunderstanding, should address the relatives of the sick person for clarification on the matter'.[20]

From this it follows that 'the sacrament of the Anointing of the Sick can be received in every case of grave illness, when existence is endangered. As has often been repeated, it is necessary to abandon once and for all the common practice of waiting for signs of imminent death before imparting this sacrament'.[21]

Usual care for the sick requires not only the administration of a sacrament but also bringing help to the sick person, visiting him or her, doing what makes him or her happy, and in addition 'one should do what is possible so that with the entering into operation of the new rite anointing becomes a feast of hope and not, as it has been hitherto, a frightening 'extreme unction'. For sick people it must become a sacrament that is well accepted, and in the community, in hospitals and rest or nursing homes it should be a daily fact of normal administration. If possible, care should be taken not to marginalise the sick person by distancing him or her from normal life'.[22]

With respect to Italy, the document of the Synod of Brescia goes back to 1990. This Synod published its *Vademecum per la celebrazione dei sacramenti* ('Vademecum for the Celebration of the Sacraments') in which, among other things, it is established that after a suitable catechesis it is advisable to propose one or more communal celebrations of the Anointing of the Sick during the course of the liturgical year, privileging the time of Advent (so that the aspect of watching and waiting for the Lord Jesus as an approach of the believer is perceived) and of Easter (because the truth of the resurrection in the light of the Cross is brought out with greater force).

In June 1997 the Archbishop of Brussels, Cardinal Danneels, after other pastoral writings, returned in a specific way to the Anointing of the Sick. He pointed to Reconciliation, the Anointing of the Sick and the Eucharist as sacraments of healing and as a condensation of the care that the Church has for the hygiene of her people. They are the ministry of health of the Church: moral health, physical and psychological health, but also spiritual health.[23] Nowadays, he observed, there is a gap between medical technology and a return of healers. Indeed, 'on the one hand medical technology reduces illness to its quantifiable aspects (temperature, number of globules…) and to encyclopaedic definitions, whereas the therapy of 'healers' reduces illness to its mythical and magical aspects (the influence of spirits, forms of sorcery…). But, he specified, the Anointing of the Sick is neither a technique of healing nor magic: it is a sacrament. Illness, as a human phenomenon, affects the whole of the person and goes beyond the quantitative aspects. An overall illness must be matched by an overall healing that includes both the body and the psyche, as well as social relationships and the spiritual dimension'.[24]

The English Bishops Msgr. Wheeler and Msgr. Moverly also emphasise the difficulties that arise in explaining the existence of pain[25] but stress the communal aspect of the Anointing of the Sick and go on to observe: 'the care of the Church must be expressed not only in the ministry of the priest who administers the anointing but also in the help of prayer of all those who are present and those who can bring spiritual help and consolation to the sick'.[26] They end with an appeal: 'every act of charity towards them is a participation in the healing work of Christ'.[27]

Msgr. Grasar and Msgr. Brewer, when expounding the theology of the Anointing of the Sick,[28] point out that in the new Ritual there is a very fine revision that comforts and encourages. Indeed, 'the communal celebrations, in which the sick are brought into church and are anointed in the presence of the faithful also helps them to understand that the sacrament of the sick is not a private matter. It concerns the whole of the community, which 'commends them to the suffering and glorified Lord so that he may lighten their suffering and save them'.[29] This link with the community means that 'through the priest who anoints the whole ecclesial community comes together with its prayer and its loving care', but, at the same time, 'through the laying on of hands and anointing with oil the sick are given the faculty to serve the Lord in a different way and the Church turns to them to have their assistance and spiritual support'.[30]

In conclusion, we can discover how this sacrament can and must be located specifically within overall care in the case of palliative care, given that – in this occasion as well – the sacramental presence of Christ and of the Church is very important for the comfort and the relief of every patient who intends to live out his or her experience in the light of faith.

Viaticum

When we consider the historical panorama of Viaticum,[31] we can note that the practice of providing the dying with the Eucharist as food for the voyage into eternity is ancient. The Eucharist associates the person with the paschal exodus of the Lord and works all its efficacy as a 'medicine of immortality' (Ignatius, *Ad Smirn.*, 3*).*

The first explicit testimony to the giving of Viaticum to the dying, which comes from the time of St. Diogenes of Alexandria (264 AD), relates to an old man, Serapione, who had become a *lapsus* during persecution and had fallen gravely ill. He sent his grandson to ask a priest to come and give him Reconciliation. The priest could not go because it was night-time and even more because he was ill, and so he thought that he would meet the directives of his Bishop on Reconciliation if he sent a piece of the Eucharist to the sick man by office of the boy with the suggestion that it be made damp before putting it into the mouth of dying man. The boy carried out the order, the elderly man swallowed the Eucharist, and then died.

The testimony on the giving of communion to those who for any were reason were about to die finds confirmation in canon 13 of the Ecumenical Council of Nicea (325 AD), by which penitents near to death who ask for Reconciliation must be given 'the last and necessary Viaticum'. And this was not an innovation but in line with 'ancient and regular law'. Children fell under the rule of giving communion to those in proximity to death.

In the fourth century we have evidence on the use of placing the Eucharist in the mouth of dying people at the supreme moment, as emerges from the account of the death of St. Ambrogius (396 AD). His biographer Paolinus tells us that after receiving the Body of Christ 'and swallowing it, he expired carrying with an excellent viaticum'. In the sixth century the *Statuta Ecclesiae antiquae*, in the case of a penitent who was about to die, referred to the priest 'reconciling him… and placing the Eucharist in his mouth'.

For this purpose was added giving communion to a dying man on more than one occasion each day. Numerous testimonies refer to the last communion in two forms. Viaticum *sub utraque* was facilitated in monasteries by the practice of taking the dying person into church and giving him communion at the Holy Mass celebrated deliberately for him in his presence. This is described as happening in the case of St. Benedict (542 AD). On being near to death, St. Benedict had himself carried into the oratory of the monastery and 'there corroborated his departure by receiving the Body and the Blood of the Lord' (Gregorius, *Dialog.*, II, 37). In other cases, given that it was not possible to engage in such a practice, remedy was made by celebrating Holy Mass at the bedside of the sick person under the formula of '*Missa pro infirmo in domo*'.

At times, beginning in the sixth and seventh centuries, Holy Communion in these two forms also took the form of intention. This practice was continued for sick people until even the fourteenth and fifteenth centuries, by which time it was no longer carried out for the healthy. The minister of Viaticum until the fifth century and beyond could be a member of the laity, and this should be seen within the context of the practice of keeping the Eucharist and Communion at the home of the faithful. From the eighth century onwards, the ministry of Viaticum appears to be the prerogative of priests or, in their absence, of deacons, even if its administration by members of the laity seems to have continued, as emerges from the proscriptions, prohibitions and condemnations that we have from the eighth to the tenth centuries.

Starting in the eleventh century, the Roman death ceremonies mention Viaticum *in extremis*: the rite of Viaticum is connected with the rite of the Anointing of the Sick, and it slowly lost its special character as a sacrament that prepared somebody for death.

At the present time specific studies are not known about that have examined Viaticum in the pre-Council proposals and in the debates in the general hall during the Second Vatican Council. Some Fathers considered above all the possibility of a renewal of the rite, which then took place in the *Ordo unctionis infirmorum* (1972). Viaticum in the *editio typica vaticana*, in relation to certain ritual aspects, is dealt with after the sacrament of anointing, but is also referred to in the premises to nn. 26-29 and 30 (for the continuous rite: namely Penance, Anointing and Viaticum).

First of all it is observed that 'When in their passage from this life Christians are strengthened by the body and blood of Christ in Viaticum, they have the pledge of the resurrection that the Lord promised: 'those who eat my flesh and drink my blood have eternal life, and I will raise them up on the last day' (John 6:54).' It is suggested that Viaticum be received if possible during Holy Mass, with communion in the two forms, given that 'communion received as viaticum should be considered a special sign of participation in the mystery which is celebrated in the eucharist: the mystery of the death of the Lord and his passage to the Father' (*OUI*, n. 26).

It follows from this, specifically because of this importance of the Eucharist, that 'all baptised Christians who are able to receive communion are bound to receive viaticum by reason of the precept to receive communion when in danger of death from any cause', and pastors must do this so that 'the faithful are nourished by it while still in full possession of their faculties' (*OUI*, n. 27). But in addition to the paschal significance of this sacrament, its dimension in relation with baptism is also emphasised. Indeed, 'it is also desirable that during the celebration of viaticum, Christians renew the faith professed at their baptism, by which they became adopted children of God and coheirs to the promise of eternal life' (*OUI*, n. 28).

Ordinary ministers in normal or emergency cases are indicated, with exclusive responsibilities as regard the rite.[32]

With regard to the continuous rite,[33] in order to administer the sacraments of Penance, Anointing and the Eucharist in the form of Viaticum to a sick person it is made clear that this is when 'sudden illness or some other cause has unexpectedly placed one of the faithful in proximate danger of death', but if there is not sufficient time to administer all the sacraments as indicated then 'the sick person should be given the opportunity to make a sacramental confession, even if it has to be a generic confession. After this the person should be given viaticum, since all the faithful are bound to receive this sacrament if they are in danger of death. Then, if there is sufficient time, the sick person should be anointed' but 'the sick person who, because of the nature of the illness, cannot receive communion should be anointed' (*OUI*, n. 30).

The new rite, although it emphasises certain instances connected with the rubrics, stresses the advisability of pastoral involvement in order to take into account circumstances and individuals, with special attention being paid to the sick person, his or her family, and those that are taking care of him or her (cf. *OUI*, n. 128).

There is a suitable reference to the baptismal significance of the holy water,[34] to the proclamation of faith (the Creed), and the Lord's Prayer before receiving Viaticum (cf. *OUI*, nn. 157, 159).

Conclusion

When the situation of illness is especially grave, indeed such as to involve foreseeing the death of the sick person, it is a very ancient practice of the Church to provide the dying person with the gift of the Eucharist in the form of Viaticum. To receive 'Viaticum' is to bear witness in a strong and especially significant way to that faith to which a Christian has been the heir ever since his baptism (*the baptismal dimension*). Like food for the journey, the Eucharistic Viaticum sustains the dying person in the passage from this life to the Father and provides him or her with the guarantee of resurrection when faced with the extreme loneliness of death (*the eschatological dimension*). Viaticum is thus an act of real faith on the part of dying people and of the love of the community that is near to its loved ones and comforts them at the most difficult moment of their existence (*the ecclesiological dimension*).

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Note

[1] G. Marconi, 'Gc 5,14-15 e l'unzione degli infermi: lo stato della ricerca', in A. Grillo and E. Sapori (eds.), *Celebrare il sacramento dell'unzione degli infermi. Atti della XXXI Settimana di studio dell'Associazione Professori di Liturgia (Valdragone-San Marino, 24-29 agosto 2003)* (CLV-Edizioni Liturgiche (= BEL, Collana di studi liturgici n.s., 45), Rome 2004), pp. 29-40.

[2] On this specific subject see E. Sapori, *La cura pastorale del malato nel Rituale di Paolo V (1614) e in alcuni Ordini religiosi del XVII secolo. Studio storico-liturgico* (CLV-Edizioni liturgiche (= BEL, Collana di studi liturgici n.s., 43), Rome 2002), pp. 92-110, 137-139.

[3] Cf. E. Sapori, 'Sacramento dell'unzione e cura pastorale degli infermi. Le premesse liturgiche, teologiche e pastorali', in C.A.L. (ed.) *La malattia e l'unzione degli infermi. I Praenotanda dei libri liturgici* (C.L.V-Edizioni liturgiche, Rome, 2002) (= BEL, Sussidi liturgico-pastorali 11, Iniziazione alla liturgia, 6), pp. 26-49.

[4] 'With the holy anointing of the sick and the prayer of priests, the whole of the Church commends the sick to the suffering and glorified Lord, so that he may lighten their sufferings and save them (cf. Jas 5:14-16), indeed she exhorts them to join themselves spontaneously to the passion and death of Christ (cf. Rom 8:17; Col 1:24; 2 Tim 3:11-12; 1 Pt 4:13) so as to contribute in this way to the good of the people of God' (*LG*, 11).

[5] 'on the Easterners, who in good faith are separated from the Catholic Church, one may confer, if they spontaneously ask for it and are well disposed, the sacraments of Penance, the Eucharist and the Anointing of the Sick; indeed, it is also licit for Catholics to ask for these sacraments from non-Catholic ministers, whose Church has valid sacraments, whenever need or a real spiritual usefulness so compels and access to a Catholic priest is physically or morally impossible' (*OE*, n. 27).

[6] *Ordo unctionis infirmorum eorumque pastoralis curae. Rituale romanum ex decreto*

sacrosancti concilii oecumenici Vaticani II instauratum auctoritate Pauli VI promulgatum (Editio typica, Typis Poliglottis Vaticanis, 1972, 82 pp.).

[7] The various Rituals in contemporary languages at times offer an opportunity for another title, for example: *Sacrements pour les malades. Pastorale et célébrations*, *Ritual de la unción y de la pastoral de enfermos, Die Feier der Krankensakramente, Unção e pastoral dos doentes*, *Pastoral Care of the Sick: Rites of Anointing and Viaticum...*

[8] Cf. Apostolic Constitution *Sacram Unctionem infirmorum* of Paul VI, in *OUI*, pp. 14-17.

[9] Cf. also *Code of Church Law*, n. 1003; *Catechism of the Catholic Church*, n. 1516; *Charter for Health Care Workers* (1994^3), n. 112.

[10] For more detailed discussion of this subject see E. Sapori, 'La "receptio" del rito dell'unzione degli infermi in alcune chiese europee: tra speranze, realtà e sfide', in *Celebrare il sacramento dell'unzione*, pp. 77-166.

[11] *Sacrements pour les malades. Pastorale et célébrations* (Chalet-Tardy, 1980) (= A.E.L.F., Paris, 1977).

[12] Episcopado Español, *Ritual de la unción y de la pastoral de enfermos, reformado según los decretos del Concilio Vaticano II, aprobado por el Episcopado Español y confirmado por la Sagrada Congregación para el culto divino*, editorial Alfredo Ortells et alii – Comisión episcopal española de liturgia, 1974, henceforth referred to with the acronym 'RUPE'. In the fourth edition of 1987 modifications were inserted in conformity with the Code of Church Law of 1983: cf. *Notitiae* n. 207, September 1983, 551-552; *Pastoral litúrgica* nn. 135-136, March 1984, 17-19.

[13] Cf. RUPE, n. 59.

[14] Cf. RUPE, n. 65.

[15] Cf. RUPE, n. 66.

[16] Cf. RUPE, n. 68.

[17] Cf. RUPE, n. 69.

[18] Cf. RUPE, n. 76.

[19] Episcopato Austriaco, 'Pastorale degli infermi e rito dell'unzione (6 novembre 1975)', in *Lettere Pastorali 1974-1975* (Magistero Episcopale, Verona, 1977), col. 1617.

[20] Episcopato Austriaco, *op.cit.*, col. 1618.

[21] Episcopato Austriaco, *op.cit.*, coll. 1618-1619.

[22] Episcopato Austriaco, *op. cit.*, col. 1620.

[23] Cf. G. Danneels, 'L'onction des malades', in *La documentation catholique*, 2170 (16 November 1997) pp. 982-985.

[24] Danneels, *op. cit.*, p. 982.

[25] Cf. W. G. Wheeler and G. Moverley, 'Il sacramento degli infermi', in *Lettere Pastorali 1974-1975*, coll. 1585-1588.

[26] W.G. Wheeler and G. Moverley, *op. cit.*, col. 1586.

[27] W.G. Wheeler and G. Moverley, *op. cit.*, col. 1588.

[28] Cf. W. E. Grasar and J. Brewer, 'L'unzione degli infermi', *in LP 1974-75*, coll. 1605-1608.

[29] W. E. Grasar and J. Brewer, *op. cit.*, col. 1606.

[30] Cf. Conferenze episcopali di Inghilterra e Galles, d'Irlanda e di Scozia, 'Un solo pane, un solo corpo', in *Il Regno. Documenti* (1999), 3, p. 130.

[31] Cf. S. Mazzarello, 'Liturgia dei moribondi', in *Liturgia cristiana, messaggio di speranza. I nuovi riti dell'Unzione degli infermi, del Viatico e della raccomandazione dell'anima*, Atti della XXIII settimana liturgica Nazionale (Bergamo 1972), edited by the Centro di Azione Liturgica, Messaggero S. Antonio, Padua, 1973 (= Collana liturgica nuova serie, 13), pp. 92-103; R. Dalla Mutta, 'Il Viatico ai morenti: panoramica storica', in Rivista di pastorale litúrgica, 33, (1995/3), pp. 23-30.

[32] 'Ordinary ministers of the Viaticum are the parish priest and parish vicars, the chaplains and the superior of the community in clerical religious institutes and in societies of apostolic life, for all those who live in the home. In case of need or with the at least presumed permission of the competent minister, any priest or deacon may administer the Viaticum; in the absence of a holy minister, any faithful regularly authorised. The deacon should use the same rite indicated in the Ritual for the priest; the others should follow the rite described for the extraordinary ministry in the Ritual 'Rite of Communion outside the Mass and Eucharistic Cult' (OUI, n. 29).

[33] For a more complete analysis of the subject see G. Cavagnoli, 'Il Viatico e il Rito "continuo" della Penitenza e dell'Unzione degli infermi', in A. Grillo and E. Sapori (eds.), *Celebrare il sacramento dell'unzione degli infermi,* pp. 201-235; in particular see the incisive conclusions on pp. 230-235.

[34] 'Relive in us, Lord, in the sign of this blessed water, the memory of Baptism and our adherence to Christ the Lord, who was crucified and rose again for our salvation' (OUI, n. 151).

BONIFACIO HONINGS

4. Faith and Secularisation during the Last Stage of Life

An analysis of faith and secularisation during the last stage of life of a sick person, appears, at first sight, to be a paradoxical subject. This is because these are two topics that have very different characteristics. Faith, in fact, is one of the three theological virtues, and thus belongs to the sphere of the sacred, of the religious, and of the transcendent. Secularisation, for its part, is one of many cultural changes and thus belongs to the sphere of the profane, the secular, and the immanent. Faith and secularisation thus appear to be existential realities that are not compatible, even for a parallel analysis. At the most an *alternative analysis* seems feasible, that is to say *either faith* and the last stage of life *or secularisation* and the last stage of life. However, an analysis in which faith and secularisation converge appears impossible. And yet specifically this *et-et* analysis of faith and secularisation during the last stage of the life of a sick person is a subject connected with palliative care that is distinctly feasible. Because they are two realities that are not only opposed but also intertwined and interrelated, they form a complementary duality. However, in order to avoid all misunderstandings, I would like to make clear that between these two realities there exists a specific distinction: faith is not secularisation and secularisation is not faith, and thus neither of these two can be traced back to each other. Indeed, the phenomenon of secularisation, which is experienced by the Christian today, places his faith in a state of crisis and also affects his theological hope in relation to his present life and his future life.[1] Moreover, in human life in general and during its final stage in particular, both faith and hope take priority in an absolute way. Thus, without excluding the use of forms of care that belong to secularisation, during the last stage of life faith remains an absolute palliative necessity. Hence the organisation of this paper: first of all I will specify certain reasons that underlie the relationship between faith and secularisation; then I will bring out certain characteristics of the secularist situation of the last stage of life; and finally I will present the primary importance of care through faith as the only transcendent reality that provides holistic or overall palliative relief.

1. The Reasons Underlying the Relationship between Faith and Secularisation

Mankind is experiencing a new period in its history; deep and rapid changes are spreading throughout the whole universe. Brought about by the intelligence and active creativity of man, these changes have repercussions for him, his individual and collective judgements and desires, and his way of thinking and acting in relation to things and men. The Fathers of Vatican Council II referred to a real and authentic social and cultural transformation with consequences for religious and moral life as well.[2] 'Today, in an industrialised and secularised society, many things have changed at the level of both custom and mentality'.[3] It should be observed that this social and cultural transformation and these religious and ethical changes have brought, and still bring, with them by no means slight difficulties, above all because of contrasts. Indeed, although on the one hand man increasingly expands his scientific knowledge and technical power, on the other, he does not always manage to place them at his service. Mankind has never had such wealth, at an economic level as well, and yet a large part of humanity still suffers from hunger and lives in circumstances that are truly inhuman. Never before have men had such an acute sense of their freedom, and yet new forms of slavery are being established. One need only think here of the increasing social phenomenon of drug addiction amongst young people, the worrying increase in alcoholism and smoking amongst women, and so forth. Immersed in these contrasting conditions, many of our contemporaries no longer manage to identify the eternal real values and to harmonise them, as should be done, with the process of secularisation, which, indeed, is increasingly leading to secularism.[4]

Thus Pope Montini perceived the need to explore in an explicit way the intimate relationship between evangelisation and the culture of secularisation. In his Apostolic Exhortation *Evangelii Nuntiandi,* after exploring the dynamism of the Second Vatican Council II in all its directions and all its dimension, and observing the various changes underway, Paul VI reaches the conclusion that to evangelise means taking on and transfiguring cultures because they constitute the life of peoples and of men. Culture is the synthesis of the life of every people, its memory, its way of being, its way of living, its way of evaluating. Culture embraces the behaviour of men with other men, with nature, and with God. The Church cannot be indifferent to peoples and their cultures. As the people of God, the Church must generate a Christian culture in the heart of every people and all peoples. The Church, as the people of God, when she proclaims the Gospel and when the faith is accepted by peoples, becomes embodied in those peoples and takes on their cultures, thereby establishing not an identification with them but more a close tie with them. For this reason, concentrating his attention on the sole reason for the existence of the Church, evangelisation in relation to the culture of our time, Paul VI makes clear first and foremost that culture and the cultures of men must be evangelised not in a decorative way, like a superficial coat of paint, but in a living way, at a deep level, and reaching to the roots.[5] This in-depth evangelisation also bears upon the roots of the economic-social aspects because they are in a certain sense the basic dimensions of every cultural process. Faith and secularisation are not, therefore, independent spheres – quite the contrary. Indeed, on the one hand, faith transmitted by the Church is experienced beginning with a pre-existent culture, that is to say by believers deeply linked to a culture, and, on the other, the construction of the Kingdom cannot but draw upon the elements of human culture and cultures.[6] Cultures are not am empty space, lacking in authentic values, nor is the evangelisation of the Church a process of destruction – it is a process involving the consolidation and strengthening of such values. Evangelisation is a contribution to the growth of the 'seeds of the Word' that are present in cultures.[7] This positive relationship between faith and culture implies that the Church must be committed to an adaptation, an up-dating, engaging in the effort involving the tradition of the Gospel message in the anthropological language and the symbols of the culture in which she finds herself.[8] In other terms, this means that the evangelisation of culture and this faith are challenged by a cultural change and an entire world characterised by a process of secularisation, which in turn is intimately bound up with the progress of science, technology and the change represented by urbanisation. Culture has been subjected to the advent of industrial urban civilisation and post-modern civilisation, which, in their turn, are dominated by two characteristics: knowledge based on physics and mathematics and a mentality based on efficiency. The advent of this kind of civilisation has threatened the very roots of Christian culture because at the level of a historical process it still involves the problems of liberalism and materialism. I say 'problems' because in both we find located not only the tendency towards a legitimate and to be hoped for secularisation but also the deviation towards secularism. However, modern culture, based upon the scientific and technical mentality, promoted by the great powers and marked by the above-mentioned ideologies, seeks to be universal. Peoples, specific cultures, and various human groups, are invited, indeed forced, to integrate themselves into it.[9] All of this underlines, in turn, the challenges that the Church has to face. On the one hand, in them are manifested the signs of the times, on the other, with ever greater urgency is imposed the evangelising task of the Church to discern these signs so as to be able to strengthen Christian-human values and knock down the liberalising and materialising idols of the process of secularising modern culture in the direction of atheistic secularism.[10] The Fathers of the Second Vatican Council perceived this process in unequivocal terms: 'Many of our contemporaries seem to fear that if the ties between human activities and religion are broken, the autonomy of men, societies and the sciences will be hindered'.[11] However, this fear is groundless, as long, that is, as one distinguishes between relative autonomy and absolute autonomy: 'If by autonomy of earthly things we mean that created things and societies themselves have their own laws and values which man must gradually discover, use and order, then one is dealing with a legitimate need that is not only postulated by the men of our time but is also in harmony with the will of the Creator. Thus the methodical research of every discipline, if it proceeds in a truly scientific way and according to social norms, will never be in real contrast with the faith because profane realities and the realities of the faith draw their origins from the same God'.[12]

The Fathers of the Second Vatican Council deplored certain mental attitudes, amongst Christians as well, which had not sufficiently perceived the legitimate autonomy of science, thereby provoking conflicts and controversies, such as to generate the view that science and faith are opposed.[13] However, if by the phrase 'autonomy of temporal realities' is meant that created things do not depend on God, and that man can use them without reference to the Creator, then anybody who believes in God will see how false these opinions are. In fact, without the Creator the creature vanishes. Indeed, the removal of God deprives the creature of light.[14] From what has been said hitherto on the relationship between faith and secularisation, it follows that the Church, in her evangelising function, must proceed with great prudence and with no less cautious discernment. Invited not to destroy but to help cultures to strengthen themselves in their being and their identity, the Church invites men of every race and people to come together, through faith in Christ, in a single and universal people of God. She witnesses with satisfaction the aspirations of mankind to universal integration and communion because this is in harmony with her Gospel principles. Moreover, in addition to approving this Catholic unity, the Church also promotes and encourages forms of communion between cultures and forms of correct integration at the economic, social and political levels.[15] All of this does not mean that religious conscience is connected with the forms of the process of secularisation because they are connected with the emergence of science, technology and increasing urbanisation. The shift to secular civilisation does not lead to the abolition of religion in general and of the Christian faith in particular. It is certainly the case, and this is the conclusion of this first part of this paper, that the process of secularisation constitutes a challenge to faith because with new forms and structures it conditions the religious conscience and Christian existence. Secularised life brings out problems that have hitherto been unknown. The habitual ways of living and structures of existence become upset, and the same may be said of the conditions of life of religious man, the faithful and the Christian community.[16] The Church is thus challenged to renew her evangelisation so as to allow her faithful and her communities to live out their Christianity and their Christian faith in an up-dated way. Thus it is of interest to see how the Church harmonises faith and secularisation in relation to the last stage of the life of man.

2. Characteristics of the Situation of Secularist Crisis during the Final Stage of Life

Illness, pain and death have always been one of the most worrying problems, not only for the human conscience but also for the Christian conscience. Christians, too, recognise their importance and perceive their complexity. Indeed, the beliefs of family relatives, health care and hospital personnel and are involved in the crisis of values: not understanding the religious aspect and thus the spiritual enrichment of illness and death, they distance for as long as possible those signs and aids of faith to which the sick believer has a right. Today, practical difficulties are raised to pastoral care for sick people, especially during the last stage of their lives. The secularised contexts of the family, of hospitals, and of nursing homes are not always suitably open to the message of the Gospel and thus to a reception of theological faith and hope of which the Church is a spokesman and bearer. Thus the sick and the dying person often do not have a direct evangelisation and are deprived of the right to know – in a way that is suited and proportionate to them – the truth that concerns them.[17] This is even more unjust when we think that Christians, illuminated and supported by faith, have a way of penetrating more deeply into the mystery of illness, pain and death, and a way of addressing them with more vigorous strength. From the words of Christ they know, with absolute certainty, the meaning and the value of the mystery of illness, pain and death not only for their own salvation but also for the salvation of other people and the whole world. Christ himself, although he was without sin, suffered in his Passion sufferings and torments of every kind, and made the pain of all men his own. Presenting himself as the Son of Man who was carrying out the mission of the servant of Jehovah, he fulfilled was written about him in Isaiah.[18] He was the chosen Son who through his obedience accepted death for his brethren – mankind.[19] For this reason, St. Paul teaches that since we are all afflicted and oppressed by pain and trials, it is he, the Christ, who suffers in us, his limbs. Moreover, these trials and these pains are of short duration and of small size when compared with the eternal amount of glory that they obtain for us.[20] As a result, the Church sees in the suffering and death of one, Jesus, who offered himself up for everyone,[21] the supreme moment in which are accumulated in the Son, who presents them to the Father, not only all the scissions and sins of humanity but also the centuries of painful history. In this light of her faith, the Church believes that she sees and welcomes in the face of every suffering and dying man, above all during his final stage, the face of the suffering and dying Christ on the cross. Thus illuminated and supported by faith, Christians believe that they see, understand and welcome the face of a dying person, the face of Christ, the face of the Son of God who takes on his sufferings and his death.[22]

However, it should not be forgotten that in the design of God and His providence man must struggle with all his strength against illness in all its forms and work in every way to conserve that great good, his health, in order to serve society and the Church. And here we come up against secularisation because not only must a sick person fight against illness: medical doctors and all those who are involved in service to the sick must do so as well. They must never neglect anything that can be done, attempted, or experimented with in order to provide relief to the body and the spirit of a person who is suffering. The greatest knowledge of medical science and the most efficient application of technical power must implement the words of the Gospel in which Christ proposes that man should be treated in his wholeness as a human being.[23] During the final stage of life as well, the forms of relief specific to ‘secularisation’ must not be lacking, and this is even more the case because medical science, with its technical instruments, is today more than ever before able to offer forms of palliative relief. I will not enter into the practical details of this, which is the task of other speakers who are much more competent in this field than me. I will point out only that every form of relief cannot be separated from a vision of man that perceives ‘in the corporeal dimension of the individual the expression of a greater spiritual good. Scientists must understand the human body as the tangible dimension of a unitary personal reality, which is corporeal and spiritual at the same time. The spiritual soul of man, although not tangible in itself, is always the root of his existential and tangible reality, of his relationship with the rest of the world, and as a consequence of his special and inalienable value’.[24] Now this value is never more fundamental and primary than during the last stage of life, when science and technology are obliged to surrender to the mystery of death and give way to the primacy of faith.

3. Faith: a Primary Palliative Cure

In the contemporary world the last stage of life forces increasingly large numbers of people to ask themselves essential questions about the meaning of pain and death, which continue to exist despite every advance, and thus about what comes after this life as well.[25] Only Christ who suffered and died on the cross can provide an answer to these questions because there he revealed his yearning to redeem every man, all of man and all men. In his suffering and his death Christ himself, and through them the Father, offers forgiveness to the whole of mankind and expresses the mystery of their grace, their mercy.[26] The last stage of the life of man on earth thus reveals, in the light of Christian faith, that reconciliation with God, the Absolute, takes place, paradoxi-

cally, not through human power but through human weakness, not with the wisdom of this world but with the foolishness of the cross, which is the wisdom of God. Christ, through his message, death and resurrection, gave us his divine life – the unsuspected and eternal dimension of our earthly existence.[27] The light of faith reveals to us that there is a close relationship between illness, pain, death and the condition of sin in which man finds himself because of original sin, which originated in his proto-relatives.[28] Jesus, who came to take away the sin of the world, thus paid special attention to the sick and manifested to them his infinite mercy, freeing from illness and infirmity all those who went to him with faith or were brought to him trustingly. The miraculous healing of physical maladies is in the Gospel, therefore, a sign of, and a prelude to, liberation from sin.[29] Thus in the Body of Christ, the Church, if one member suffers, all the others suffer with that member.[30] It is therefore a very good thing if all the baptised take part in palliative care intended to alleviate every human need, above all during the terminal stage of life. All Christians must make the care and charity of Christ and the Church towards the sick in general, and people who are in the last stage of life in particular, their own. Each person must take care in a concerned way of sick people according to the special task of his own state and his specific responsibilities. In this service of charity, family relatives and those involved in the treatment of the suffering and the dying have a special task. They must comfort such people with words of faith and shared prayer, turning them to the suffering and glorified Lord, exhorting them, indeed, to unite themselves spontaneously with the passion and death of Christ so as to contribute to the good of the people of God.[31] This is why during the terminal stage of life the most suitable form of palliative care is the light of faith. This is the moment to suggest words that are able to help sick people to understand the meaning of their terminal situation; to exhort them to allow themselves be guided by the light of faith that leads them to unite themselves with the suffering Christ, sanctifying with their prayer that time that still remains before their face-to-face encounter with him. The moment has come for the divine invitation to give to the remaining immanent *cronos* of earthly life its value of being a transcendent *chairos* of celestial life. The *historic* moment has come when secularisation must open up to the *meta-historical* moment of faith. The human person has now, more than ever before, reached the moment when he can welcome with theological faith and trust the sacramental gesture of the merciful love of Jesus, to entrust himself, that is to say, to the most efficient form of palliative care. I am referring to the special gift of grace, the sacrament of the anointing of the sick. Established by Christ, 'the physician of body and spirit', the sacrament of the anointing of the sick was proclaimed by St. James with the following phrases: 'Is any among you sick? Let him call for the elders of the Church, and let them pray over him, anointing him with oil in the name of the Lord; and the prayer of faith will save the sick man, and the Lord will raise him up; and if he has committed sins, he will be forgiven'.[32] The formula that accompanies the anointing reads: 'Through this holy anointing and his most pious mercy may the Lord help you with the grace of the Holy Spirit, and freeing you from your sins may he save you and in his goodness raise you up'.[33] We well observe the emphasis on the primacy of faith in the most overall palliative care celebrated by Jesus himself: it is help for the whole of the man, undivided living being, to achieve his overall salvation. 'The sacrament wants to be a remedy for the body and spirit of every Christian, whose health is seriously compromised by illness or old age. The two elements, the corporeal and the spiritual, which are always by their nature connected, must be borne in mind when one wants to understand the sign and the sacramental grace of the anointing of the sick. Physical illness, in fact, aggravates the spiritual fragility, specific to every Christian, and could lead him, without a special grace from the Lord, to a selfish closing up within himself, to rebellion against Providence, and to desperation'.[34] All of this brings out that palliative care *par excellence*, based upon faith, consists in the personal presence of Christ in the sick. He who, like no other man, knows suffering and dying, is near to him to give him strength and help him to maintain his trust in God the Father and be patient towards his fragile body, which is destined for resurrection. Strengthened by trust in God, the terminally ill person obtains the strength to defeat the temptations of evil and worry about death.[35] The Fathers of the Second Vatican Council add that together with Christ the whole of the Church is present and at the side of the sick person. 'With the sacred anointing and the prayer of priests the whole of the Church commends the sick to the suffering and glorified Lord so that he may lighten their sufferings and save them'.[36] Through his sacramental palliative care, Jesus communicates the grace of the Holy Spirit, whose specific effects are the relief and the reinvigoration of the sick person, the reunification of his being, which has been lacerated by illness, the understanding of its meaning, and help so that it can be experienced in a healthy way.[37] All of this stakes place above all else during the terminal stage of life. Indeed, 'when the illness is destined in the design of God to lead on to death, then the sacrament will increase faith and hope in the sick person so as to give him the strength to address the final trial. Through the dynamic presence of the risen Lord and his vivifying Spirit, the anointing will be the active sign of the last and definitive insertion into the Easter of the Lord. In this way, the sacrament will be preparation for that definitive victory over evil and death that will complete the assimilation to Christ begun with baptism'.[38] Two things are by now *luce clarius*: the first relates to the immanent limitation of secularisation; the second concerns the transcendent primacy of faith. As regards faith, it is evident that it is necessary for palliative effects, above all the sacrament of the sick. Faith is necessary not only for efficient cooperation on the part of the terminally ill patient but also so that the prayers of the priest and the community have their hoped for efficacy. For this reason, those who take part in the celebration of the sacrament are invited to a participation of humble and deep faith that is at the same time a full self-abandonment of trust and confidence in the merciful love of the Father.[39] Secularisation can no longer not admit its scientific and technical limitation. Faced with terminal illnesses, and thus with death, only the primary palliative care of faith is able to give true meaning to suffering and death – the passage to eternal life. The therapeutic limitation of secularisation should lead us back to the unlimited salvific horizon of theological life. Secularisation would thus recognise its relative autonomy because it would show itself open to the fullness of future life, giving existential actuality to the strong desire of St. Paul to leave this earthly world so as to be always with Christ.[40] Secularisation converges with the faith of the Church, which, with Peter, provides a reason for the hope that is in us.[41] In a special way, the Church repeats with St. Paul to those who suffer and are about to die the Gospel of the resurrection so that we 'may not grieve as others do who have no hope'[42]. The terminally ill will not only not feel alone, separated, or useless, but will become increasingly aware that they are called by Christ to be his living and transparent image and to work with him for universal salvation. Specifically for this reason, it should be proclaimed more than ever before that when secularisation can no longer offer anything else but the immanent *care* of the hopelessness of secularism, i.e. '*euthanasic' death*, faith is able to offer the transcendent care of the hope of Christianity, the *crossing over to eternal life*. When medical science closes the window to every therapeutic hope, faith throws open the door to the palliative care of the salvific message of Christ.

I would thus like to conclude with the following words: 'Most merciful God the Father, who knows the hearts of men and welcomes the sons and daughters that return to You, have pity on them during the last stage of their lives, ensure that holy anointing with the prayer of our faith sustains them and comforts them, so that in the joy of Your forgiveness they abandon themselves with trust in the arms of your mercy. For Jesus Christ, Your Son and our Lord, who overcame death and opened to us the way to eternal life, and lives and reigns with you for all centuries to come. Amen'.[43]

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Notes

[1] See the pastoral document of the Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi* (Elle Di Ci, Turin, 1974, n. 118.

[2] See the Pastoral Constitution on 'The Church in the Contemporary World' *Gaudium et Spes* (*GS*), n. 4.

[3] Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi*, n. 121

[4] See *GS*, n. 4.

[5] See Paul VI, *Evangelii nuntiandi* (*EN*), 20.

[6] See *ibidem.*

[7] See *GS*, n. 57.

[8] See *EN*, 53 and 62; *GS*, n. 58.

[9] See PUEBLA, *Comunione e partecipazione* (*CP*), edited by P. Vanzan, translation by A. Marranzini, Editrice Ave, Rome, 1979, n. 2970.

[10] At an essential level secularism detaches man from, and places him in opposition to, God, and sees the construction of history as the exclusive responsibility of man, seen in his immanence. This is a conception of the world in which the world is explained in itself without there being need to have recourse to God, who in this way becomes superfluous and an obstacle. Such secularism, in order to recognise the power of God, ends up by doing without God and by denying Him. New forms of atheism – anthropocentric atheism that is no longer abstract and metaphysical but pragmatic, programmatic and militant – seems to follow from this. In connection with this atheistic secularism, there are proposed to us every day, in the most varied forms, the civilisation of consumption, the will to power and dominion, and forms of discrimination of every kind – equally inhuman inclinations of this humanism (See Paul VI, *EN*, n. 55; see PUEBLA, *CP*, n. 2984).

[11] *GS*, n. 36.

[12] *Ibidem*. See Second Vatican Council Cost. Dogm. *De fide cath.*, chap. III: denz. 1785-1786.

[13] See *GS*, n. 36.

[14] See *ibidem.*

[15] See PUEBLA, *CP*, nn. 2974 – 2975.

[16] See PAUL VI, *Octogesima adveniens,* n. 10.

[17] See the pastoral document of the Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi*, n. 120.

[18] See Is. 42 and 53:4-5.

[19] See Mk 12:6-8.

[20] See 2 Cor 4:17.

[21] See Rom 15:18-19.

[22] See Mk 15:34; Mt 25:34-40; 27:46.

[23] See CEI, *Sacramento dell'Unzione e cura pastorale degli infermi*, nn. 3-4.

[24] Pontifical Academy for Life, *Etica e ricerca biomedica. Il Regno-documenti*, Sept. 2003, p. 274.

[25] See *GS*, n. 10.

[26] See Rom 3:21-26.

[27] See 1 Cor 15:48-49.

[28] See *Catechism of the Catholic Church*, n. 379. However, it would be an error to see illness itself, at least in general terms, as a punishment for personal sins.

[29] Pastoral document of the Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi*, n. 133.

[30] See 1 Cor 12:26.

[31] See Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi,* nn. 33-34.

[32] Jas 5:14-15.

[33] Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi,* n. 139.

[34] Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi,* n. 140.

[35] See CEI, *Sacramento dell'Unzione e cura pastorale degli infermi*, n. 6; see also Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi,* nn. 142-143.

[36] *Lumen Gentium*, n. 11.

[37] See Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi,* n. 144.

[38] Italian Episcopate, *Evangelizzazione e sacramenti della Penitenza e dell'Unzione degli infermi,* n. 146.

[39] See *ibidem*, n. 148.

[40] See Phil 1: 19-23.

[41] See 1 Pt 3:14.

[42] 1 Thess 4:13.

[43] CEI, *Sacramento dell'Unzione e cura pastorale degli infermi*

WILLIAMS JACOBUS EIJK

5. Proportionate and Disproportionate Treatment, Exaggerated Treatment and Palliative Care

Whoever reads the history of mankind is struck by its ambiguity. What appears not only to have the appearance of progress really does constitute progress, thereby providing a possibility to solve problems that were previously thought to be insoluble, by no means rarely creates new problems. The same happens with scientific progress in the medical field. The introduction of anaesthesia in 1840 made surgery possible. The application of radiotherapy in the 1920s and chemotherapy in the 1950s of the twentieth century provoked an earthquake in the treatment of malign tumours. The discovery of sulphonamides and antibiotics, starting in the 1930s and the 1940s, which opened a breach in the fight against bacterial infections, and the development of systems for pulmonary ventilation in the post-Second World War period, gave medical doctors the possibility of saving the lives of many patients whose conditions would previously have been considered desperate.

However, the possibility of prolonging life has raised new ethical questions that were previously unknown. One can certainly prolong life but such an undertaking has not always been a reason for unbounded happiness. I remember that in the 1970s, during my studies in medicine at the University of Amsterdam, in the neurology department of the university hospital some patients received artificial respiration for more than five years. With the passing of time a deep doubt gained ground: should we really continue with artificial respiration? To what end? What possibility is there that the patient will recover consciousness? On the other hand, the question arose as to whether it was licit to 'take out the plug'. Many will still remember the vigorous debate about the Karen Ann Quinlan case during the 1970s: would the interruption of artificial respiration in the case of a patient who is not capable of autonomous breathing, thereby bringing about his or her death, not be equivalent at an ethical level to causing death?

The Resistance to Exaggerated Treatment and its Consequences for the Debate on Euthanasia

In 1969, in Holland, a Professor of Psychiatry at the University of Leida, Prof. Van der Berg, published a book which bore the significant title '*Medische macht en medische ethiek*' ('Medical Power and Medical Ethics'). In this work he sharply criticised the exaggerated treatment of his time. In order to justify his criticisms he presented the extreme case of a man who had been paralysed in both his legs since childhood.[1] With time, this paralysis extended progressively to the lower part of his body. A sore emerged and then malign tumours formed in the wound which encountered difficulty in healing. The only way of preserving the man's life was to carry out an emicorporectomy, that is to say the amputation of the lower part of the body, the legs, the waist and a part of the abdomen. The operation was carried out with the conservation of the man's kidneys and the liver. In addition, the surgeon created orifices for the faeces and urine. A photograph in the book referred to above shows the man: his body is made up of a head, two arms, a small trunk that ends under the thorax. This is a typical example of the period of exaggerated treatment of the 1950s and 1960s, a period when medical doctors, because they were not yet experienced in the application of the new techniques, had still to discover the limits to their new medical power. In a public debate, Van den Berg not only asked whether it was *incumbent* to carry out such a surgical operation to save the life of this man but went beyond this and asked whether it would not have been *incumbent* to reject such an operation.

An even more important aspect to emerge from this debate was that on the basis of this case and others Van den Berg proposed allowing the possibility of bringing about the death of incurably ill patients through active intervention if such patients found themselves in a condition of unbearable suffering: if one could suspend medical treatment, with the consequent death of the patient, active intervention to end the life of a patient could be considered as being equally licit. In the opinion of Van den Berg: 'It is licit for the medical doctor to end

human life in two ways: by interrupting a medical act and by carrying out a medical act. In the first case the medical doctor is passive… In the second case the medical doctor is active – he kills the patient. An act whereby a medical doctor kills a patient appears to be cruel. It is something that is abnormal, that is inappropriate. However, it would be even more inappropriate to make people vegetate for a long period in an inert state, people who some time previously had been defeated, were dying and were already dead. This should be considered as being unusual. Whatever the case, it is cruel'.[2]

The bringing about of death through lethal injection in order to avoid atrocious sufferings on the part of the patient is said by this author, therefore, to be more human in its approach. Van der Berg's book provoked a famous public debate in Holland on the subject of euthanasia. This debate was to last for more than a third of a century and ended with the legalisation of euthanasia and assisted suicide in conformity with a law that has been in force since 1 April 2001.[3]

Recently, this debate received a new impulse from the set of questions and issues connected with the active bringing about of the death of newborn children who have congenital or genetic diseases or handicaps, about which public opinion in Holland was informed in August of this year.[4] In 2001, some medical doctors administered pharmaceuticals with the explicit intention of hastening the arrival of death in about a hundred cases out of 1,088 dead children of the ages of under a year to a year according to the inquiry into the practice of euthanasia in Holland carried out in the 2001-2002. The problem derives from the fact that between 1996 and 2001 on the average only three cases a year were communicated to the judicial system of the active ending of the life of newborn children. This was because the paediatricians who were involved in this practice were afraid of the judicial consequences of what they had done.[5] In this climate of concern generated by the mass media a paediatrician publicly posed the question of whether the problem of unbearable suffering is not in fact caused by the various attempts to save newborn children, who would die anyway, at any cost, but who are kept alive through artificial supports and have a level of quality of life that gives rise to concern: 'We can now keep them alive from the age of twenty-four weeks onwards, but at times one can only weep… And it is often because of technology that these children suffer for so long… If we add the suffering caused by our technical instruments we have to ask ourselves very seriously whether we are actually doing the right thing'.[6]

It is obvious that this is a question with very wide repercussions that we must take very seriously. The first question we must answer is an ethical one and it is whether the suspension of medical treatment, with the consequent death of a patient, is equivalent to bringing death about in an active way.

Is Allowing to Die Equivalent to Killing?

Even that medical doctor who sees human life as a fundamental good and thus rejects euthanasia at times finds himself or herself in situations that involve having to decide whether to interrupt a treatment that could prolong life. Such a medical doctor, therefore, must ask himself or herself why he or she is not allowed to give a fatal injection that has the same effect as the interruption of treatment, whose consequence, too, is the death of the patient. The Congregation for the Doctrine of the Faith, in its Declaration on Euthanasia of 1980, includes both active intervention to end life and the suspension of treatment which has the same effects within its definition of euthanasia: 'By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used'.[7]

In his famous article of 1975, Rachels wrote that allowing to die was always equivalent to bringing about death in an active way: 'If a medical doctor, for human reasons, allows a patient to die, he or she has the same moral responsibility as if he or she had given a fatal injection for humane motives'.[8]

If we take the example given by Rachels, this is true. An uncle sees that his little nephew has slipped in the bathtub, has hit his head on the rim of the tub and has disappeared under the water in a state of unconsciousness. Thinking that he will obtain his inheritance, the uncle does nothing and allows the little boy to drown. If a judge discovered the truth about how things had really taken place he would consider the man guilty of murder. In this case, from an ethical point of view, allowing to die is ineed equivalent to killing.

However, we could also imagine a different situation. For example: a situation where the little nephew falls out of a boat into a raging river that is infested with hungry crocodiles. In this case nobody could accuse the uncle if he failed to engage in an attempt to rescue his nephew. It is clear, therefore, that allowing to die is not always equivalent to killing.

Mutatis mutandis, one can transpose this argument onto the medical sphere. The case that has just been cited could be compared with the situation described by Van der Berg of the patient who underwent an emicorporectomy in order to be cured in a definitive way of a malign tumour. If this man had died after refusing such a surgical operation, with all the mutilations that it involved, nobody would have dared to state that he had wanted to secure his own death.

However, the distinction between killing and allowing to die is less clear, for example, in a case in which one suspends the administration of antibiotics, insulin, food and liquids. These are means by which in general one can keep a man alive without there being any complications. One must, therefore, have a criterion by which to distinguish between cases in which the suspension of such attempts to prolong life is equivalent to securing death in an active way on the one hand, and those in which such equivalence is not so evident, on the other.

The Distinction between Ordinary/Proportionate Means and Extraordinary/Disproportionate Means

From the sixteenth century onwards, moral theologians made a distinction between *ordinary* and *extraordinary* means.[9] The employment of ordinary means to keep people alive was considered to obligatory, whereas one could not engage in extraordinary means: for example the amputation of a leg. This was the case above all in the period before the use of anaesthesia.

Within the context of the relatively static medicine of recent past centuries, it was not on the whole particularly difficult to define a form of medical treatment as 'ordinary' or 'extraordinary'. Today, the question is much more complicated because of the rapid developments and advances that have taken place in science. The terms 'ordinary' and 'extraordinary' evoke the idea that one is dealing with forms of treatment that are respectively 'usual' or 'not usual'. Artificial respiration, at the end of the 1940s, was considered, without any doubt on the matter, to be 'extraordinary', in the sense that it was not usual, that it was rare or special. Today, however, artificial respiration forms a part of daily practice in every hospital. Whether it is extraordinary in the ethical sense of the term, depends on a series of factors. Here we are dealing, on the one hand, with assessing the possibility of a cure, the preservation of life, and the condition of a patient who has hopes of the treatment, and, on the other hand, of the side effects and the complications involved in that treatment, in addition to the investment in terms of effort and expenditure.

Indeed, given that we are dealing here with the existing relationship between the various sets of factors referred to, the tandem 'ordinary' and 'extraordinary' was replaced from the 1970s onwards by the tandem 'proportionate' and 'disproportionate'. As the Congregation for the Doctrine of the Faith declared in its Declaration on Euthanasia': 'In the past, moralists replied that one is never obliged to use "extraordinary" means. This reply, which as a principle still holds good, is perhaps less clear today, by reason of the imprecision of the term and the rapid progress made in the treatment of sickness. Thus some people prefer to speak of "proportionate" and "disproportionate" means. In any case, it will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources'.[10]

In the case of the example given by Rachel of the uncle and his nephew, allowing to die is equivalent to dying because there is a relationship of proportion between the risks and the disadvantages of the rescue attempt, on the one hand, and the possibility of success, on the other. Without doubt this is the case given that the uncle needs to do nothing else than take his nephew out of the bathtub. The relationship referred to above is manifestly disproportionate, however, if the rescue attempt requires the uncle to dive into the raging river full of crocodiles in order to save his nephew.

The application of this criterion in medicine involves the following context: interrupting a treatment that can prolong life, where this has a consequence the death of the patient, is equivalent from an ethical point of view to euthanasia if the relationship between the advantages and the disadvantages is proportionate. When a person, although he or she can keep himself alive without many risks with a proportionate means such as a penicillin derivative (for example in the case of pneumonia), decides not to use this means, one can only suppose that he or she is securing his death so as to avoid problems. In this case, one should, in fact, refer to a form of euthanasia or suicide. If somebody foregoes employing disproportionate means in order to keep himself or herself alive, then his or her intention is to forego a purpose, i.e. that of getting better. It may well be that at the same time he or she hopes that he or she will die. In essential terms, this is not illicit in itself but one cannot attribute to him or her the intention of using his or her death as a means to end his or her suffering. In other words, one is not dealing here with direct euthanasia.

In the case in which a patient dies because the application of disproportionate treatment has been suspended is not the equivalent of suicide or euthanasia. As John Paul II states in his encyclical *Evangelium Vitae*: 'To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death' (n. 65).

One has to consider the fact that the task of safeguarding life belongs to a general norm. However, this is not an absolute norm that allows of no exceptions. The norm that one should not end the life of an innocent human being in an active way through, for example, euthanasia or assisted suicide, is absolute.

The reason for this is that human life is a fundamental good, an intrinsic dimension of the human person. The physical life of a human being – like a human being himself or himself – must not be exploited and therefore it must not be sacrificed in order to eliminate suffering, The obligation to save physical life is a general norm that is valid in most cases but also has exceptions. This obligation no longer applies in a case in which saving life requires disproportionate action.

In some cases the disproportion between the positive effects and the negative effects of medical assistance can become extreme. In this case continuing to make attempts to prolong life may be defined as constituting exaggerated treatment. Extreme cases in this field were the attempts to keep Marshall Tito and General Franco of Spain alive for political reasons, without there any being any hope of saving their lives or restoring their health. If medical assistance becomes extremely disproportionate it is incumbent to forego it. It should be borne in mind that exaggerated treatment reveals, in the final analysis, the same mentality that underlies euthanasia, that is to say wanting to command life and death, to dispose of life as one wishes. This in the ultimate analysis implies – consciously or unconsciously – a rejection of trusting to the loving mercy of God.

Even if the distinction between proportionate and disproportionate means is clear, it does not provide a concrete answer to all questions. The patients, medical doctors and other people involved may have discordant opinions on the assessment of proportions. One person may see a certain treatment as proportionate whereas another may assess it in a different way. In order to weigh the relevant proportions, it is necessary to have more concrete supplementary criteria.

Concrete Supplementary Criteria

Some more concrete criteria, if considered not in themselves but at the level of their mutual coherence, could facilitate the distinction between proportionate and disproportionate means.[11]

Some important factors of assessment relate to the character of the treatment as such: its duration (acute or chronic treatment); the effect of the treatment (directed a towards total or partial cure or only a support treatment, as in the case of artificial respiration); the possible complications, the side effects and the mutilations that might be involved; its experimental character: the patient may decide to subject himself or herself to experimental treatment on the condition that the risks are proportionate to the risks of the illness he or she is suffering from, but he or she is not obliged to do this – 'If there are no other sufficient remedies, it is permitted, with the patient's consent, to have recourse to the means provided by the most advanced medical techniques, even if these means are still at the experimental stage and are not without a certain risk. By accepting them, the patient can even show generosity in the service of humanity'[12]; another aspect of the treatment that should be considered relates to the financial expenditure and the investments needed for the staff and the instruments that are required, considered within the perspective of the overall resources available to health care.

Other factors relate to the condition of the patient: the physical condition of the patient prior to the application of the treatment: is he or she able to cope with a medical intervention? Whatever the case, it is clear that life should not be prolonged when inevitable death in imminent. The envisaged physical condition of the patient after the treatment: what will be his or her quality of life once the treatment has had the desired effect? In addition to the physical condition of the patient, it is also necessary to consider his or her mental, psycho-social and spiritual strength. In this context one can use the phrase 'quality of life', on the condition, however, that a quality seen as negative does not become an argument in favour of euthanasia. The essential quality of life of a human being, created in the image of God, does not depend on its accidental qualities but on its physical condition, as indeed John Paul II observes in his encyclical *Evangelium Vitae*: 'Life is always a good… The life which God gives man is quite different from the life of all other living creatures, inasmuch as man, although formed from the dust of the earth (cf. *Gen* 2:7; 3:19; *Job* 34:15; *Ps* 103: 14; 104: 29), *is a manifestation of God in the world, a sign of his presence, a trace of his glory* (cf. *Gen* 1:26-27; *Ps* 8:6)...Man has been given a *sublime dignity*, based on the intimate bond which unites him to his Creator: in man there shines forth a reflection of God himself' (n. 34).

It is amazing perhaps, in this context, that in order to achieve an overall assessment one also takes into consideration the expenditure and investments at the level of staff and instruments. The Declaration on Euthanasia of the Congregation for the Doctrine of the Faith, cited above, lists these amongst the factors that are relevant in order to make a distinction between proportionate and disproportionate treatment. In Western Europe, where the majority of people enjoy health insurance or can draw upon national health services, not much emphasis is placed on the cost factor. However, in Western Europe as well health directors and the heads of health insurance companies hesitate before financing the introduction of a means made available by very advanced medicine or refunding costs for new medical techniques. This is because of the enormous increase in general health expenditure.

Another situation exists in the United States of America. Hardwig is of the opinion that there is an obligation to die – including the obligation to end life in an active way – in certain circumstances, and he mentions the following case: a woman aged eighty seven is suffering from grave heart disease; although everything indicates that she has less than a 50% chance of living for another year she wants to be treated at any case. She lives for another two years and the medical assistance and treatment cost her daughter (aged fifty-five) – who is her only relative – her savings, her home, her job, and her career.[13] In this case one should ask oneself if the treatment involved should not be seen as being disproportionate. I would not like to speak, as Hardwig does, of the 'obligation to die', but at the most of an ‘obligation to forego preserving life and accepting the inevitable end of life’. Between these two enunciations there is a world of difference. We have seen that according to Hardwig the obligation to die involves not only forgoing a treatment designed to prolong life but also the obligation to actively procure death.

Special Problems in the Application of the Distinction between Proportionate Means and Disproportionate Means

The Magisterium of the Church can only refer to the distinction between proportionate treatment and disproportionate treatment as a general principle. Only the medical doctor can decide what is proportionate or otherwise in concrete cases on the basis of his or her professional skill and expertise, experience and prudence. The patient would do well to inform himself or herself about the possible advantages and disadvantages of the treatment. In the end, it must be the patient himself or herself who decides whether to subject himself or herself to the treatment. In the situation in which he or she is not able to do this, the medical doctor will make the decision in agreement with the patient’s family relatives.

The distinction between proportionate means and disproportionate means is clear in many cases. Despite the concrete supplementary criteria listed above, there remain, however, cases in which the application of this distinction is so difficult that the people involved can, in good conscience, have different opinions on the matter. What should be decided, for example, in the case of a woman aged fifty who has a brain tumour? If the tumour is not removed she could have neurological dysfunctions and perhaps die with great suffering, whereas she would have the possibility of a full recovery following a surgical operation. On the other hand, one could foresee that because of such an operation her cerebral centre responsible for the use of language could be damaged with the result that she is not able to speak and express herself. Such assessments can be very difficult at the level of practice, above all when it is not possible to discuss them with the patient.

This set of problems and issues arises above all else in the case of patients who are in a persistent vegetative state, to whom one has to administer food and liquids through a gastric tube. Such patients can be kept alive at times for decades. In 1999 a violent discussion arose in Holland about this problem, with specific reference to a woman who, following an error of anaesthesia that had been made during a caesarean operation, was in a permanent vegetative state and was kept alive for sixteen years by the administration of food and liquids through a gastric tube. Some people were of the view that the policy had to be continued because it involved a procedure of normal and not medical assistance.[14] Those opposed to such a policy thought that this mode of administering food and liquids was ‘not natural’ but ‘artificial’.[15] This argument may be seen as not being convincing. Indeed, some patients who have been in a coma for a long time can swallow food without notable difficulties through the swallowing reflex, if, that is, the food is placed behind their tongues. This, too, is not, in a strict sense, a ‘natural’ way of receiving food and liquids. Others see this way of prolonging life as an absurd treatment.[16] The distinction between humanly suitable and humanly absurd, however, involves in itself the risk that there will be an easy move to the question of the meaning of the life of a human person and that one will lose sight of the fact that this is a fundamental and not a purely functional good.

Whatever the case, attention must be paid to the fact that the phrase ‘permanent vegetative state’ is misleading. The term ‘vegetative’ suggests the idea that the patient, who is reduced to being a vegetative being, is no longer a living human being. However, as long as there is no irreversible loss of the function of the cerebral trunk, the patient is a living human being who has the right to proportionate medical assistance. In addition, one has to consider the fact that a certain number of these patients can reacquire a state of consciousness even after many years, although it is indeed difficult to make a prognosis about the immediate future of a patient in a permanent vegetative state.

In this case how one should one apply the distinction between proportionate and disproportionate means? Food and liquid meet, in general terms, the fundamental needs of life, and in themselves do not belong to the field of medical assistance. The Supreme Pontiff John Paul II, in March 2004, declared: ‘how the administration of water and food, even by artificial routes, are always a *natural means* for the preservation of life and are not a *medical act*. Its employment, therefore, is to be considered, at the level of principle, *ordinary and proportionate*, and as such morally obligatory, to the extent to which and as long as it is shown to achieve its specific purpose, which in this case is procuring nutrition to the patient and the reduction of suffering’.[17]

Only the way in which food and liquids are administered is a matter of medical assistance and as such a proportionate or disproportionate means. But, as the Supreme Pontiff explained, the artificial administration of water and food in itself is not disproportionate; indeed, at the level of principle it is proportionate. And the fact that there is a low chance of recovery, when the vegetative state continues for more than a year, does not justify in an ethical sense the interruption of their administration.[17] However, we can state that the administration of water and food through a drip tube into the subclavicular vein is disproportionate, in general, in the permanent vegetative state, give that such drip feeding can be used for only a limited period. The administration of food and liquids through a gastric tube should in general be seen as being proportionate, on the condition that it can be applied without complications, such as *ab ingestis* pneumonia or repeated vomiting. The *Charter for Health Care Workers*, published by the Pontifical Council for Pastoral Assistance to Health Care Workers,[19] contains the following directive: 'The administration of foods and liquids, even artificially, is part of the normal treatment always due to the patient when this is not burdensome for him: their undue suspension could be real and properly so-called euthanasia' (n. 120).[20]

The Use of a Correct Terminology

When a patient dies because of the interruption of a therapy, reference is easily made to passive euthanasia.[21] In an editorial of the *Boston Medical and Surgical Journal* of 1884, which was entitled 'Permissive euthanasia', we encounter the first reference, as far as we know, to the distinction between active euthanasia and passive euthanasia: 'although we never want to become destroyers of life, we suspect that there are few doctors who have avoided the suggestion, following the policy of *laisser aller*, in a desperate case of prolonged suffering, of remaining passive and foregoing every further attempt to prolong life that has become torture for its owner'.[22] Although this title referred to 'permissive' euthanasia, in the same article we also find employed the terms 'active' and 'passive', which, indeed, were used generally in the 1960s and 1970s. By 'active euthanasia' is meant ending or shortening life through the effect of a death-inducing act carried out for the most part by a medical doctor. If life is shortened because the medical doctor does not engage in the treatment that can prolong life or if he or she interrupts that treatment, then one refers to 'passive euthanasia'.

Because of the confusion that often reigns in the use of the terms employed in the discussion of euthanasia, one encounters a strong tendency to no longer employ the distinction between active euthanasia and passive euthanasia. Some people expressly do not want to employ this distinction because merely to accept the use of the term euthanasia implies, from a logical point of view, acceptance of the use of active euthanasia. Others, on the other hand, perceive in the acceptance of the term 'passive euthanasia' an attempt to mask the fact that interrupting a treatment implies, as an intended effect, a shortening of life on a par with what takes place in the case of direct active euthanasia.[23]

Those who wish to continue to use the concept of passive euthanasia would do well to define it on the basis of the distinction between proportionate means and disproportionate means, as indeed we have already seen in this paper. If one interrupts a disproportionate treatment or foregoes that treatment, one can certainly not say that the intention was to hasten death or that one did not want to preserve life. In contrary fashion, if one omits to engage in a proportionate medical treatment we must suppose that the underlying intention was to hasten death or bring it about. In this case one could, possibly, refer to passive euthanasia.

In addition, it is important to define distinctions and concepts in a clear way from a clinical point of view, including the distinction between active euthanasia and passive euthanasia, if we want to engage in an analysis of clinical practice in relation to euthanasia that is based upon the research data on euthanasia in Holland during the period 2001-2002. The percentage of deaths in 2001 (140,377) in which a treatment that would have prolonged life was suspended or not engaged in was 20%. In 7% of these cases (about 10,000) the medical doctor was aware of a hastening of the end of life and in 13% of these cases (about 18,200) this was his or her explicit intention.[24]

In the final report of this research it is not clear if these were cases involving the interruption of a proportionate or disproportionate treatment. We may ask, however, whether these cases should not be added to the total number of those involving an active ending of life, i.e. 4,800.[24] In terms of the total population, the decisions to refrain from a treatment have influenced the number of deaths in a way that is markedly higher than those caused by euthanasia, assisted suicide and the ending of life without there being a request to do so.[26]

From all of this it is clear that to achieve a good analysis of clinical practice in relation to euthanasia we need an apparatus of clear basic concepts, as is indicated in the following table:

Number of cases in which medical doctors have intentionally brought about the death of patients in Holland in the year 2001

Euthanasia and assisted suicide	3,800
Cases of the ending of life without a request to do so	1,000
Cases of treatment that would have prolonged life but was suspended or not begun, with the explicit intention of hastening death.	18,200
Total number	23,000

Help to Go on Living

In a situation in which the obligation to apply a therapy in order to treat an illness or save a life no longer applies, the work of the medical doctor and his or her collaborators, such as nurses, does not end. Another endeavour begins which, from many points of view, is more onerous than that which involves therapy. The patient, even if he or she is in the terminal stage of life, is still alive. If saving his or her life is no longer an option, passive resignation is not called for: what is needed is active commitment, a commitment to help the patient to continue living that part of his or her life that still remains to be lived

This commitment takes the form of palliative care, which is described by the World Health Organisation in the following terms: 'an approach that improves the quality of life of patients and their families faced with the problems connected with illnesses that threaten life, through the prevention or the relief of suffering through the identification in its first stage, the faultless assessment and the treatment of pain and other problems, of a mental, psycho-social and spiritual character. Palliative care… seeks neither to hasten nor to bring forward death'.[27]

Palliative care is directed towards providing assistance to a person who is incurably ill so that he or she can on living without shortening that life or prolonging it. 'A phrase that is often heard in this context is that palliative care does not add days to a person's life but life to days'.[28] Such care is not only medical-technical in character but also concerns all the aspects of human life: the mental, the social and the spiritual. We are dealing here with overall care.

It has always been the case that in medical circles a 'palliative' has been a pharmaceutical that is used to reduce symptoms but not to cure the underlying illness of a patient. The Latin term '*palliare*' means 'to mask' or 'to cover with a cloak'. In addition, the phrase 'palliative care' could derive from the Latin '*pallium*' which means a 'cloak'. St. Martin cut his cloak in two parts in order to give one half to a naked beggar who was at the gates of the city of Amiens. In this way he did not solve the problem of poverty: what he did do was to gave a little warmth to a man. Similarly, palliative care does not cure an illness that threatens a person's life but alleviates the suffering, the sadness, the fear and the loneliness of the patient during that part of his or her life that still remains to him or to her. In the vision of the Catholic Church, pastoral and spiritual assistance is an integral part of palliative care. It is clear that palliative care, in all its different aspects, is not the task and responsibility of the medical doctor alone.

Following the debate on euthanasia in Holland, the Bishops' Conference of Holland has requested on a number of occasions for palliative care to be offered at a structural level as assistance to the dying.[29] The primary aim of palliative care is to make the terminal stage of life bearable. An indirect but to be hoped for effect is to avoid the patient finding himself or herself in a such a condition as to lose hope and thus to ask for an action that involves euthanasia. In the autumn of 2001 a number of medical doctors who work in Amsterdam, as consultants in cases of euthanasia, and who, of necessity, reject it, communicated that the number of requests for euthanasia had diminished in a dramatic fashion following the introduction of palliative care.[30]

From a medical point of view, palliative care in itself does not require the application of a therapy by which to prolong life. However, it may happen that palliative care requires a therapy which, although it prolongs life, does not seek this end but serves only to reduce unbearable symptoms and symptoms that cannot be treated in any other way. Tumours that penetrate the skin can cause surface necrosis and the terrible odour of putrefying flesh. A tumour that presses on sense nerves can cause terrible pain. In these cases a surgical operation, radiotherapy or chemotherapy can form a part of palliative care. Palliative care, which in general is not very invasive or technological, can at times require drastic interventions, if necessary to suppress symptoms for which there is no alternative remedy.

Conclusion

As regards the ethical problems connected with the end of human life, in general a great deal of attention is paid to the question of euthanasia. However, in practice and in the main, problems are encountered that are connected with decisions about whether to continue or interrupt the medical treatment by which life is prolonged. Such decisions are frequent and often difficult in character given the consequences, which are by no means rarely grave in nature. After interrupting the forms of treatment directed towards preserving or prolonging life, the medical doctor and his or her collaborators still have the task of engaging in what is in general something that is even more demanding that treating illness, namely: palliative care. In performing this task the medical doctor may perhaps discover the most demanding challenge – that of living out his or her vocation to follow '*Christus Medicus*'.

H.E. Msgr. WILLIAMS
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Notes

[1] J.H. van den Berg, *Medische macht en medische ethiek* (Nijkerk. G.F. Callenbach, 1969), pp. 31-34.

[2] *Ibid.*, p. 53.

[3] 'Law for the Control of the Ending of Life on Request and Assisting Suicide' *Staatsblad van het Koninkrijk der Nederlanden* (2001), n. 194.

[4] 'Kinderartsen dringen aan op toetsing', *Trouw* (2004), 26 Aug., p. 1.

[5] G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen, and P.J. van der Maas, *Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie* (Utrecht, De Tijdstroom, 2003), p. 121.

[6] J. van Klinken, 'Ik denk vaak: Hoe kunnen jullie leven?', 4 September 2002, see http://refdag.nl/website/artprint.php?id=31929.

[7] Congregazione per la Dottrina della Fede, 'Declaratio de euthanasia', *AAS* 72 (1980), p. 546, Italian tranlsation from http://www.vatican.va/roman_curia/congregations/cfaith/documents/r…\&IMAGE.Y=1. The word euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used' refers to the classic distinction between direct and indirect killing, which is also relevant in analysing the field of euthanasia. If the ending of life is an intentional effect or a means by which to end the suffering of a patient, then one may refer to direct killing. The ending of life can be in certain cases a collateral or indirect effect of medical acts and decisions. In this sense some people have made a distinction between 'direct euthanasia'

and ‘indirect euthanasia’, but not always in a clear and precise way when we consider the contents of their affirmations (cf. *Encyclopedia of Bioethics*, ed. W.T. Reich, New York/London, The Free Fress/Collier Macmillan Publishers, 1982, vol. I, pp. 272-274.

[8] J. Rachels, ‘Active and Passive Euthanasia’, *The New England Journal of Medicine* 292 (1975), p. 79; cf. D.W. Brock, ‘Voluntary Active Euthanasia’, *Hastings Center Report* 22 (1992), n. 2, pp. 10-22.

[9] W.J. Eijk, *De zelfgekozen dood naar aanleiding van een dodelijke en ongeneeslijke ziekte* (Brugge, Tabor, 1987), pp. 159-161.

[10] Congregazione per la Dottrina della Fede, ‘Declaratio de euthanasia’, pp. 549-550.

[11] Cf. Congregazione per la Dottrina della Fede, ‘Declaratio de euthanasia’, pp. 550-551; K.W. Wildes, ‘Ordinary and extraordinary means and the quality of life’, *Theological Studies* 57 (1996), pp. 500-512; W.J. Eijk, *De zelfgekozen dood naar aanleiding van een dodelijke en ongeneeslijke ziekte*, pp. 333-343.

[12] Congregazione per la Dottrina della Fede, ‘Dichiarazione sull’eutanasia’, p. 550.

[13] J. Hardwig, ‘Is there a duty to die?’, *Hastings Center Report* 27 (1997), n.. 2, pp. 34-42.

[14] H. van der Kolk, ‘Verhouding medische taak en verpleegkundige taak’, *Vita Humana* 18 (1991), pp. 11-13; cf. in this sense the discussion of three judicial sentences in the United States (Californian Court of Appeal [1983], New Jersey Superior Court [1983] e Massachusetts Appeal Court [1984]) in H.J.J. Leenen, ‘Het bëndigen van voedselen vochttoediening aan patiëten’, *Nederlands Tijdschrift voor Geneeskunde* 41 (1985), pp. 1980-1982.

[15] R.T.W.M. Thomeer, ‘Abstineren bij irreversibel coma’, *Vita Humana* 17 (1990), p. 119; M.M. Plomp-van Harmelen, ‘Verhouding medische taak en verpleegkundige taak’ *Vita Humana* 18 (1991), pp. 14-15.

[16] W.C.M. Klijn, W. Nieboer, *Euthanasie en hulp bij zelfdoding. Ethische analyse en waardering. Wet en recht* (Utrecht: Katholieke Vereniging van Ziekeninrichtingen, 1984), pp. 17-18.

[17] Giovanni Paolo II, ‘Ai partecipanti al congresso internazionale su ‘I trattamenti di sostegno vitale e lo stato vegetativo. Progressi scientifici e dilemmi etici (20 marzo 2004)’, n. 4, http://www.vatican.va/holy_father/john_ …/hf_jp-ii_spe-20040320_congress-fiamc_it.htm.

[18] *Ibid.*

[19] Pontificio Consiglio della Pastorale per gli Operatori Sanitari, *Carta degli operatori sanitari* (Vatican City, 1995, 4th edn.).

[20] Shannon and Walter perceive in the speech of John Paul II that has just been cited a change in relation to traditional doctrine on the distinction between proportionate means and disproportionate means, seeing in this speech a break between a theological approach and a deontological approach (Th. A. Shannon, J.J. Walter, ‘Implication of the papal allocution on feeding tubes’, *Hastings Center Report* 34 (2004), n. 4, pp. 18-20). However, this is not the case. The only thing that the Supreme Pontiff does is characterise the administration of food and liquids as a normal treatment which must take place at the level of general principle even in the case of a patient who is in vegetative state. The method of the administration of food and liquids, for example through a tube into the subclavicular vein (which is not without its risks) or through a gastric tube, if it is the case that this causes problems, can be or become disproportionate and must therefore be interrupted. The administration of food and liquids through a gastric tube in the case of a patient in a permanent vegetative state is, however, in general proportionate. The distinction between proportionate means and disproportionate means has not, therefore, been abandoned by the Supreme Pontiff.

[21] Cf. W.J. Eijk, ‘Eutanasia: terminologia e prassi clinica’, *Rivista Teologica di Lugano* 2 (1997), pp. 221-243.

[22] ‘Permissive euthanasia’, *Boston Medical and Surgical Journal* 110 (1884), pp. 19-20, quotation p. 20.

[23] D. Tettamanzi, *Eutanasia. L’illusione della buona morte* (Casale Monferrato, Piemme, 1985), p. 24.

[24] G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen, and P.J. van der Maas, *Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie*, p. 64.

[25] That is to say 3,800 cases of euthanasia and assisted suicide (*ibid.*, p. 52) and 1,000 of the ending of life without there being a request of the patient to do so (0.7% of140,377, *ibid.*, p. 56).

[26] *Ibid.*, p. 71.

[27] ‘Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications’, see http://www.who.int/cancer/palliative/definition/en/.

[28] R. Bruntink, *Een goede plek om te sterven. Palliatieve zorg in Nederland. Een wegwijzer* (Zutphen/Apeldoorn, Plataan, 2002), p. 12.

[29] ‘Care during suffering and dying’, in *Euthanasia and human dignity. A collection of contributions by the Dutch Catholic Bishops’ Conference to the legislative procedure 1983-2001,* Utrecht/Leuven, Peeters, 2002, pp. 144-152.

[30] M. Oostveen, ‘Spijt. Voorvechters van de euthanasiepraktijk bezinnen zich’, *NRC/Handelsblad* (2001), 10 November, Saturday Supplement, p. 25.

6. Inter-religious Dialogue: Palliative Care in the Other Great Religions

ABRAMO ALBERTO PIATTELLI

6.1 Judaism

The subject of this international conference on ‘palliative care’ refers in the first instance to a very painful and deeply dramatic problem – that of the pain and suffering endured by an individual.

For Jewish culture as well, the problem of suffering in general, and physical suffering in particular, has always been a central question both in theology and the daily practice of each believer.

Looking at the terrain of reality, where, that is to say, the work of Providence continually expresses itself, the words of the traditional saying resonate: ‘every day God renews with His mercy the work of creation’. This is to say that there is an awareness that divine will establishes the destiny of every man, what the quality of his life must be, and if his life must continue or end. For the believer, the existence of man is incomprehensible if it is separated from divine will.

But how can the existence of suffering and evil be justified in the eyes of the faithful, that is to say the person who believes in the mercy and justice of God? The question becomes even graver if it is set beside the constant passion and concern that God has for man. ‘Why do you hide your face from me and treat me as an enemy’? implores Job, who thereby expresses the imploring of so many unhappy suffering people.

It is superfluous to repeat that suffering and its inexplicable character constitute an element that can have negative results for religious practice and faith, and even for those who assist and surround the suffering. This is because for the most part suffering is seen as the ruin and the failure of an existence, the breaking of physical and spiritual equilibrium, and the loss of the integrity that is necessary to religious service and the performance of one’s own responsibilities.

We well know the position of the Bible in this matter: suffering can be an instrument for a retrieval of a man’s relationship with God: ‘ Blessed is the man whom thou dost chasten, O Lord’ (Psalms 94:12), or again ‘I suffered distress and anguish. Then I called on the name of the Lord’ (Psalms 116:3-4). However, suffering remains something that is highly negative if what the Talmud states in relation to it is right: ‘whoever’s body is subject to suffering has a life that is not worthy of that name’ (Bezà 32b). And Rabbi Jochanan answered those who tried to explain to him the high meaning and the envisaged reward for the great suffering that he was undergoing in the following way: ‘I accept neither suffering nor the reward envisaged for it’.

The Jewish masters of antiquity posed themselves the question of how to reduce suffering and pain. In Rabbinical literature, potions and medicines are envisaged that are designed to remove certain kinds of suffering. More interesting are the suggestions that evoke the mentality and their ethical-religious culture of the time. Thus, for example, study of the Torah, the moral law, is held to be an important antidote in the reduction of pain. In a certain sense this was a matter of making contact with divine words and understanding their meaning and their suggestions. Thus was recommended a reading of the psalms and the saying of prayers, above all those written for such a situation, prayers such as: ‘if I have sinned, cancel, O Lord, my wrong, thanks to your great mercy, and not through suffering and grave illness’. In addition, actions such as initiative involving charity, works of philanthropy, visiting the sick, comforting people afflicted by mourning, rejoicing at the weddings of young people, and so forth, were all recommended.

In the Jewish approach, pain and suffering are seen as a real and authentic illness and are thus treated on a par with every other malaise, taking into account all the risks and dangers present in their treatment as well. The role of the medical doctor is to heal but also to reduce pain, even though a full cure may not follow from such treatment. Indeed, such treatment is very much to be suggested because it may happen that the patient will return to the fundamental rhythms of his existence, especially as regards diet and his relationship with his immediate environment, once the burden of his suffering has been reduced. The medical doctor, today, is faced with a broad spectrum of means by which to intervene in relation to pain. What is required is knowledge of the techniques connected with the suitable administration of suitable drugs and medicines. This must take place with the support and help of other professionals and workers who are skilled in supporting the condition of the patient and the administration of palliative cures.

A Jewish believer accepts malady with faith but he does not love it; he fears it because he is never sure that he will be able to bear the trials involved and keep his faith intact. Suffering and pain lead man to look inside himself and accompany him also in searching for closeness to God. Through prayer he hopes to influence the inscrutable paths of God and the eternal decisions of Providence.

In the Jewish approach, life is something that has an infinite value; it is an experience that is destined never to be repeated throughout eternity. Relief from illness and suffering exalts the value of life and the sacredness of life. 'The Lord has chastened me sorely, but he has not given me over to death' (Psalms 118:18), declares the man who has been cured and has had his health restored.

From this experience is born the teaching that in life nothing is ours and that what we possess, including life, is a pledge that can be taken back, suddenly, when we least expect it. But as long as a pledge such as life is in our hands, we are responsible for the feeling of mission that we must have and for the use that we must make of it, in conformity with the words: ' the living, the living, he thanks you as I do this day' (Isaiah 38:18)

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6.2 Rhythm Restoring Therapy and Palliative Care

In spite of the advance achieved by medical science it is still practiced as an empirical art based on experience. Medical is the art of how to apply given information (scientific, experiential or otherwise) in order to achieve what is known as health. Health is not simply the absence of certain illness or symptoms. The process of human health should be basically based on some process orientation.

The concept of 'health': a process approach

Health is a process rather than a static decent quiet state of body or mind. Health is achieved through active harmony between hierarchical levels of organisation starting from intrapersonal levels up to innumerable cosmic levels. Achieving health cannot simply be a linear pre-determined sequence. It is essentially an active biorhythmic pulsation of living matter in a crescendo open ended march that allows assimilation alternating along some open-ended rhythm. These processes are usually associated with optimum accompaniments including growth pains and variable degrees of serious striving.

On the other side, disease is not simply the opposite of health in a linear polarised fashion. It is some sort of handicapping and/or agonising disharmony of the natural healthy processes. The main goal of managing illness hazards is not simply to get rid of the noxious agent but is essentially to promote health march to its ultimatum.

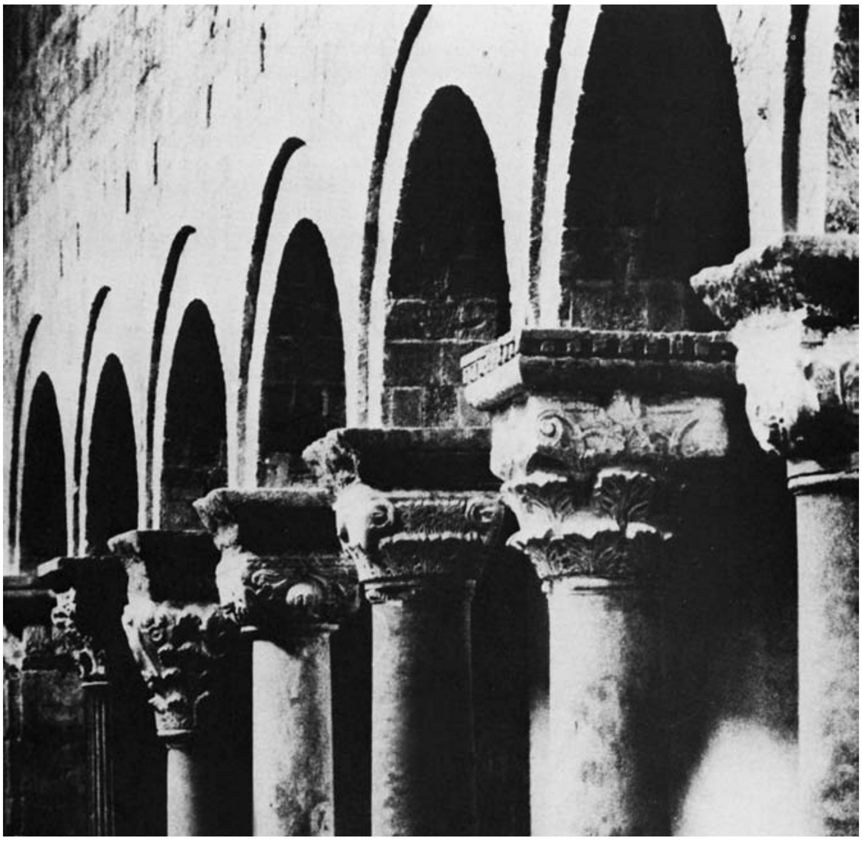
Not infrequently, we are confronted with diseases that are certainly incurable as far as the current medical resources allow. They are usually terminal and refractory to any sort of curative management. The practical goal in such a case is to alleviate pain, maintain some realistic hope and provide the available best chance for living or leaving, peacefully and with dignity. This is what is usually referred to as *palliative care*.

Death is part and parcel of life

script. As much as disease is not simply the linear opposite of health, death is not the mere opposite of life. Uncovering the profound meaning of such concepts is beyond the naive common connotation of words. However, we live it by all means.

Pain palliation and harmony

Pain, as traditionally conceived, results from the perception of some noxious intolerable stimuli. Pain could be alarming, agonising or handicapping. It turns to be ‘hell’ if it induces disrupting disharmony extending to the whole of existence (including the ‘soul’ with its different connotations) perpetuated through intolerance despair and infantile dependency. Psychic or physical pain can be tolerated to a certain degree if it is confined to perception of limited disharmony. If its effect extends to the whole of existence the ‘hell of agony and despair’ results. This is what this paper suggests calling ‘Disharmony Hell’.



Religion as tranquilizer

Religion is one of the most basic constituents of any culture regardless of the attitude of each individual in such culture. When religion is invited to participate in palliative care it may be reduced to some sort of spiritual tranquilization or naïve encouragement. However the role of religion as a tranquilizer should not be devaluated. Religion used as a tranquilizer could pursue many leads; some of which could be:

1. Enhancement of patience and surrender to one’s fate (occasionally called God’s will).
2. Emphasis on the coming comfort in the after life.
3. Keeping hope in a divine miracle going beyond medical considerations.
4. Living pain as an opportunity for salvation for some known or unknown guilt.
5. Inviting certain mental mechanisms such as ‘denial’ or ‘dissociation’ to neglect actual pain through directing the focus of awareness to some more central idea (here: faith or God).

All such procedures could be helpful and may achieve some level of comfort. However, the restriction of religious support to this level of help may devalue the role of religion as a means to pursue profound and extending harmony.

The essence of religion as a harmonising biological programme

Religion acts ultimately to maintain, enhance and restore natural harmony within the self and beyond it. The extended harmony, even in the after life, could be more conceived as a natural sequence of current cultivated harmony. Death could also be part of such extended melody. The hypothesis made by the author considers such a tendency to be both biologically and existentially rooted. The following are but some broad lines of such an approach.

Basic assumptions

1. The whole world (living and non living) is maintained in some sort of harmony.
2. The living world’s harmony is essentially biorhythmic.
3. The concept of health is related to the maintenance of native harmony along an open-ended extending scale.
4. Disease is but some sort of disharmony.
5. The hypothesis made by the author claims the existence of a drive (programme, instinct) for which he has coined the name ‘harmonising biorhythmic programming (or instinct)...’
6. Considering the nature of such a programme could allow dealing with health and disease as some positive or negative processes needing proper management (promotion and maintenance) or reparation (re-harmonising or rhythm restoring).

Broad lines of ‘The hypothesis’

1. There is an innate tendency of living structure to reorganise itself in order to synchronise its own harmony with that of wider and wider circles of organisations to-

wards the open-ended unknown macro-cosmos.

2. Plants and almost all sub-humans are not aware of such a programme (or instinct).

3. Man could be partially aware of this unfolding. A wide range of individual differences are met with.

4. Certain creatures are more aware of such a programme.

5. Prophets are much more aware.

6. Presentations and consequences of such awareness differ according to many variables such as language, culture, historical era and available tools.

7. The most useful and objective acting out of such a programme have been represented in faith and religion all through human history.

Religion as rhythm restoring in palliative care

Disharmony hell is more liable to occur in those persons who have their personal egos so inflated as to replace the whole world including God. An inflated isolated exclusive self-centered ego is more vulnerable to deflation and disharmony. Proper religious faith and practice emphasise some continuous 'in-and-out programme' between the individual and the cosmic uterus perhaps analogous to the one hypothesised by the object relational theorists along the march of individual growth between the individual and the womb.

The relation of this harmonising function of religion as a profound basis of human life, not only spiritual but also biological, is apt to achieve alleviation of the hell of disharmony (not simply the agony of pain) regardless of the possibility of cure. This could occur through dilution of whatever limited discordance there is through integration with the extending melody. Including death as part and parcel of the macro-melody may put it in the proper place of the holistic harmony.

What is called 'Rhythm Restoring Therapy' draws its basic assumptions from the teleological function of both religion and evolution. Rhythm restoring is primary natural. Any disharmony bears its self-reparation mechanism unless blocked or handicapped. However, in terminal and refractory illnesses this natural coping is wholly or partly deranged. Rhythm restoring therapy is an attempt to reactivate such natural processes by all means. This needs a trained therapist cultivating his own harmony through his patients towards the ultimate cosmic harmony.

The so-called Rhythm Restoring Therapy is not an exclusive religious approach. It is basically related to many theoretical and practical disciplines some of which are:

1. The biorhythmic approach.
2. Jung's synchronicity.
3. The structural diagnosis (Eric Bern).
4. The in-and-out programme (object relations theorists)
5. The evolutionary rhythmic theory (Rakhawy)
6. The therapist as a co-pulsating organism.
7. Extending harmony via faith and creation.

Some Merits of Islam

as an example of the non-exclusive harmonising role of religion and faith

Achieving such harmony through Islam is accomplished through its basic simplicity and essential assumptions which the author realises and summarises as follows:

– Cognitive perception of God (Shahada) (i.e. not simply intellectual conviction of, or thoughtful believe in God).

– Direct relation with God (no intermediate authority).

– Direct relation with nature (almost all Islamic rituals function in the direction of sensory awareness and are timed by personal human relation with cosmic bio-rhythms especially circadian ones).

– As a result: object relations (especially human) are essentially achieved along with, and under the umbrella of, God as active participant.

– Man is the ultimate judge of his doings 'here and now' and afterwards.

– Most Islamic praying and rituals could be perceived in terms of:

- Emphasising the direct relation with raw nature especially along its biorhythmic pulsations.
- Personal freedom is profoundly achieved through genuine monotheism and continuous direct relation with the macro-cosmos as some biological concrete fact rather than an abstract concept.

- Enhancing convergence towards a common central idea and goal idea which may be represented by some central location as symbolic as it could be.

Islamic praying goes on in circumferential circles, converging towards a central goal along certain signals of circadian rhythm while the raw earth at large is but 'my mosque'. Fasting (through Ramadan) is also declared by the direct vision of the crescent rather than the astronomers' discipline or calculations. The rituals of Islamic pilgrimage also illustrate the everlasting biorhythmic circulation (around Al Kaaba), the 'in-and-out programme' between Al-Safa and Al-Marwa and the dislodgement phase by jogging (Harwala) in certain area during this trip. Standing on mount Arafa during pilgrimage could be another reference to the emphasis of the direct relation of man to naïve nature.

All such observations are not in the least an attempt to interpret certain rituals in some scientific jargon. It is simply an attempt to show how Islam is simple, directly related to native nature and extending along some harmonising activity to achieve an open ended biorhythmic growth march.

Conclusions

– Using a religious approach to alleviate pain (palliative) should not reduce religion to some possible tranquilizer acting through naïve encouragement.

– Rhythm restoring therapy is a multi-dimensional discipline including religious approach in biological existential terms. It utilises almost all modes of therapy where palliation is considered as the by-product of proper handling.

– Cultural, sub-cultural and individual differences should be considered all the time.

– In spite of the possibility that terminal patients have the right to leave in peace and dignity, *euthanasia* seems to be a shortcut solution more related to conceptualising the individual apart of his extension in the universe both transversely and longitudinally. Rhythm restoring approach makes euthanasia less rational.

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6.3 Palliative Care – Hinduism

Overview of Hinduism

What is Hinduism? Many questions are asked about Hinduism:

– Is it a system of beliefs?
– Is it a medley of rites?
– Is it a mere geographical expression?
– Why have its contents altered form age to age, and vary from community to community?

To the west, it tends to appear as a rich but rather baffling tangle of myths with endless gods and goddesses worshiped in countless different forms

The Hindu civilization is so called since its original founders and followers occupied the area drained by the Sindhu (Indus) river system (*Rig Veda*). The term *Hindu* is a Persian word and means simply India. *Hinduism* is this Ism of Indian people.

It is one of the oldest religions of the world with about nine hundred million followers. It is over five thousand years old although the elements of faith are much older. It does not have any single founder, teacher or prophet. A Hindu believes there is one ultimate reality behind the universe called *Brahman*, which is manifested as God and Goddesses. The same ultimate reality exists within all human beings as an inner soul.

Him who is the one real sages name variously (Rig Veda I- 164.46)

He is never born, nor does he die at any time, nor having (once) come to be will he again cease to be. He is unborn, eternal, permanent, and primeval. He is not slain when the body is slain. (Bhagavad-Gita 11-20).

Hinduism recognises three paths of salvation:

– Path of Knowledge (Janana).
– Path of devotion (Bhakti).
– Path of Work and religious performances (Karma- action).

The *Karma (action)* is central to the Hindu faith. You reap what you sow.

But he controls the senses by the mind, O Arjuna, and without attachment engages the organ of action in the path of work, he is superior. (Bhagavad-Gita 111-7)

Therefore, without attachment,

perform always the work that has to be done, for man attains to the highest by doing work without attachment. (Bhagavad-Gita 111-19)

A common Hindu may not have read vast majority of religious scriptures, his life is influenced by traditions, stories and practices of people.

To summarise, Hinduism is more an approach to the universe, a way of living, rather then an intellectual system of philosophy. Therefore it is difficult to separate religious elements of Hinduism from social, racial and even political elements which also make up Hindu culture.

Acceptance of incurability of disease and death as a natural process

In palliative care, the patients and family accepts the disease as incurable, which leads to understanding that death is inevitable and is not a disaster. In fact while the patient is heading towards the end, for the family and social unit it is a preparation for the inevitable.

Hinduism believes in the rebirth and re-incarnation of the soul. Therefore death is never a calamity. Rather it is a part of cosmic cycle. There are four stages of life:

– Brahmcharya Ashram (student life).

– Grahasth ashram (family life).

– Vanprasth Ashram (retirement life).

– Sanyas ashram (detachment and renunciation).

For to the one that is born death is certain and certain is birth that has died. Therefore for what is unavoidable, thou shouldst not grieve. (Bhagavad-Gita 11-27)

Euthanasia

– *WHO*. Palliative care affirms life and regards death as a normal process, it neither hastens nor postpones death.

– You matter because you are you. You matter to the last moment of you life and we will do all we can to help you die peacefully*, but also to live until you die (Dame Cicely Saunders)*

Euthanasia:

– This is a controversial subject involving moral, ethical and legal issues.

– The majority of countries including India have not legalised it.

– It weakens the societies' respect for the sanctity of life.

The Hindu view on euthanasia

There is hardly any direct reference on euthanasia. As I said before, a common Hindu bases his life on traditions and stories. Let us see what is the Hindu view on euthanasia is.

– Path of Ahinsa (Non-Violence).

– Dharma (religion). For a common Hindu it is a moral and ethical duty to take care of older members of the family and community.

– Killing. This interferes with the soul's natural progress of liberation due to untimely death.

– Karma (actions). They are central to Hindu faith. Killing in any form brings bad karma (action) to the killer because of the principals of non-violence.

Non-violence, equal mindedness, contentment, austerity, charity, fame and ill fame are the different states of being proceeded from me alone. (Bhagavad Gita X- 5)

Euthanasia or suicide should not be confused with *Prayopavesa-* fasting to death in Hinduism. It is acceptable under certain circumstances and is only for people who are fulfilled and have no desire or ambitions in life.

Spirituality

What is spirituality? It defies a single definition. It is not restricted to those who belong to a religious denomination. In fact spirituality can do without religion but the opposite is not true. This is often expressed as a relation with a god, but it can also be about nature, art, music, family and community or whatever belief or value gives a person a sense of meaning and purpose in life.

In fact spirituality is a constitutional part of human life and for this reason a carer cannot ignore the spiritual needs of patients in palliative care setting. Though dying is often taken as a biological event, it is a physical, social and spiritual event.

Spiritual practices in Hinduism

Spiritual care in the Hindu tradition starts from the moment of conception and continues throughout life and into the next one.

– In Hinduism we believe that quality of death depends upon quality of life. Therefore spiritual practices are important to life, to death and to transmigration to a new body.

– Death should not take a person unaware; rather it should we peaceful, voluntary and willed.

– Conventionally, the soul should leave the material body behind with the name of God on the lips heart and mind of the dying.

– If the dying person is unable to do this, the responsibility to chant, read from scriptures, lies with relatives, friends and spiritual masters.

He who utters the single syllable Aum (which is) Brahman; remembering me as he departs, giving up his body, he goes to the highest goal. (Bhagavad-Gita VIII-13)

There is another way at looking at the spiritual aspect of palliative care. In palliative care we try to find a solution to the problem that can be solved. If we cannot solve a problem the only way out is to learn to live with the problem without being troubled by it. This is possible if the person's mind has moved beyond the problem though the problem continues to exist. The capacity of the mind to move beyond the problem – transcendence – also helps the person find peace.

To attain this transcendence there are many methods in Indian scriptures:

– Karma Yoga (Action).
– Bhakti Yoga (Devotion).
– Raj Yoga (Meditation).
– Janana Yoga (Knowledge).

There is no single solution to offer for the spiritual needs of the dying person in Hinduism. People from diverse cultural traditions achieve this transcendence in their own way.

Bereavement Care

Bereavement may be viewed as a 'state of thought, feeling and activity which is a consequence of the loss of a loved or valued object.' (Peretz, 1970).

Bereavement is a highly stressful event, frequently evoking a powerful emotional, physical and/or intellectual reaction. Very often the bereavement states are self-limiting and require no specific treatment.

The purpose of any bereavement support programme is to provide comfort, support and information to surviving relatives and friends in an effort to alleviate the distress of bereavement

Hinduism and bereavement care

In the Hindu tradition the bereavement support is a spontaneous process. Traditionally, Hindu families have a joint family system. Therefore family and financial support are taken as granted and automatic.

There are well laid down norms and traditions that a common Hindu follows after the death of a near and dear.

Normally the eldest son of the deceased performs the last rituals. As a tradition he gets his head shaved. To be part of his grief, the other male members of the family also get their heads shaved.

The food is not cooked for ten days and is offered by the relatives and community.

On the third day of death, the members of the community gather together with the family to share the grief.

On the tenth day of death, the family and members of the community gather together, distribute food and clothing to the poor and the eldest son of the family is declared the head of the family.

On the thirteenth day again, food and other things are offered to various priest of community.

Then there is a shantipath-prayer for the peace of the departed soul.

On the date of death, every month for a year, the family priest is offered food and other things.

No celebrations and marriages are performed for one year. On the completion of one year, the family, relatives and members of the community gather for prayer for peace and food and other things are offered to the priests.

Conclusion

Although the modern palliative care movement started in the United Kingdom in the last century, various elements of palliative care i.e. approach to death, spiritual, psychosocial and bereavement support, are part of Hindu culture and have been practiced for thousands of years. Thus, the Hindu way is most suited to support the many elements of palliative care.

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6.4 Buddhism and Palliative Care in Japan

First, I would like to thank the Pontifical Council for inviting me to join this conference. In this speech I would first like to talk about the relation between Buddhism and palliative care. Then I would like to follow that with a discussion about palliative care in Japan. Buddhism was started by a man who found the answer to the problem of suffering that comes from the fact that there is no escape from death. Hence, Buddhism has been related to palliative care, especially spiritually, since its birth. Buddha descended from the noble family of Shakya who shared in governing the small state of Kapilavastu which is now near the border of India and Nepal. His whole life was quite different from that of Jesus Christ. He was not arrested and was not crucified. He grew up as a wealthy aristocrat, got married, and had a child. His happiness ended when he became conscious of the basic facts of existence. He saw old age, sickness and death. He worried that he too would grow old, sicken and die. He decided to leave his home and chose a life of homelessness, seeking salvation from suffering – such as aging, disease and dying – in the practice of Yoga. He was twenty-nine years old. After 6 years of practice, he solved the problem of suffering, reconciling with the fact that there is no escape from death. That led to a way of life where one continues to control one's egoism completely. The spiritual pain of aging, disease and dying disappeared in Buddha once he realised complete freedom from attachment to the self, which included the attachment to his own life. At the same time, the compassion not to discriminate others from oneself appeared in his heart. Buddha was enjoying a kind of Yoga that blew away the spiritual pain related to death. He thought his knowledge was foreign to the world. How could the world be expected to understand him? He hesitated to tell people about this salvation. Telling the truth often harms a person if the truth is that their life will end. But without telling this truth, the chance that others would realise their own salvation would be missed. It is interesting to note the similarity between Buddha's hesitation to tell the truth about his salvation and telling a cancer patient the truth about their condition. To tell patients that their cancer cannot be cured could cause them spiritual pain. After an inner struggle with paradox, Buddha decided to teach others about his salvation out of compassion for humanity.

Buddha's first students were his five former ascetic companions. He told them about 'the fourfold noble truths' which are 'suffering', 'the cause of suffering', 'the extinction of suffering,' otherwise known as Nirvana, and 'the path to Nirvana'. 'Suffering' was Buddha's main concern. Here, 'suffering' is a translation of the Sanskrit word *'dukkha'* which means, literally, 'to be denied what we desire'. Buddha said that there are eight sufferings. The first four are birth, aging, disease and death. The last suffering summarised all sufferings. It is the attachment to oneself. Attachment to the self is the fundamental suffering. 'The cause of suffering' is passion, such as the passion for sex, the passion to live and the passion to die. These three passions correspond to the three elements of life in biology, those being: reproduction, dynamic equilibrium and death. 'The extinction of suffering' is the state of Nirvana where passions are extinguished and suffering, i.e. attachment to self, is also extinguished. 'The path to Nirvana' is where one controls passions completely. Attachment to the self being controlled compassion for all others appears. Buddha's doctrine has no purpose in and of itself. It is but the means which brings happiness to the people. And Buddha showed, using the metaphor of a raft, that the essence of the doctrine was to leave attachments. Imagine a person walking down a road. He comes to a large river. The shore on his side of the river is dangerous, but the shore on the distant side is peaceful. He makes a raft. He crosses the river using the raft and reaches the other shore. After arriving at the other shore, he should leave the raft on the shore and continue on his journey. In this case, the raft is a metaphor for Buddha's doctrine itself! Metaphor literally means "to carry over". And Buddhism too is just a metaphor that carries people over to the other shore of happiness. The raft should be thrown away once one has crossed to the other shore. A Buddhist does not attach to Buddhism itself and also the non-attachment of Buddhism does not attach to non-attachment itself. Buddha said what I can control freely according to my desires is mine. But, what I cannot control freely according to my desire is not mine. We do not have control over our bodies as far as birth, aging, disease and dying are concerned. So, in order to control ourselves we must recognise that our bodies are not our own. There is nothing that can be said to be mine or myself because even this body does not belong to me. If one considers oneself thus, one does not discriminate others from oneself. This is the wisdom of equality in Buddhism. Having compassion for all people without attachment to oneself is the situation of the

Buddhist who affirms all others' religions equally. Therefore, many personalities gradually came to be included in Buddhism, and the concept of Mandala, which encompasses all types of human life, was developed.

Buddhism as such expanded thoughout Asia thanks to its association with medicine. In the third century B.C., Ashoka, King of India, made a medicinal herb garden which is the oldest one of its kind in the world. He sent Buddhist priests to many foreign countries to treat people with medicine from his garden. In this way they could save people from physical diseases through medicine and from spiritual suffering through Buddha's teaching. It is interesting to note that in Japan the first national hospital was built in a Buddhist temple. Unique Buddhist manners and rituals for dying were developed in Japan. One of the ideas that was developed is contained in a text named 'The most important mystery in this life.' It has nine chapters. In the first chapter it says that while a disease can be controlled by medicine one must never give up to nor accept death. Second, it says that if a disease cannot be controlled, and there is no way to be healed, one must not cling to life. Third, if this is the case one should move to a palliative care unit, because if one stays home, one would cling to life as it is at present. If no palliative care unit is available, one should imagine being moved to such a place. The fourth to eighth chapters instruct one to bring and pray to one's principal object of worship, which may be one of various Buddhas, Bodhisattvas or any god or goddess, confess one's whole life to that object of worship, seek salvation, imagine the other shore of one's ideal personality of worship and prepare for death by concentrating one's mind on one's own ideal personality of worship – which is the essence of yoga. Ninth, it says that during the memorial service the family should do good deeds in place of the deceased so that the deceased's soul will rest in peace. This describes Buddhism's approach to illness and death.

Next I would like to talk about how this relates to the current approach toward illness and death in Japanese medicine. The word 'religion' was translated into Japanese as two characters, '*shuu*' and '*kyou*', which literally mean 'mystery' and 'doctrine'. The latter half, 'doctrine', corresponds to the rational part of religion which can be transmitted easily by words. The first part 'mystery' corresponds to the part of religion that is outside rationality and cannot be transmitted by words and requires a master-disciple type transmission. Almost all Japanese culture developed under the influence of esoteric Buddhism and followed the formality of 'mystery and doctrine' and included a master-disciple type transmission. The Japanese cultural changes that grew from this esoteric influence include the Japanese art of flower arrangement, poetry, calligraphy, painting and theatrical performances. Also, a non-verbal communication style gradually became more important than that of open verbal communication. To understand something difficult which cannot be expressed in words easily, one needs to relive it or experience it vicariously. But vicarious experience requires that one has already, at some point, had the actual experience. If they have not, metaphors or symbols were frequently used to help people vicariously understand these experiences. The most difficult things to understand, such as the mystery of Buddha's realisation, are called 'secrets'. The word 'secret' in Japan did not mean to hide the truth but described something that was difficult to understand by verbal communication.

To help you understand the current state of palliative care in Japan, please consider some things that have appeared in the medical journals. The May 1988 issue of a weekly magazine called 'Medical Tribune' reported that a summit conference on cancer was held using satellite communication. The chairman of the Soviet Union Cancer Society mentioned that he does not tell cancer patients their true diagnosis because it gives the patients mental pressure and this, in turn, has a negative influence on their condition. The American doctor said that he tells cancer patients their true diagnosis as a matter of course. I think it is because American hospitals have spiritual care workers that doctors there tell their patient the truth, whereas former Soviet hospitals did not. How to prolong life depends on refutable matters so science and doctors can handle it properly. But how to live a limited life does not belong to science. So, spiritual care workers must take care of it. In a paper ironically titled 'Cur-

able cancers and fatal ulcers: attitudes toward cancer in Japan' published in 1982, it was pointed out that Japanese patients having terminal cancer are generally not told their true diagnosis. Japanese doctors do not approach patients by open verbal communication. It points out that vagueness is an important part of Japanese culture and that there is a principle of secrecy in Japanese culture. This culture of secrecy and vagueness originated in Buddhism. Unfortunately, Buddhism was excluded from Japanese society in 1868 by the revolutionary government of the Meiji period emperor. When Western culture was adopted to modernise Japan, the government tried to exclude Christianity from the adopted western culture. Instead, the government tried to replace Christianity with Shintoism, the religion of the emperor. However this attempt did not succeed and the people in charge of spirituality disappeared from Japanese hospitals. After that revolution, the formal vagueness was left without any attachment to its important Buddhist spirituality. The resulting absence of spirituality, and therefore spiritual care workers, in Japanese hospitals makes it difficult to give a true diagnosis to cancer patients. Maintaining the principle of informed consent still is not perfect in Japan although it has become the most important principle in medical ethics through the Helsinki and Lisbon declarations. Buddhist priests are not doing their essential work, using the raft to transfer patients to the other shore of palliation, in present day Japan. Currently, many palliative care units exist in Japan. The main job at those palliative care units is not the relief of spiritual pain but only the relief of physical pain. The training of spiritual care workers is necessary since they are currently absent from most medical institutions in Japan. And we hope to learn a great deal from the Vatican about how to educate our spiritual care workers. Thank you.

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Reference

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JÁN ĎAČOK

6.5 New Age, Post-modernity

Introduction

To examine palliative care from the point of view of New Age and post-modernity is certainly an original undertaking. But it is also clear that it is not easy to offer a satisfactory answer. This paper of mine seeks to offer a schematic representation of the New Age movement and the complex phenomenon of post-modernity. Both of these concepts will be presented from a philosophical-social-cultural and ethical-cultural point of view. Palliative care is examined within this context.

New Age

The New Age movement belongs to the principal characteristics of post-modernity. Called also 'the age', the 'Age of Aquarius' or the 'new era',[1] New Age constitutes a religious subjectivity that is particularly widespread in the industrialised West. More than engage in a definition of what New Age is,[2] in general terms one can offer a description. The recent inter-decasterial document of the Holy See describes New Age in the following terms: 'New Age is not exactly a religion, but it is interested in what is called 'divine'. The essence of New Age is the free association of various activities, ideas and people to which and to whom this term can be applied. Therefore, a definitive organisation of something like the doctrines of the principal religions does not exist. Despite this, and notwithstanding the immense variety that exists within New Age, one can identify certain shared points: the cosmos is an organic whole; it is animated by an Energy that is also identified as Soul or Spirit; and there is a great deal of belief in the mediation of various spiritual bodies. Human beings are able to ascend to invisible higher spheres and to control their lives beyond death. The existence of 'perennial knowledge' is affirmed and this is said to have existed before, and be superior to, all religions and cultures. People follow enlightened teachers…'.[3]

Jean Vernette, the French scholar of New Age, explains its 'creed' in an interesting way, in the form of 'Ten Commandments' which are as follows: 1. You will wait for the Age of Aquarius with impatience. 2. You will believe firmly in the Great Change. 3. Your consciousness will awake in a careful way. You will be concerned with your body in an active way. 5. You will respectfully follow your teachers. 6. You will believe in the irrational completely. 7. You will worship the goddess Gaia (the earth) with loyalty. 8. You will rigorously reject existing religions. 9. You will speak with spirits in all naturalness. You will laugh at death with serenity.[4]

The movement of Aquarius will offer mankind the opportunity of creating a religion that is completely suited to man. It prefers man to become God and denies that God became man. This movement has the hope that it will take the place of Christianity. For this movement, God is not a person, or the God of Abraham, of Isaac, and of Jacob, or the God of Jesus Christ, but the highest vibration of the cosmos or the highest expression of transcendental consciousness. All of this is expressed in one of the chief mottos of the New Era: 'if you believe it, it is true'.[5] The man of the 'new age' no longer needs Revelation and as a result he does not need faith, grace and salvation through the cross of Christ. These can be replaced by inner illumination. As evil does not exist, nobody can be responsible for the evil that they have done to other people.[6] It is thus useless to be afraid of death because man will never die but will be reincarnated. To summarise: the religion of Aquarius and Christianity are two different things, two irreconcilable realities. It is not possible to believe in the resurrection and at the same time to believe in reincarnation. This new pseudo-religion explicitly rejects the Christian concept of God, the Christian concept of the person, and the work of Jesus Christ.

Post-modernity

Of the different attempts to offer a definition of post-modernity, here only two will be presented. The first comes from the Italian theologian Ignazio Sanna, for whom the term 'post-modernity' refers to 'the dissolution of the modern cultural synthesis and the advent of weak thought and the crisis of reason'.[7] The second attempt is the description of the concept of 'post-modernity' presented by John Paul II in his encyclical *Fides et Ratio*: 'Our age has been termed by some thinkers the age of "postmodernity". Often used in very different contexts, the term designates the emergence of a complex of new factors which, widespread and powerful as they are, have shown themselves able to produce important and lasting changes. The term was first used with reference to aesthetic, social and technological phenomena. It was then transposed into the philosophical field, but has remained somewhat ambiguous, both because judgement on what is called "postmodern" is sometimes positive and sometime negative, and because there is as yet no consensus on the delicate question of the demarcation of the different historical periods' (n. 91).

When, therefore, did 'post-modernity' begin from a historical point of view? There are different views on the matter. However, it is to be observed that a group of scholars see the year 1968 as 'the last explosion of modernity and the first birth of the 'age of after': after revolution, after reason, after history, after the vanguard, after religion'.[8]

Michael Paul Gallagher, an Irish theologian, points out certain features that constitute 'five of the chief columns of post-modernity': 1. distrust of man and his thought. 2. The dominion of aesthetic rationality. 3. The concept of narcissistic freedom at the social and political levels. 4. Distrust of the future. 5. The return of mystery and pseudo-religiosity.[9] To these characterising pillars of post-modernity may be added others, and these are in particular: a) nihilism; b) the difference principle; c) tolerance; and d) ecologism.

According to Gianni Vattimo, the post-modern abandons the 'strong' categories of traditional metaphysics and, basing itself on F. Nietzsche and M. Heidegger, offers a 'weak' vision of being. Philosophy, understood as 'weak thought', has lost is founding role and as a result truth is unceasing interpretation and no longer an adaptation of thought to reality. In this approach, the anthropology of post-modernity is seen as weakened. For a schematic comparison of modernity and post-modernity, one could take three 'concepts' or 'subjects' typical of every form of culture: God, the world, and man. From a theological point of view, for modernity these terms are 'strong' and from the perspective of faith they are understood as the Creator, the creation, and the creature. For post-modernity, on the other hand, these same subjects have become 'weak'.[10] In this sense one can speak about three anthropological concepts of post-modernity: 1. the weakening of the concept of God. 2. The weakening of the concept of the world. 3. The weakening of the concept of man.

Post-modernity is a broad concept characterised by heterogeneousness, indifference towards values, uncertainty, the provisional, fragmentation, difference, nihilism, pragmatism, the indeterminate, the end of history, the strong influence of the mass media, distrust of man, of his dignity, of languages and of universal syntheses. Nietzsche's concept of the 'death of God' leaves an empty space. In this space the 'super man' develops, who becomes his own yardstick. Human life loses its intrinsic value, its religious and sacred meaning, and is thus exposed to every kind of exploitation.

To summarise, post-modernity is a complex reality of a philosophical-social-cultural kind that is also anti-metaphysical, relative, partial, nihilistic, aesthetic, secularised, lost, ironic and cynical. It leads to the obscuring or the weakening of being, the dissolution of the stability of being, and moral disengagement. Post-modernity prefers a spontaneous and infinite game of interpretations; it prefers a rhetorical and aesthetic experience to an experience of truth. Indeed, it rejects metaphysics and knowledge of truth. In other words, it tries to convince people that one cannot take seriously God, being, life, human language or science. As a result, post-modernity has a misleading, anti-human and anti-Christian character.

Palliative Care

In New Age there is no distinction between good and evil; sin does not exist. Only imperfect knowledge is recognised. Human action is the fruit of ignorance and of enlightenment. As a result, nobody needs forgiveness and nobody can be condemned. Those who believe in evil can encounter only negativity and fear. These can be overcome through love. In New Age acting against nature leads to suffering and illness. In contrary fashion, acting in harmony with nature leads to a healthier life and also to material prosperity. Suffering is also understood as an inability to exploit all human resources. In man himself is to be found the source of healing and this can be reached by entering into contact with the inner energy of man or with cosmic energy. According to some currents of New Age, man does not even need to die: through the development of human potential one can enter into contact with human inner divinity and with those parts of man that have been suppressed or alienated. New Age has a low evaluation of traditional science and medicine and sees these as inferior and as obstacles to the advent of the Age of Aquarius. New Age prefers holistic approaches and wants people to break with the traditions that they have grown up in. A typical element of New Age is reincarnation and this is understood as a necessary step towards spiritual growth, a progressive spiritual evolution that begins with birth and continues after death. Death is nothing else but the move of a soul from one body to another.[11]

For Peter Singer and Hugo Tristram Engelhardt, who are seen as the principal representatives of post-modern bioethics, life as such has no meaning. The value of human life is relative, obscured, and there is no recognition of its gradualness and ontological and axiological differences. The status of the human person is only attributed to self-aware individuals who can express their will. The bioethics of both these authors attribute no meaning to suffering, which is part of normal human life, to the terminal stage of life, and to death: in the face of these realities, one takes refuge in suicide, in assisted suicide and in euthanasia.

How can we locate palliative care in this context? When human life has no meaning, as nihilism affirms, or reincarnation is accepted, as New Age affirms, what is the point of dedicating oneself to a life that is coming to an end? Palliative care has no meaning in this approach. From the point of view of New Age, palliative care can only block the move to reincarnation. From the point of view of post-modernity, palliative care is a waste of material resources (medicines, occupation of beds, etc.) and personal resources.

Conclusion

New Age belongs to the specific characteristics of post-modernity. The contribution of palliative care in this context is denied by the nihilism that dominates European post-modernity and by the pragmatism that dominates post-modernity in its American form. For New Age and for post-modernity, palliative care has no meaning and thus such care must look for its justification in other systems of thought, and in particular in the Christian vision of life.

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Note

[1] Cf. C. Siniscalchi, *Il dio della California. La New Age cinematografica* (Rome, 1998, pp. 33-34); see also G. Filoramo, *Il risveglio della gnosi ovvero diventare dio* (Rome/Bari, 1990); *Figure del sacro. Saggi di storia religiosa* (Brescia, 1993); A.N. Terrin, *New Age. La religiosit‡ del postmoderno* (Bologna, 1993).

[2] From a grammatical point of view, the term 'New Age' is generally used in the female (understood as 'religion', 'religiosity', 'new age', 'new era', 'alternative spirituality', 'cultural current' and in the male (understood as 'movement', 'complex phenomenon'). The inter-decasterial document *Ges˘ Cristo Portatore dell'acqua viva. Una riflessione cristiana sul ?New Age*? in general uses the term in the male. In this paper, in its Italian version, both grammatical forms are employed.

[3] Pontificio Consiglio della Cultura/Pontificio Consiglio per il Dialogo Interreligioso, *Gesù Cristo Portatore dell'acqua viva* (Vatican City, 2003), pp. 30-31.

[4] J. Vernette, 'La nuova era', in C. Siniscalchi, *op. cit.*, pp. 112-116.

[5] J. Vernette, 'La nuova era', pp. 115-123; see also, I. D?s Del Rio, 'Postmodernidad y nueva religiosidad', *Religi? y Cultura*, XXXIX (1983), pp. 72-91.

[6] To the contrast between spirituality and Christian faith, on the one hand, and New Age and the theological analysis of this pseudo-religious form, on the other, are dedicated chapters 3, 4, 5 and 6 of the inter-decasterial document on New Age: cf. Pontificio Consiglio della Cultura/Pontificio Consiglio per il Dialogo Interreligioso, *op. cit.*, pp. 43-70.

[7] I. Sanna, *L'antropologia cristiana tra modernità e postmodernità* (Brescia, 2001), p. 20.

[8] I. Sanna, *op. cit.,* p. 253. Amongst these scholars reference may be made in particular to Agnes Heller, the Australian sociologist, and to Ferenc FehÈr, the American philosopher. See also A. Heller and F. Feher, *The Postmodern Political Condition* (Cambridge/ Oxford 1988), pp. 133-145. M. Nacci, 'Postmoderno', in P. Rossi (ed.), *La Filosofia. Stili e modelli teorici del Novecento,* IV (Turin, 1995), pp. 370-372; R. Ceserani, *Raccontare il postmoderno* (Turin, 1997), pp. 34-42.

[9] Cf. M.P. Gallagher, 'Parlare di Dio nella cultura di oggi', in P. Poupard (ed.) *Parlare di Dio all'uomo postmoderno. Linee di discussione* (Rome, 1994), pp. 5-22.

[10] Cf. G. Vattimo and P.A. Rovatti, ed., *Il pensiero debole* (Milan, 1983); G. Vattimo, *La fine della modernità. Nichilismo ed ermeneutica nella cultura post-moderna* (Milan, 1985, 1999)3.

[11] Cf. Pontificio Consiglio della Cultura/ Pontificio Consiglio per il Dialogo Inter-religioso, *op. cit.,* pp. 22-24; 32-39; 57-81.

III Section

What Should Be Done?

CARLOS AMIGO VALLEJO

1. The Pastoral Renewal of the Sacraments for the Sick: Reconciliation, Anointing, Viaticum

What should be done? After examining in previous sessions the situation of the sick, in circumstances that are certainly special, and after allowing ourselves to be illuminated by the light of revelation, theology and religious traditions, a question remains: what should be done? This was the same question that was posed to John the Baptist. The answer is faithfulness to he who was to baptise with the Holy Spirit and fire (Lk 3:16). The pastoral renewal of the sacraments must always take place along the path of a new encounter with Christ and faithfulness to him. This, too, is a very important point in what must be a new evangelisation.

1. The Sacraments for Life

'Just as we see that the human body is adorned with its own means for looking after the life, the holiness and the increase of its own individual limbs, so the Saviour of mankind, by his infinite goodness, looks after in an admirable way his mystical body of Sacraments, with which the limbs, almost through uninterrupted levels of graces, are sustained from the cradle to the last link and contribute with every abundance to the social needs of the whole Body' (*Mystici Corporis Christi*, 9).

I believe that this 'from the cradle', which is expressly affirmed by the *Mystici Corporis Christi*, should be borne in mind when reference is made to pastoral care in relation to sacraments for the sick. This is because pastoral care in relation to what is practically the last moment of life should be separated from pastoral care in relation to the whole of a person's existence. When, during one's life, one works in union with Christ, and for his growth, one also prepares for those moments when illness (and especially the last illness) arrive. One should say that everything should contribute to union with Christ or to conformity with Christ.

The words of the encyclical of Pius XII place us on the best road possible by which to draw near to the practice of the sacraments. This is because faith in Christ is a way of living and the sacraments are the sources that come from the spring of the Vivifying Christ who gives life to a person in all his or her individual reality, 'body and soul'. The exterior and tangible signs express all of this but grace alone gives life and sanctifies. Man, therefore, whatever his situation, has the duty and the right to draw near to the sacraments and to receive them.

Penance re-establishes, attends to, and strengthens the alliance with the Merciful One. Anointing is a sign of strength and of the hope of being recognised amongst those who belong to the body of the Anointed One. Viaticum is *pignus futurae gloriae* and perfect communion with the Lord, who gives life.

The renewal of pastoral care in relation to these sacraments must take place by means of this journey of life, placing them deeply in the existence of the believer and finding there experience itself of God. To achieve this, one may observe that in any attempt to renew pastoral care in the relation to the sacraments, unity between faith, the sacrament, charity and mission is of inescapable importance. Without faith, a sacrament would be reduced to mere ritualism. Without charity, one would fall into escape from responsibility towards the requirements of the new commandment of the Lord. Without evangelising witness, it would be a failed mission, a hidden light.

2. Illness: a Special Moment of Grace to Celebrate Reconciliation, Anointing and Viaticum

Between illness and the desire to live there is an important space for the great encounter with God: an extraordinary *kairós* in which communication and the experience of the transcendent, and at the same time of communion with Christ and his Church, can become more desirable.

In such a special time as illness, it is extremely important for pastoral workers to be aware of the situation, which is probably critical, of the patient and his or her family. And not only as regards his or her illness but also his or her Christian life, his or her formation, and his or her experience of faith. This is because every new circumstance of life is a special moment since within the believer there takes place a growth in union with Christ. That person who during his or her life has contemplated the Passion of Christ and has worked to unite his or her own passion to him, at the time of illness must live out this spiritual experience with a supreme intensity. As is natural, amongst the pastoral remedies that should be presented, and by no means at a secondary level, there are the sacraments, whose purpose is to unite us to Christ.

At such times it is always important to distinguish between what the illness represents in itself and what it represents in specific extreme circumstances. To distinguish does not mean to try to escape the delicate moment in which the patient and his or her family find themselves but, rather, with the greatest serenity possible, to allow that situation to be seen and to provide an appropriate pastoral remedy.

One of the points that should be always emphasised (with words, actions and rites) is that one is dealing here with religious actions, sacraments to help the patient, and not a sort of almost magical treatment for a dying person who has by now reached the end of his or her days…

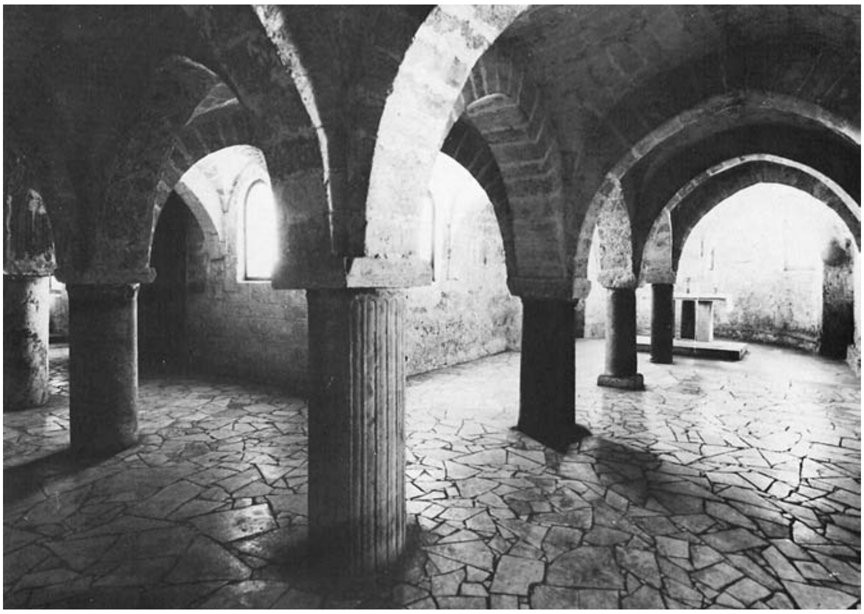
The request for, or rejection of, the sacraments by the patient or his or her family is a sensitive question. This rejection usually takes place when the sick person is not a fervent believer, even though the behaviour of the family, which is usually afraid that the sick person will become frightened, is worse. The pastoral journey must always be that of offering religious help in such a way as to generate the wish on the part of the sick person and his or her family to receive a spiritual remedy.

The family usually steers between social conformism (which is increasingly less reliable) and fear (more as an excuse to flee from its own responsibility than as a real situation) about the emotional impact that the sacramental rite might have on the patient.

It is necessary to lay emphasis, in the most suitable catechetic and pastoral form, on a religious instruction that creates in Christians suitable approaches of faith to life and death. The problem here is that we are not speaking about hope, which is one of the three theological virtues and which refers to heaven – indeed we are not speaking about heaven. The desire to remain on this earth for as long as possible can indicate that we do not have faith in the fact that our destiny is heaven. For this reason ,we do not even have the slightest preparation to address an inescapable spiritual approach at such a decisive moment.

It should be repeated that this is an encounter with Christ, who does not open the doors to death but is the God of hope and life. When Christ with his open wounds appears, eyes open to faith, as happened with the disciple Thomas.

A life is placed in the hands of God and the Christian feels that he or she is united with, and takes part in, the paschal mystery of Christ. The encounter with the Lord places him or her on the pathway of health. Christ is the Saviour not so much because the infirmity of the body has gone away but because he has cured the internal wounds with the balsam of mercy. The sick person, although he or she continues to be such, is now a new person because he or she has found a peace that he or she previously did not have. The love of God is placed ‘upon every human weakness so as to gather it in the arms of His mercy’ (*Incarnationis mysterium*, 9). All of this also takes place in the family when it takes part in prayer and in the celebration of the sacraments together with the sick person.



The time of illness can be this propitious occasion, this time of grace for the encounter with God, for the interior drawing near to Christ, and for becoming reconciled with oneself and with other people. A man who is reconciled feels a certain inner harmony and tranquillity, a sort of psychological liberation, which is legitimate and natural (*Reconciliatio et poenitentia*, 30), but, and above all, he feels that he is in the arms of Christ the Saviour.

In this special situation, at such a critical moment, the communal celebration of the sacrament of penance with the sick person and his or her closest relatives could be of great help. On the basis of established rules, this kind of celebration could help notably in the pastoral retrieval of the sacrament of reconciliation at times of illness.

'Lastly, to men who find themselves in the languor of death, pious Mother Church is near, and with the sacred anointing of the sick, although not always, because the Lord so disposes, she gives holiness again to the body, offers still a supreme medicine to the wounded spirit, transmitting to heaven new citizens and procuring for the earth new protectors, who for all centuries will enjoy divine goodness' (*Mystici Corporis Christi*, 9).

The anointing of the sick, in continuity with reconciliation, is the sign of full acceptance, on the part of the Father, of the sick son. It is not so much the sick person who entrusts himself or herself to the Father, but the Lord who receives and makes His own the man wounded by sin and places him on the oil of mercy. It is the whole Church that entrusts the sick person to the Lord so that He may raise him or her up and save him or her, but also so that this suffering Christian may voluntarily associate himself or herself with the passion and death of Christ and be an example for the Christian community itself (cf. *Sacram Unctionem infirmorum*).

Through forgiveness and mercy takes place the personal encounter itself with Christ who becomes Viaticum, Eucharist, and bread of grace that nourishes and fortifies so that the sick person can go down his or her pathway intimately united with the Lord.

3. General Proposals for the Renewal of Pastoral Care in Relation to the Sacraments

The first proposal has to be a kerigmatic invitation to reconciliation and an appeal to hope (*Pastores gregis*, 39). Great care should be devoted to knowing how to unite evangelisation with, and distinguish evangelisation from, pastoral care. The former involves the whole of the mystery of Christ; the latter involves those actions by which the task of the evangeliser is performed, as well as the various ministries of prophecy, sacramental celebration, charity and mission, which should be exercised always taking into account the special circumstances in which all of this must take place.

With respect to the renewal of pastoral care, one cannot think solely of a new organisation, almost a technical form of organisation, without engaging in an exploration of theological and ecclesial reflection and thought.

Reconciliation, anointing and viaticum form that unity that recalls and re-evokes the celebration of the paschal mystery, although each of these sacraments has its own identity and its own development in pastoral terms.

Renewal of pastoral care in relation to the sacraments for the sick requires:

– Converting everything that is connected with the illness into a space of prayer and not reducing the life of faith to a mere practice involving the moments of the sacraments.

– Fleeing from any tie and relationship to which a formalistic practice could lead of a magical kind between the sign and the effects that it produces.

– Including pastoral care in relation to sacraments for the sick within a specific catechesis for the 'most intense times' of life itself. Catechistic instruction for adults imparted by suitable and well-trained catechists is the best guarantee for this catechesis for sick people.

If the nearness of Christ is not made apparent, the sacrament will be considered a mere religious service and not a celebration in which not only the sick person but also all of his or her family and the Christian community itself take part.

The sick person for his or her part must look for the best conditions of freedom, acceptance, awareness and preparation.

Every kind of routine and formalism must be overcome by creating an environment of prayer and by attending to actions, language and meaning.

A habitual practice and celebration of the sacraments is the best preparation there is to experience reconciliation, anointing and viaticum in an authentic Christian spirit.

The chaplain, parish priest or priest who assist the sick person are inescapable and fundamental figures. They are not specialists in the psychology of pain and personal harmony but ministers of Christ and servants of the sick. Their presence must be continuous, frequent, usual and pastoral. In this way they will not be seen as outsiders and their presence will not be seen as the sign of a situation involving danger and the end of life.

Next to the chaplains and parish priests there are the workers, servants and ministers of pastoral care in health who help the sick person to lead a Christian existence. Piety and good will are not sufficient. A specific and suitable kind of training for this kind of pastoral care is thus required. The sacraments for the sick must 'exit' from the hospital. This means that their celebration cannot be left to specific difficult moments and moments that are perhaps the last ones that will be experienced by the patient. The parish must see the sick person as one of its members and the sick person, in turn, must feel that he or she is an active part of the community in which he or she lives and celebrates the sacraments.

But for the Christian to accept the help that is given to him or her so that he or she can live and die with the dignity that is his or hers as a Christian, the Christian community should regularly receive a suitable catechesis on the mystery of the Cross, education in hope, so as to avoid fears and magic solutions. There should be a sense of charity and devotion, by offering his or her own pain and his or her own sacrifice in union with that of Christ, while he or she is given the sacraments for the sick as a remedy for sin and a help of grace and not as a announcement of a final situation, the anti-chamber to death. In this way, trusting devotion will be generated, as well as approaches involving a wish for Christ and an encounter with Christ.

4. Specific Proposals for a Renewal of Pastoral Care in Relation to the Sacraments for the Sick

Three moments have to be considered: being faced with illness, the celebration of illness, and reintegration into the Christian community. This means acting so that a relationship exists between usual Christian existence and special celebration during specific times, which are certainly important and distinct.

Reconciliation

Faced with an evident abandonment of the practice of reconciliation at the level of the sacraments and of confession, ‘ a renewed pastoral courage in ensuring that the day-to-day teaching of Christian communities persuasively and effectively presents the practice of the Sacrament of Reconciliation’ (*Novo millennio ineunte*, 37) is required.

‘Priests should dedicate due time to the celebration of the sacrament of Penance, and with emphasis and will should invite the faithful to receive it, without pastors neglecting frequent personal confession’ (*Ecclesia in America*, 32). The readiness of priests to hear confession, and their exhortation to administer it, is of essential importance.

Here one is dealing with proposing the sacrament of penance as the best medicine and the most effective therapy for spiritual infirmity: not as a way of escaping from a difficult situation but as a way of facing up to it with Christian strength.

In order to direct the person’s heart to God and to experience real repentance, good preparation for the receiving of the sacrament is indispensable.

Assiduous and frequent personal practice of the sacrament of penance helps the sick person to rediscover the joy of reconciliation with God (cf. *Pastores dabo vobis*, 26, 48).

The habitual celebration of the sacrament of penance with those who are chronically ill, with individual confession and absolution, can be of great help. All of this gives greater emphasis to the ecclesial dimension.

Reconciliation exists in order to feel the wickedness of sin and the desire for forgiveness. Christ has a right to the return of the sinning son, and the penitent, aware of a ‘free right’, has a right to the wealth of the home of the Father, because God is rich in mercy.

The forgiveness of God must lead to reconciliation with ourselves, with our own body, which is wounded and sick. This is not fatalistic resignation in the face of the inevitable but living the mystery of the incarnation of the Word, who took on our weakness and immolated himself for our salvation.

Anointing

To adopt for one’s own illness the meaning given by Christ to the cross: scandal for some, stupidity for others, and for us, the power of God and the wisdom of God (cf. 1Cor. 1:24).

To emphasise the need to have trust in the promise made by Christ to cure all evils. Christ passed through this world doing good and healing the sick. A sick man ‘indeed needs, in the state of worry and suffering in which he finds himself, a special grace of God so as not to become downcast, with the danger that temptation will make his faith vacillate (*Praenotanda del Ritual*, 5).

To bring out the sign of hope which heals the pride of a certain kind of secularism that does not recognise any greater effectiveness than that which can be added to the journey of human means. Your wounds have healed us! (1Pt 2:24).

To show the meaning of the holy oil. ‘The cross is like a touch of eternal love on the most painful wounds of the earthly existence of man’ (*Dives in misericordia*, 8). This ‘touch of love’ is what the anointing of the sick involves. The prayer of the blessing of the oil of the sick is as follows: ‘may those who receive the anointing of this oil obtain comfort, in body, in soul and in spirit, and may they be free of all pain, of all weakness, of all suffering’ (cfr. *Rituale Romanum, Ordo Unctionis Infirmorum eorumque Pastoralis Curae*, n. 75).

The anointing reveals ‘the meaning of suffering, which is truly supernatural and at the same time human. It is supernatural because it is rooted in the divine mystery of the Redemption of the world, and it is likewise deeply human because in it the person discovers himself, his own humanity, his own dignity, his own mission’ (*Salvifici doloris*, 31).

God has all evils done so that life is manifested to the full. The anointing is a presence of the Consoler, an expression of the covenant with the love of God.

The sacrament is a sign of the consolation of Christ, who draws near to the sick as he did during his mortal life. The sick person is not a mere patient but a son of God and a brother of Christ.

God does not resign himself to the death of his children. The anointing brings out the encounter of the resurrected Christ with the sick person and the encounter of the sick person with Christ. Those who believe in Christ will have life.

People should be encouraged to see in the anointing with oil a sign of the care and concern of the Church for the sick person. The Church applies the balsam of charity and mercy.

With the anointing of the sick is experienced trust in the reintegration of the sick person into the community. God, who has marked him or her with holy oil, sends him or her to his brothers and sisters so that he or she may be a real witness to Christ, the Anointed One.

The periodic celebration in parishes and hospitals of the anointing of the sick is a pastoral practice that will enable people to see the need for, and the meaning of, this sacrament.

Viaticum

The Eucharist is a guarantee of eternal life (*pignus futurae gloriae*) and a source of immortality. He who eats of this bread will not know death (cf. Jn 6:50).

For sick people, Viaticum is an evident sign of wanting to take on death with total dignity and with the best possible testament – that of leaving behind an inheritance of being exemplary in relation to faith.

The risen Christ visits the sick person and offers him or her, for his or her passage and journey, the best guarantee of living for ever – the Eucharist. This is the great proof of credibility – giving one's life for one's friends (Jn 15:13).

The real presence of Christ creates a completely new life. He who ate other bread, died. He who partakes of the Eucharist will never die (Jn 6:50).

The weakness of man encounters the Bread of life and enables him to remember the words of the prayer of the Church: 'His body immolated for us is our food and gives us strength, his blood shed for us is our drink and washes away every sin' (*Prefazio dell'Eucaristia*, I).

'In the passage from this life to the other, the Viaticum of the Body and Blood of Christ strengthens the faithful and provides him with the pledge of resurrection, according to the word of the Lord 'He who eats my flesh and drinks my blood enjoys eternal life, and I will raise him up on the last day' (Jn 6:56)' (*Praenotanda del Rituale*, 26).

Viaticum must have a place in the pastoral line of the frequent celebration of the Eucharist for the sick and in the practice of sacramental communion.

The spiritual drawing near of the sick person to the Tabernacle and inviting him to worship and spiritual communion: 'the conservation of the sacred Host, motivated above all by the need to be able to use them at any moment to administer Viaticum to the sick creates in the faithful the praiseworthy habit of gathering in front of the tabernacle to worship Christ who is present in the Sacrament'

The renewal of the sacraments of the sick can only take place through an invitation to holiness. This is what John Paul II does in *Novo millennio ineunte*: 'all pastoral initiatives must be set in relation to holiness' (n. 30). This is our most urgent evangelising task and the most effective and fertile renewal that we can hope for from the sacraments for the sick.

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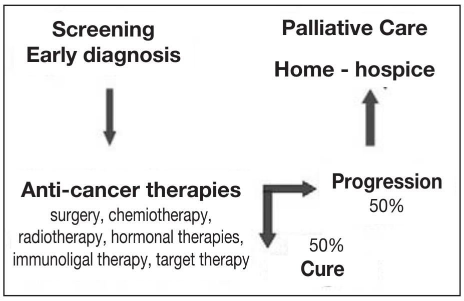
2. Present-day Directions in Palliative Care

Cancer and the Need for Palliative Care

Today in the world there are more than twenty-two million cancer victims. In the year 2000, ten million people fell ill with cancer – 5.3 million of them men and 4.7 million of them women. In the same year, 6.2 million people died of cancer. This is an illness that is on the increase. Indeed, between 1990 and 2000 the rate of cancer increased by 19% and the number of people who died of cancer rose by 18%. Today, one in every eight people dies of cancer, and deaths from cancer in the world are greater than the deaths caused by AIDS, tuberculosis and malaria put together. If the increase in the trend observed over the last decade should increase, we can expect by the year 2020 an increase in the incidence of cancer of the order of 50%. Contemporary estimates predict that by 2020 there will be fifteen new cases of cancer each year and ten million deaths from cancer each year. Figure 1 presents the relevant stages of, and the advance in, cancer as a pathology.

Figure 1. Stages of cancer.



The specific anti-cancer therapies that are available today allow the cure of cancer in about 50% of cases. After a varying period of treatment these patients often go back to a 'normal' life and are returned to their social and family roles.

For the other 50% of patients the cancer progresses, despite the treatment, for varying lengths of time until the terminal stage of the illness and death. These are the patients that need palliative care and by palliative care is meant moving from 'treating' to 'taking care of' the patient so as to assist him or her and accompany him or her during the final stage of his or her life with the aim of assuring him or her the best quality of life and quality of death that are possible without seeking to prolong life or to shorten it.[1, 2] Where structures that are specifically dedicated to palliative care do not exist, the stage when the cancer advances is lived out between the hospital and the local services and the patient's home often in an uncoordinated way between one structure and another, if not, indeed, between contrasting structures.

As we know, cancer changes the life of a person and his or her family. It does not only alter the physical sphere of the patient but also his or her functional, psychological, social and spiritual aspects. Care for the cancer patient, therefore, both during the initial acute stage and during the stage when the malady is well advanced, cannot be confined to mere 'medical service' but requires a global approach to the patient in order to respond to all his or her needs, whether expressed or not, and to support his or her family as well.[1]

Essential points stand out when we consider the provision of assistance to cancer patients:

a) More needs are expressed by the patient and more professionals are required who must intervene in a co-ordinated way to provide a solution to all that patient's needs.

b) There is a need for more structures dedicated to providing assistance during the various stage of the illness, in particular hospital structures for the acute stage and local and home structures during the advanced stages. This obstructs continuity in care and treatment and the sharing of the pathway of assistance by often causing the abandonment of the patient in the move from anti-cancer therapies to the control of symptoms, which is the most critical stage of the illness, Palliative cures, if used wisely, can be a good glue and bestow continuity on the pathway of clinical help and assistance for the sick person, thereby avoiding a feeling of feeling abandoned and loneliness.

Barriers that Impede the Optimal Use of Palliative Care

Palliative care places the patient who is at an advanced stage of his or her illness at the centre of attention so as to provide relief to him or her from a physical, functional, psychological, spiritual and social point of view, with the aim of optimising the quality of life of the patient and of his or her family relatives.[1,2] Even though palliative cures are indicated for a very large number of illnesses (in particular AIDS, neurological patients, heart disease patients, patients with bronchial-pneumonia disorders, and elderly people with chronic illness), at the present time 80%-90% of the patients who receive palliative cures are cancer victims.[3]

The spread of palliative cures is relatively recent and at the moment such diffusion is not homogenously spread amongst the nations of the world.[4, 5] The facts provided by the literature in the field, indeed, indicate that over 50% of cancer patients continue to die in hospitals for acute sufferers and only 50% of cancer patients can today benefit from palliative cures.[5, 6] This statistic gives rise to dismay because to die in hospital often means running the risk of exaggerated treatment or not receiving adequate therapy (instead receiving it in excessive forms or defectively) in relation to the principal symptoms of the advanced stage of the illness (pain, insomnia, fatigue, nutrition, etc.). Indeed, the hospitals for acute cancer sufferers are designed to act to 'save' lives and not to help the patient to die in the best way possible and in a way that does not seek to add or take anything away from his or her life expectancy.

Today, it is possible to die well, without physical pain, in 90% of cancer patient cases, and with less suffering, if in the context that receives the patient, or better still in his or her home, a climate of serenity is established, a climate, that is to say, of listening, of empathy, of sharing and of accompanying.[7-11]

Today, many causes still obstruct the ability of all cancer patients to receive adequate assistance until the end of their lives. This is the case not only in poor countries but also in the so-called rich countries.

The statistics provided by the literature in the field, indeed, indicate that at the present time there are various barriers to providing optimal assistance until the end of a patient's life (table 1).[5, 6]

1. *The heterogeneous character of the distribution of services in the local area and of the quality of the services that are provided.* Albeit taking into consideration the differences connected with the various countries involved, in the world as a whole a homogenous distribution of such services to meet the needs of all patients does not exist and in no country at the present time does palliative care assure all patients the assistance that they need.

2. *The shortage of knowledge on the part of the medical classes* about the services, about what these services provide, and the ways and criteria by which access is gained to them. This takes place both because this is a new branch of medicine but above all because it requires a new way of approaching patients as well as the acceptance of death as a part of life.

3. *The resistance of some medical doctors* who think that these services are superfluous. Not all medical doctors, in fact, believe in the usefulness and the advantage of palliative cures, something that has by now been scientifically demonstrated in a wide sense, and thus they do not direct their patients to palliative cures.

4. *The reluctance of patients and their family relatives.* This is due to a shortage of knowledge about such services, the fear that they will find themselves alone outside the hospital, and the belief that people die better if they are in a hospital.

5. *The belief that these are structures that are exclusively dedicated to cancer patients.* It should instead be pointed out that an increasingly large number of sick people could use these structures and services: AIDS victims, patients with chronic bronchial and pneumonia problems, patients with neurological afflictions, elderly people suffering from a number of illnesses, and so forth.

6. *A shortage of economic and financial resources.* I would like to observe that in the United States of America most of the hospices are paying institutions and thus there is the risk that only those people with greater financial resources will be assured access to palliative cures and palliative care.

Directions for an Adequate Development of Palliative Care

Despite the differences that exist as regards the various countries of the world, the international literature in the field is unanimous in stressing four aspects that have absolute priority: the training and educational aspect, the cultural and social aspect, research, and the economic-financial aspect (table 2).

Table 1: Barriers to the Optimal Use of Palliative Cures

The heterogeneous character of the distribution of services in the local area.
The heterogeneous character of the quality of the services that are provided.
Scarce knowledge about services on the part of medical doctors.
Scarce understanding about the utility of the services on the part of medical doctors.
Reluctance on the part of patients and their family relatives.
The belief that these are services solely for cancer patients.
A shortage of economic-financial resources.

Table 2: Contemporary Directions in the Development of Palliative Care

1. TRAINING
a. Recognition of schools of specialisation in palliative care.
b. Specific training programmes for various professional figures.

2. CULTURAL AND SOCIAL ASPECTS
a. The dissemination of knowledge about palliative care and the structures dedicated to it.
b. The dissemination of the culture of palliative care within the general population.
c. The dissemination of networks of assistance and the provision of local services.

3. RESEARCH
a. A methodological approach.
b. Indicators of life expectancy, quality of life, and quality of death.
c. Clinical research into new pharmacies.
d. The definition of homogenous criteria for access to the service.
e. Research into new models of assistance.
f. The testing and control of the quality of the assistance that is provided.
g. Discussion and exchange of experiences.

4. ECONOMIC-FINANCIAL ASPECTS
a. The provision of resources to increase the availability of resources in the local area.
b. Support for the services provided by voluntary workers.

Indeed, palliative care does not only involve simple notions which must be learnt and applied but also amounts to a different philosophy as to how to approach patients, an approach that has cultural, philosophical, economic, social, ethical and moral aspects.

1. The educational aspect

There are two priorities in the educational field:

a. The development of training programmes for personnel in relation to palliative care.[6,7,9,10] The training programmes should be intended for different professional figures: medical doctors, nurses, psychologists, physiotherapists, nutritionists, spiritual and social assistants, and voluntary workers specifically involved in helping these kinds of patients.

These people should also be trained in care for the human person, the recognition of his or her needs, respect for his or her choices and decisions, care for the death of the sick person, and support for the family in managing and addressing mourning.[11]

In addition, people should be trained to work together, to engage in mutual dialogue and exchange, to engage in readiness to listen to the patient and to his or her family relatives, and to test and assess results so as to achieve constant and mutual improvement.

b. The recognition that palliative medicine is a specialisation of general medicine. At the moment palliative care is recognised in this way in only some countries. Palliative care, in fact, is a branch of medicine that has developed only recently.

International palliative care associations and American and European oncology associations have for years been involved in this sector in order to improve the contemporary standards of the knowledge of medical doctors in the field of palliative care. They promote international debates involving the discussion and exchange of experiences between experts and give major space to the testimony of sick people and their family relatives.[9, 12-16]

2. *The cultural and social aspect*

The culture of palliative care and of the structures that provide it is not widespread or known about in Western countries. Knowing about such structures would allow patients and their families to avoid experiencing the move from the hospital to the local area as an abandonment, experiencing it, instead, as an entrusting to those who are most well suited to helping and looking after the patient until the end of his or her life. Thus the local population should be informed about the specific features and possibilities that the structures dedicated to palliative care offer, the distribution of these structures within the local area, and how access can be gained to them.

Indeed, citizens should know about their rights to the various options at the level of therapy and assistance (home assistance or residence in a hospice) before they actually need them. The mass media have an important role to play in spreading knowledge about palliative care, as well as in disseminating the culture of palliative cure, so as to reduce the distrust felt by sick people and their family relatives towards unknown structures.

In addition, it is necessary to standardise and unify the criteria for access to the structures that provide palliative care so as to be able to compare and contrast the results that are obtained and assure a homogenous level in the provision of assistance, to the less well-off sections of society as well.

There are also various Internet sites that disseminate information about the structures that provide palliative care, as well as international links that promote the spread and exchange of information amongst citizens about existing structures that provide palliative care.

3. Research

Research is the third element around which palliative care is developing. Such research is primarily directed towards:

a. The development of an appropriate *methodology* for palliative care. This is a methodology that has still not been defined. Indeed, specifically because of the different approach to the sick person that is required by palliative care, it is not possible to transfer *tout court* the method of research that has been developed for the initial stages of cancer to palliative care.

b. Specific research into new pharmacies: analgesics, relaxants, anti-insomnia drugs, anti-fatigue drugs etc.

c. The establishment of homogenous criteria by which to decide when to suspend anti-cancer therapies (and continue only with support therapies), the search for new models of assistance, and for new and correct criteria for the assessment of the life expectancy of patients, are also indispensable.[17]

d. The discussion and exchange of different experiences is a fundamental element.[3]

e. The testing and control of the quality of the assistance that is provided, the testing of the perception of the quality of assistance, including assistance provided to members of the family in the living out and management of mourning.[9-11]

f. The stimulation and dissemination of the experiences of patients and families. This helps people to have a better idea of the needs of the patient, the discussion and comparison of the quality of his or her remaining life and his or her death, both of which are very subjective.

An increasingly large series of data and statistics on the experiences of palliative care are now emerging in the international literature in the field and are of great help in achieving a better orientation for future programmes.[18-20]

4. The economic-financial aspect

The distribution of the structures dedicated to the provision of palliative care has a very heterogeneous character. It is true that the affluent world is privileged when it comes to the economic means available for the provision of palliative care. But I believe that in poor countries, too, it is possible to provide palliative care: Mother Teresa of Calcutta was an example for everyone and to the full may be listed amongst the women who have shaped the history of palliative care, together with C. Saunders and Kübler-Ross. Indeed, palliative care requires a low level of technological and pharmacological action but a great deal of human commitment and input (sharing, empathy), as well as professional service.

In addition, access to such structures and therapies is not always free. And today's structures are insufficient, even for cancer patients alone. Moreover, many of the structures that provide palliative care are maintained and administered by voluntary workers and associations.

It is thus necessary to sensitise the governing classes of society so that they provide funds for the provision of assistance to patients who are at the terminal stages of their lives and thereby assure that all citizens can benefit from the development and advance of palliative care.

The Model of Overall Assistance in the Department of Oncology of the Fatebenefratelli Hospital on the Tiber Island, Rome

I would now like to describe the experience of the Department of Oncology of the Fatabenefratelli of the Tiber Island in Rome where we have created a model for an overall approach to the cancer patient in line with the mission of 'hospitality' proposed by St. John of God, the founder of the Fatabenefratelli. In historical terms, St. John of God, in the sixteenth century, was amongst the first to stress the importance of looking after both the souls and the bodies of sick people, thereby predating to a certain extent the concept of an overall approach to sick people and thus palliative care as well.

By overall assistance we mean placing the sick person at the centre of the attention of the various kinds of health care workers in order to try to provide a solution to the various needs that are expressed by a cancer patient during the various stages of his or her illness.

The most critical moment for a cancer patient is without doubt the stage when the tumour advances. This coincides with his or her becoming aware that therapies are no longer available that can stop the cancer, and from that point onwards it will only be possible to intervene at the level of controlling the symptoms of the patient's condition. Still today this stage is experienced by many patients as a move to closed compartments, that is to say that when the therapeutic stage to combat the tumour finishes the various forms of palliative care begin with the accompanying risk that the patient will be abandoned by the oncologist who was treating him or her and will have to look for someone who can deal with his or her new problems and difficulties (pain, nutrition, social problems, the need for help at home, etc.).

In order to avoid all of this we created, and have sought to implement, a model for approaching the patient that envisages an *early* use of forms of palliative care, i.e. from the beginning of the anti-tumour therapies. Indeed, this model envisages integration between the specific anti-tumour therapies and forms of palliative care, where the various professional figures act according to the needs of the patient and to a certain extent foresee the needs of the patient (figure 2). Such a model for approaching the patient, from the diagnosis of the tumour to the living out and management of the mourning of his or her family relatives, is the model that is suggested today as being the best there is for the provision of assistance to the cancer patient.[1]

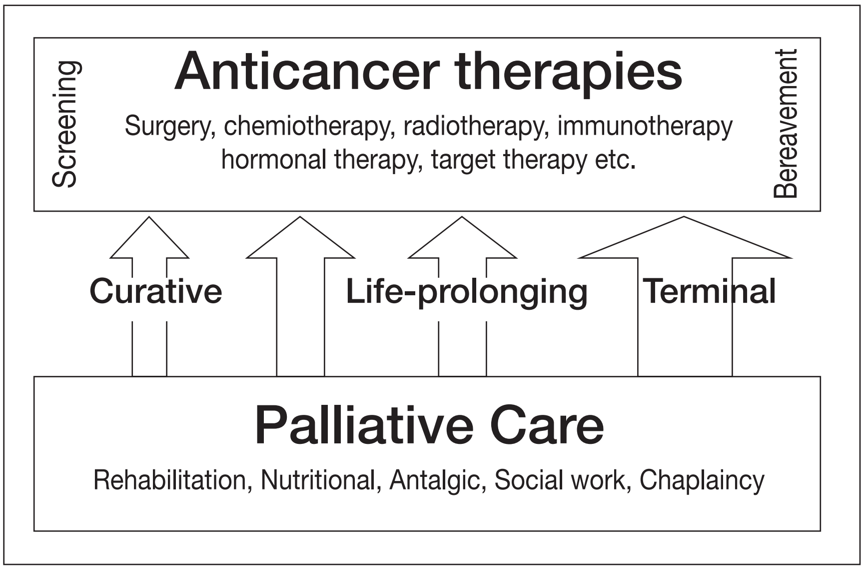
Indeed, this model helps to establish a relationship of trust between the patient and his or her family and the structure that is looking after and treating that patient, and we have seen that it improves compliance with, and the results of, the anti-tumour therapies, and assures an optimal quality of life from the physical, psychological, social and spiritual points of view.

In addition, it is clear that an overall approach to the patient that does not separate the therapies that are directed towards combating the tumour and the therapies that are directed towards reducing the symptoms produced by the tumour, avoids and pre-empts those 'critical' human situations that involve exaggerated treatment or a request for euthanasia.[11]

In order to provide this kind of assistance, what is required is a cultural change and a change in relation to the organisation of work. This should also take place during the initial stage of becoming responsible for the patient, a stage which is no longer seen as involving a relationship based solely upon the medical doctor and the patient but as the sharing of a project involving the provision of therapy and assistance by an integrated team made up of medical doctors, nurses, psychologists, social workers, a spiritual assistant, a nutritionist and a physiotherapist, all of whom share of moments of discussion and dialogue in order to establish a single programme of assistance that is modulated around the needs of the patient and his or her family.

In this context the psychologist and the spiritual assistant perform a dual role directed not only towards helping the sick person and his or her family but also towards sup-

Figure 2. The Model of Overall Assistance to Cancer Patients



porting the team at moments of (psychological) burn out and towards reaffirming the great human, communal and Christian value of the help that is provided to sick people who are dying (the priest).[11]

When the sick person is no longer responsive to specific anti-tumour therapies, he or she receives a different approach that involves a reorganisation of basic therapy on the basis of his or her needs and a planning with him or her and his or her family of the kind of subsequent assistance (at home or in a residential-hospice style structure) that he or she will receive. Given that at the present time we do not provide home or hospice assistance directly, we have drawn up protocols of agreement with certain local area teams that provide these services for those patients who find themselves at the advanced stage of their illnesses. We thus contact the team that works in the local are and through a joint assessment carried out within hospital we share a programme of therapy and assistance. Together with the patient's family, the transfer of the patient to a hospice or his or her return home for home assistance is thus planned and programmed.

From March 2000, the year when we opened the Oncology Unit at the hospital on the Tiber Island, until September 2004, we implemented and set in motion palliative care, employing this approach, for over five hundred cancer patients.

Our model of assistance has today been corroborated by a recent statement on the distinction between two kinds of palliative care which was proposed by a European oncological committee on palliative care.[13] Indeed, Ahmedzai points out that there are two kinds of palliative care:

Basic palliative care, that is to say a basic level of palliative care that has to be provided in hospital together with anti-tumour therapies, i.e. those therapies that all those people who are engaged in treating cancer patients must know how to administer and also assure to their own patients; and

Specialised alleviative care, that is to say a higher level of forms of palliative care. These are needed during the final stage of a patient's life and require greater skill and competence, as well as specialists who are dedicated exclusively to their administration.

Ahmedzai points out that both these levels of care are indispensable for cancer patients and it is precisely palliative care that allows the sick person to have that continuity of assistance that avoids feelings of being abandoned during the most critical stage of the illness.[13]

The model of overall care proposed by the Fatebenefratelli has as its objective that of constituting for the patient and his or her family a secure and constant reference point in which dialogue, readiness to listen and information play a decisive role.[11,20]

As Father Turoldo, who also died of cancer, declared: 'I don't ask you to cure me: a request to do something you cannot do would be offensive. I ask that you save me and do not allow me to live lying under this daily death the whole time'.[21] It is above all the feeling of being abandoned that we must avoid in relation to our patients, and which, indeed, is often the reason for a bad death.

The early insertion of forms of palliative care within a programme of assistance for cancer patients improves the quality of life of these sick people and of their family relatives, and is also a guarantee that there will be a better quality of death.

Special reference should be made to the spirit of the team that begins the provision of assistance to patients during the final stage of their lives. The Holy Father has made us reflect upon the meaning of suffering and we can only help those who suffer if we are able to accept our own suffering.[22] Indeed, we must see that in reality we are all 'terminally ill', that we are ill people who are providing assistance to the sick.[11]

But it is above all with certainty about the other life that our care is provided, and for workers such as ourselves it is always a great privilege to be able to accompany a man towards his encounter with God.

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TONY ANATRELLA

3. The Role of the Psychological Sciences in Palliative Care

Introduction

The scientific development of medicine has enabled medical doctors to employ new technical measures to avoid suffering, in particular through analgesics, and in the same way it has enabled them to delay the final moment of death. Equally, however, this greater technical element has at times distanced medical doctors from their relationship with the patient. In response to this connected loss of relational quality, the meaning of palliative care has been upheld in order to pay attention to the specific needs of patients who are at the ends of their lives and their family relatives. In recent years, therefore, a new openness to this situation, which is so special in human existence, has gained ground. This is due, among other things, to the contribution of the psychological sciences. I now propose to examine some of these contributions connected with the operational concepts of psychology, that is to say:

1. Human finiteness and the psychic life.
2. The conflict between the wish for life and the wish for death.
3. The speech that expresses symptomatic requests.
4. The effects of listening to sick people.

1. Human Finiteness and the Psychic Life

Faced with the difficulties and the sufferings, but also the intrinsic limits, of human life, against which we have to struggle and which we have to take upon ourselves, an individual at times tends to avoid them and to act as though he or she should not enter into his or her own subjective analysis. To flee from them, to ignore them or ‘neglect them’, as the French philosopher Pascal said, does not help a person to address them or to humanise them. Indeed, the individual runs the risk of becoming rooted in the impulses to death, which leads to passivity, even though he or she has never reflected on his or her own mortal condition. Such impulses to death rend to reduce the tensions that are generated by various questions about existence and to reduce a living being to an inorganic state. We need to return to a sort of state of tranquillity without limits or constrictions in a fused relationship with beings and things in the image of the foetal life, that life, that is to say that exists before birth. This is a movement of thought that invites people to conserve themselves in peace and quiet and to engage in the negation of need and psychic frustrations rather than to strive to overcome them in order to obtain satisfactions through the pleasure of living. One is dealing here with a reactivation of a pagan vision of existence of that seeks to break free of the human condition by disembodying it. Rather than consenting to life, the individual can find refuge in thoughts and attitudes of death with the idea, which is confessed to in varying ways, to eliminate those questions that arise in relation to life. In this way, death denies life and in the same movement death is dissimulated as the end of earthly life.

Illness often raises the question of human finiteness. Contemporary thought eliminates death from reflection and all the manifestations of its reality are minimised and cancelled in daily life. Death has been de-ritualised in an individualistic and subjective society in which culture no longer performs its therapeutic role of socially supporting respect for the deceased and accompanying the mourning of the family involved. Each person is simply directed back to his or her own psychological experience of mourning for the deceased person. If a person does not manage to work out his or her own affective suffering and the existential crisis provoked by the loss of the loved one, psychotherapy is prescribed to him or her. At times this suggestion helps the person involved but it also, and above all else, marks the failure of a culture that no longer intends to give a meaning to death and to ritualise it. After this, one is surprised at the fact that some cemeteries are profaned by asocial and character-based personalities. Through their pathogenic structures they experience all the symbolic dysfunctions of a society of meaningless that becomes rule-breaking, sadistic and masochistic. Culture no longer performs the role of being a container, a psychic envelope, thanks to its system of values that allows the individual to differentiate the values of life from the inclinations to negation and death. Today, we live as though death did not exist.

Death is increasingly presented as an accident of life or as the result of medical incompetence, and not as a dimension bound up with existence. The contribution of contemporary psychology, which places the person within his or her psychological history from conception to the end of his or her life, leads us to take into account the fundamental question of death within the framework itself of the economy of impulses and upbringing so that each person can learn to address the finality of existence and attend to every aspect of life.

In other terms, in order to avoid being prisoners of the infernal tandem made up of masochism and sadism, it is indispensable that find a way of eliminating suffering – our own and that of other people – rather than suppressing ourselves or other people, as, for example, is the case with abortion, suicide and euthanasia. Otherwise, in privileging the impulse to death we place ourselves in the situation of no longer experiencing anything, of no longer feeling anything, of no longer doing anything, and this is an approach that can reach the point of seeking death through self-destruction having the illusion of going on living after death but in a different way. This is a wish for immortality that does not coincide with the meaning of the resurrection. The wish to end suffering by ceasing to live is an expression of masochism where self-annihilation is eroticised. Paradoxically, in human psychology that is no longer governed by the values of life, there is a sort of fascination for death that is accompanied by a pleasure in disappearing under the belief that one will survive. In this way, man sees himself as the master of death within a pantheistic vision of himself. He confuses himself with nature (which renews itself), and reaches a desire for immortality – which is inherent in human psychology – in which man imagines that he has the power to live again in another way. Now, seeing himself in this way, man does not realise that he is seeking to make himself die although, in fact, the meaning of conception, birth and death lies in the resurrection of Jesus Christ. Life is given by God, and man is its mediator.

The development of the practice of cremation can, for that matter, be placed in this approach and confirms the existence of a 'hygienistic' vision of death. One is dealing here not only with making a body disappear, a body which could contaminate the living and nature as well, but also of a way of addressing death itself by conceding it very little visibility or getting rid of traces of its presence in cemeteries. The ashes of the dead person are scattered, and of him or her nothing then remains. It is believed that death has been defeated through an avoidance of all the symbolic portrayals of it that can help the living to remember their ancestors and adopt the idea of being mortal. Instead of placing themselves in front of death, people are led (once again in history) to kill life in a variety of ways.

2. Between the Wish for Life and the Wish for Death

The analysis of the Fathers of Church brought out the ambivalence of human psychology, which is divided between impulses to life and impulses to death, as Freud himself emphasised in his works. These are impulses to death that take the form both of masochism, in which the individual seeks pleasure by doing himself or herself harm, and of sadism, where he or she feels pleasure and satisfaction in doing harm to others.

Daily experience confirms the ambiguity of that human wish that expresses itself in the need to build and develop relationships and foster life, but which can also express itself in inverse behaviour which involves destroying and killing, Freud wanted to clarify the conflict that opposes eros, the impulses to life, and thanatos, the impulses to death. One should recall that St. Augustine in his Confessions dealt with this duality well before Freud.

If the impulses to death are not sublimated and transformed into the wish to live, they revolt against the individual or are projected outwards against other people.

2.1. The impulses against oneself

Given that the impulses to death are at the outset directed towards oneself, the individual has to free himself or herself from this internal conflict through the impulses to life. These require the individual to take on his or her own autonomy or to accept help, and to engage in dynamism of action by finding in his or her psychological, moral and religious resources the solution to his or her torments. However, when these are provoked by illness, the individual will find resources by which to reduce them and bear them thanks, amongst other things, to medicine. Unfortunately, he or she uses the impulses to death when he or she has recourse to self-destruction so as to avoid feeling the disturbance that he or she feels anymore. In attaching himself or herself to his or her own existence through thoughts about suicide and the wish to die with the masked intention of 'dying with dignity', he or she does nothing else but put the impulse to death to work. This is masked by fine intentions and by a manipulation of language with the statement that this is done 'to help another person to depart', clearly 'out of love', at the same time as meeting the person's request to 'give him or her death', to practice euthanasia. One is dealing here with murder that is to be committed under cover of medicine and which goes against one of the taboos that underlie civilisation: the prohibition of murder in the rejection of euthanasia. When, however, one of these taboos is touched upon, such as respect for sexual difference, the difference between the generations and the prohibition of incest, all the other civil and moral laws are destabilised. Citizens run the risk of having an altered vision of what law does and of appreciating all laws.

2.2. The impulses against others

The individual can in the same way direct his or her destructive impulses outside himself or herself, deviating them onto other objects or other people in order to avoid becoming attached to himself or herself or to his or her own life. He or she prefers to bring into play and to attack what is outside him or her, and expresses himself or herself through an impulse to aggression against another person or against other people. In this case, the impulse to death becomes an impulse to dominion and the will to power over other people. In this way, the impulse to death becomes sadistic, and it is sadism because the individual hopes to obtain pleasure by doing harm to another person or by attacking that person in various ways. To give a fatal injection is a sadistic act carried out with an unconscious feeling of omnipotence that no civilisation should allow.

2.3. The sadistic and masochistic impulses must be sublimated in order to transform the wish for dominion over others and mortal omnipotence

At the beginning of human life the masochistic and sadistic impulses are active, as can be observed in the psychology of babies and children, in particular when they experience new physical perceptions connected with dominion over the functions of corporeal excretion. This is a sensitive period when binary emotions and thoughts are developed: the clean and the dirty, the kind and the naughty, the pleasurable and the unpleasant, good and bad, birth and death etc. In this way there is an interaction between corporeal power, by which the child plays and which he or she learns to control, and the strength of positive and negative feelings, which can be for or against him or her or for or against other people. He or she feels fear and the fear of suffering or making others suffer, and this is often infused with infantile cruelty. The child finds himself or herself in an interaction of masochistic and sadistic impulses in particular when he or she translates all his or her own corporeal perceptions into subjective and affective experiences. At times he or she behaves in a bad way, wants to impose his or her will at any cost and resists the requirements of upbringing, breaks the objects that are given to him or her, attacks other people, tortures animals, has ideas about murdering people, and so forth.

The sadomasochistic impulses, which are the impulses to power, have the vocation of being sublimated, that is to say transformed into higher functions, as for example in the case of trying to dominate unpleasant experiences by avoiding suffering or making others suffer. But when sublimation is not authentic or society no longer supports the values of civilisation that allow the transformation of impulses to death into impulses to life, we witness their dangerous regression. They run the risk of becoming an irresistible force that is independent of, and in opposition to, the impulses to life. The calling into question of unvarying values, fracture, destruction, and death, appear as solutions in the face of difficulties of life that cannot be managed in another way. In the cases of abortion and euthanasia, the adaptation of legislation runs the risk of securing murder in a deceptive way from planned death, although remaining within the framework of civil laws that calculate the conditions in which death can be given. Is this not perhaps a way of pacifying the conscience when transgression is engaged in, in the name of so-called democratic laws, founding taboos, laws that do not depend on democratic discussion?

This is a sadistic approach, that is to say the will to power and dominion over the lives of other people, which seeks the death of an elderly person or a sick person whose life prognosis is uncertain in the long term. In placing themselves within a logic of death in order to alleviate, so to speak, a sick person in relation to his or her painful life, those who are in good health confer upon themselves a pernicious power in order to suppress the lives of such a sick person. One is not dealing here with unreasonable exaggerated treatment but with what involves an emphasis on the sadism of the contemporary age, an age that implements solutions of death in the name of good feelings.

2.4. A clinical experience of the wish for death

It is astonishing that nobody has thought of analysing the behaviour of a French mother who sought to secure the death of her own son of twenty-two years of age. This young man suffered from the locked-in syndrome (SLA), that is to say mechanical survival by means of artificial ventilation. After an injection that should have been fatal, he fell into a coma and was then placed in reanimation. The medical doctor decided to end the life of this young man. This patient had expressed the wish to die the day that he had learnt that he had to leave the hospital and be transferred elsewhere. The absence of structures to take in these kinds of patients raises grave problems for the patients and their families. Whatever the case, up to that point this patient did not have problems in the structure that had admitted him and in which there were other patients in the same condition. It is interesting to observe, as was brought out by a dossier published in France by Quotidien du Médecin (7 October 2003), that when the patients in this structure learned of the fatal action of the medical doctor in the reanimation department they panicked because they thought that they would meet the same end at the hands of the medical staff and at the fact that the law could allow medical doctors to engage in such a policy. The nursing staff, who were very attached to this boy and who did not understand the role of the mother in wanting the death of her child, were very moved. Some of them did not hesitate to say: ‘we are devastated. People accept the information provided by the mass media without understanding our problems and our work…this is the kingdom of a single approach’ The mother who had set in motion this fatal action did so in order to satisfy, so to speak, the request of her son, who wanted to stop living, and justified it as an act of love. But how is it possible to kill one's own child out of love? One is dealing here, instead, with an incestuous act of a mother who had confused wishes as regards her son. Following this dramatic episode, this woman was presented in the mass media as a courageous mother worthy of respect. This was an assessment by the mass media that led her to be received on television programmes with an insane reverence and in the palaces of the Republic by the high representatives of the state as an expert in the field.

That mother closed herself to other people together with her son, differently to what had been done with the other patients and their families who had engaged in life projects (in which they were helped by the staff in charge of their cases of the hospital and by psychologists). This morbose closure of the son with the mother in a fused relationship, in the name of which the son refused exit doors, activities and treatment, should have been analysed at the time. He did not receive visits from other people. As I have already observed, this mother-child relationship resembled an incestuous relationship that explains, on the one hand, the murderous approach of the mother: she engaged in her action as though she was freeing herself of a rule-breaking desire by killing her own son. Subsequently, she expressed a feeling of liberation and of relief in relation to her son whereas it appears that in fact she had tried to free herself from a fused relationship that was suffocating her. What she did not manage to do psychologically by forgoing an incestuous relationship with her son, she did by moving on to an act involving his elimination, his death. This constituted a true psychic haemorrhage. Giocasta killed Oedipus and did not have problems with the law, which, indeed, displayed a compassionate approach to what she had done. This allowed her to go and rest on an island, in the sun, for a number of weeks, and then to return, expressing a feeling of 'rebirth'.

The mass media took over this sinister episode and totally defended the complaint of the son, as though the request of the son, the approach of the mother and the initiative of a medical doctor working in a reanimation department, who acted without consulting the head of the department, were self-evident. The mass media exalted the power of the mother 'to give death' in the name of the perverse notion of a 'situation of great difficulty' which allows the removal of basic prohibitions. In extending ever further the limits that exist, one has the impression of being increasingly emancipated, whereas in fact one is creating the objective conditions for existential depression and violence between citizens. Policies have allowed themselves to be intimidated by the breadth of transgression and the law has inhibited its own function by invoking a painful problem. This lack of distance manifests an absence of knowledge about human psychology and the system of morbose representations, that is to say sadomasochistic ones, within which some people shut themselves up. It can be believed that today it is the perverse who make law by attacking the prohibition of murder and euthanasia: subjective requirements and the most unreasonable requirements take pride of place over objective and universal norms.

Progressively, we move from constitutive law to evolving law according to the feelings and sentiments of people and amplified by the apparatus of the mass media. How in these circumstances can the meaning of law not be lost? Following this Oedipal murder and under the aegis of this mother who was presented as a victim, it has been worrying to see the formation of a movement that calls on the legislature to produce a law that is favourable to euthanasia. The reply to such militant activity has been a 'law on the end of life' that will now be presented to the National Assembly. It does not involve any innovations because it repeats the regulations that are in force – this law repeats the law. It is a 'symbolic' act that allows one to think that we are near to the opening of a debate on euthanasia. How can we think that legal and medicalised murder does honour to a civilisation? The democracy of opinion that has been established and which represents neither citizens nor a shared view of the common good, and which multiplies law after law in response to an individual episode or in order to respond to subjective requirements, can only devalue the meaning of law, which, indeed, becomes no longer based on universal principles.

From a special case, which does not correspond to the pathway of all those who are in the same state, the intention has been to make a national cause to advance the idea of euthanasia or assisted suicide. This is a wish clearly expressed in the name of individual freedom, autonomy and equality so as to be able to dispose legally of the choice to die when the individual so decides; this is called the right to 'die in dignity', as though there were unworthy deaths.

This claim is that much more unacceptable because today we have available analgesics that prevent sick people from suffering and we have understood that exaggerated treatment is useless when the prognosis about the life prospects of a patient is unfavourable. There is a difference in nature between 'allowing to die' and 'giving death' or 'putting an end to one's life'. Socially, we are in a deleterious environment that goes beyond the liberal claim to give death or to commit suicide. We are in a regression in the heart of civilisation at a time when this is destabilised at its foundations. Language seeks to mask the most important transgression by stating that this is a matter of 'helping someone to leave' rather than 'giving him death'. Rather than speaking about a 'fatal injection', the term 'sedation' is used or it is said (employing a pseudo-scientific language) that the injection is 'to facilitate going to sleep in a more prolonged way than with normal sleep'.

'To die when you want to die' is not a sign of the health of people or of a society. One is not dealing here with choosing between two ways of dying, one as a complement to life following an illness or old age and the other involving deciding to leave a life that is deemed to be unworthy. We are, instead, within a suicidal dynamic supported by a society that is managed by ideas that are purely executive and materialistic in character and which appeal solely to the resources of sado-masochistic impulses in order to achieve self-affirmation in life by killing or wanting to die. This is a denial of the reality of human psychology in which the psychic and spiritual integrity of the person is not taken into account in relation to questions about death.

In other words, we halt at symptomatic questions without having the curiosity and the will to understand what is said beyond complaint. If we remain within an understanding that is solely factual and operation we will be unable to imagine that behind words there is another hope. The study of contemporary psychology has been able to stress listening and understanding to human words that are often expressed in a masked or indirect way. It is for these reasons that one of the principal requirements in the sphere of palliative care is knowing how to listen, hear and understand the patient and the members of his or her family beyond the first forms of evidence of what is involved behind the complaints and the questions. Contemporary psychology has known how to explore these challenges.

3. Speech is the Site of Symptomatic Questions

The requests made by a sick person need to be analysed and interpreted. Thus it is necessary to analyse the militancy of today that promotes assisted suicide or the wish to give death to patients at the terminal stage of their lives, and in the same way to analyse the requests for death made by certain sick people. Militancy for death can reveal a desire for power over beings, things and events, whereas in the second case the wish for one's own death can express a need to be taken into consideration and to live in a different way. One is dealing here, therefore, with understanding what is taking place with prudence and clarity of vision.

Some people who wanted to commit suicide and whose action, fortunately enough, was not successful, often expressed the chief desire to end a situation that had become unbearable. They confused liberation from a difficult condition with the ending of their lives. After regaining consciousness, and once they had returned to reality, they expressed a different point of view: 'I did not want to die, I only wanted to change my life'.

The militancy of some people who are involved in the campaign for the legal recognition of 'the right to make a patient to die' or 'the right to assisted suicide' confuse intelligence with an understanding of what takes place in a subtle way within a personality. When a person thinks about suicide his or her idea is more a symptom that refers to the difficulty that is encountered in agreeing to life and living in a relationship with other people than an evident manifestation of ending his or her own existence. That person needs his or her physical and moral suffering to be alleviated. He or she needs to be accompanied, acknowledged and respected in his or her person rather than being abandoned to loneliness or anonymous medical assistance. If the accompanying meets this need for presence and person-to-person exchange, the request for death, which at one time was indeed made by the patient, will in the best of cases be abandoned. In contrary fashion, even if this question is repeated when the end of life draws near, some say that after mature reflection this is not a reason for meeting this request in a positive way. Experience suggests to us that it is often healthy people, more than patients themselves, who have this approach. Only a very small percentage of those who are at a terminal stage of their illnesses actually ask to be helped to die. We should not be misled by those very rare cases that are not in line with dominant requests and practice. To ask for useless forms of treatment to be interrupted, even though forms of care to avoid pain are continued, is humanly and morally legitimate. Palliative care has means and instruments to reduce pain and offer a form of accompanying for patients and their families. But allowing the drawing up of a protocol for death at the end of life, rather than involving the accompanying of a person, is psychologically unacceptable.

The law must always maintain the general interest that is expressed in respect for life. To take away the prohibition on giving death in this circumstance will have consequences for those social and psychological phenomena that appeal to respect for life. The direct or collateral effects will manifest themselves in a rapid way, as indeed already takes place with the attacks on the weakest, sick people at the end of their lives, the disabled, and the elderly carried out on economic grounds. After being directed towards an abortionist mentality we are now being prepared for euthanasia masked by language and protocols arranged by civil law that avoid the most important questions. The role of civilisation is to contain asocial impulses when these are not sublimated into higher functions. In banalising in law these exceptional requests for death, we support the impulse to death, an impulse that at times is stronger than the impulse to life, above all else when this is not supported by social, moral and spiritual values.

A person is structured psychologically around different representations that he or she elaborates during the course of his or her subjective history. These representations give a figure to that person's self-image and to that person's relationships with others and with existence. When a person expresses a fear, a doubt, a wish for death, he or she always does so with reference to his or her own internal universe, whose motivations most of the time are unknown. His or her analysis is without doubt authentic because the person gives oral expression to what he or she thinks and feels but without always being able to wait for what his or her request – for example to put an end to his or her life – actually represents. For this reason, a request that touches upon such essential and intimate realities as birth and death must always be clarified rather than being understood with reference to its initial formulation.

4. Listening to the Request of the Patient

Despite the burden of the handicaps experienced by sick people, the requests for death, in fact, are very rare. Patients affected by the locked-in syndrome, who at times only have their eyes and a finger by which to live and to use a computer in order to make themselves understood, are far from wanting to die. They suffer from not being able to communicate in a rapid and complete way with those who surround them, from being exposed to their families in their condition, and in particular to their children, and as regards the youngest of these patients from not being able either to speak or to communicate. In the majority of cases, a minimum amount of recovery allows them to use a computer and to engage in a few activities. The mere fact of listening to music procures them a kind of joy at being alive.

Jean-Dominique Bauby, a French journalist and the head copyeditor of the magazine *Elle*, who was struck down by the locked-in syndrome at the age of forty-five, wrote a book entitled 'The Diving Suit and the Butterfly' (Robert Laffont), in which he described, with humour and elegance, the experience of inner freedom that he had experienced in his hospital bed. In France, another book by Paul Melki, an adolescent with a number of handicaps (a tetraplegic with sight defects), has also recently been published, this time with the title *Journal de bord d'un détraqué moteur* (Calmann-Lévy). This boy demonstrates an enthusiasm, energy and an imagination that bring out his desire to live. This is a beautiful invitation to us not to become discouraged.

Both these authors are surrounded by their families and their friends and are on the side of life without needing to reach death. The mass media speak very rarely about these infirm people but instead exploit those who provide a dramatic picture of their wish for death and their exaltation to transgress a taboo.

How can contemporary psychology help is in caring for sick people in the field of palliative care? The psychological sciences, inspired by the discoveries relating to the unconscious, have three reasons to help such people.

1. In all the questions formulated by the sick person and his or her family it is advisable to search for the *structures* that organise those questions. We have emphasised the importance of the conflict that opposes the impulses to life to the impulses to death in the wish of that mother to give death to her own son out of love. The justification of an act involving murder through an argument that is against it reveals a perverse approach, in a psychiatric sense, a form of behaviour that tends to falsify the truth of the act under the appearances of virtue.

2. A request is always the consequence of the *representation* of what we do with ourselves and with reality. This representation should be analysed and defined using *savoir-faire* of a pedagogic character in order to carry out this work. This approach can be marked by a feeling of powerlessness in addressing the difficulties of life and resignation when faced with the limitations and failures that is expressed in a call for death. In contrary fashion, a difficult situation can be an opportunity to achieve a solution by addressing it without abandoning oneself or subjecting oneself to the facts. Each person has his or her own inner freedom by which to react and find solutions in order to discover new outlets in reality.

3. The request also throws light on the person who receives it and onto whom the patient's hopes can be *projected*, as in the case of interpretative neuroses or allowing the inducing from the other of the image of the hysterical personality that drags the other person into its own wishes. The person who receives the message from the person who sends it can believe that he or she is responding objectively to a request whereas in fact he or she is under the dominion of the other person who leads him or her to act according to his or her own interests. A lack of relational distance, of discernment as regards the contents of the request and the challenges of the person, that is to say the symbolic system of society, are the features that characterise an individualistic society that has become lost in the subjectivism of the claims of each individual.

The psychic structures, self-representation and the representation of society, but also the approaches of projection and fusion, are the key concepts by which to decipher the complaints and the requests of people who are sick or in situations of great difficulty.

Conclusion

Human communication is often characterised by misunderstanding and a lack of comprehension. A person may well not understand what he or she is really expressing in some of his or her questions. For this reason, it is necessary to have a good understanding of psychology. The health-care militancy in favour of euthanasia, which begins with certain accommodations in relation to the end of life in order to attain its objectives, creates a morbose and ideological climate that prevents attention being paid to psychological care of a very special kind being provided to sock people. Such people need to be acknowledged and respected and to be united to their families and their friends or, in contrary fashion, to find caring staff, benevolent visitors and members of a chaplaincy, a relationship that helps them to go on keeping possession of their own lives and not be abandoned to loneliness. Equally, the psychological training of staff engaged in care and of people who intervene actively is needed in order to improve their practice and their ability to understand the requests that sick people make in relation to their own deaths. Our societies attend to looking after sick people and provide them with the comfort that is required by their condition until the last moments of their existence: but our societies are relatively ill-equipped as regards preparing people for these last moments of existence. We should complain about a defect as regards accompanying and the ritualisation of relationships so as to be actively present in relation to those who are about to die. Preparing for death and preparing to die constitutes a decisive challenge as regards ennobling human existence as a whole. The pastoral action of priests must play its role and be responsible for following sick people and their families in a spiritual sense during the death of the loved one. The catechistic approach and the homilies that address the problem of the ultimate ends of life also have their role to play from a spiritual point of view but from a psychological point of view as well. They will be of great help in our reflection about these matters. We must rediscover the importance and the meaning of death, which is a privileged moment. Death cannot be left solely to the medical profession or to the merchants who deal in death. It is often the avoiding of the patient's personal questions that makes him or her suffer, just as at times one should know how to discern and respect that which the patient cannot talk about.

Freud was right when he argued that it is difficult to give a meaning to one's own death when one has not given a meaning to one's own life.

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4. A New Cultural Approach to the End of Life

Premise

If we engage in a rapid survey of the fears of contemporary man, one fear stands out in a particular way – the fear of death. This is an instinctive reaction to a reality that can never be seen as a pure biological and neutral fact. Indeed, just as life cannot be identified with the set of physiological conditions that ‘keep us on our feet’, so death is not recognisable only in the cessation of the physical functions. Both – life and death – bring into question the sphere of meaning which, beyond being a category reserved to the experts in the field (philosophers and theologians in particular), is able to markedly change the way of experiencing life and death.

In pre-Christian antiquity, death was generally perceived as an entrance into the undifferentiated kingdom of shadows, a move to a larval existence, and was experienced for the most part as an ineluctable sentence. The pagan sarcophagi are full of nostalgia for existence, but the Christian tombs attest to serene faith in eternal life to which earthly life was seen as a responsible prelude. After centuries of faith, iconography and symbolism have returned to an evocation of the macabre whose baroque paroxysm explodes in a tragic steeped in hopelessness.

Two descriptions of death borne from two juxtaposed cultures, two conceptions of life: those that express the peaceful joys of existence and those that exalt the admirable actions of heroes.

It was Christianity, with the event of the Resurrection of Christ, that broke this perception, and opened up spaces of unimaginable hope: ‘the death of Christ impressed another character on death, restoring to it the meaning of the end that should have been the end of the first man: the move to a new life’.[1] Adopting this perspective, we can state that death is not death: it is a lamp that goes out when the Dawn comes. In addition, the death of a Christian was not at the outset seen as an individual event but rather as a stage on a larger journey during which we were not left completely alone. Beginning in the fourth century, however, the worry and the fear that death, despite this, also provoked in Christians, began to be considered, above all in the presence of the fact of a Christian’s sudden decease, which did not allow a believer to prepare himself or herself. This is a worry that was also present throughout modernity when by a no means few number of works on the *Ars moriendi* appeared – writings of spirituality that were all dedicated to the search for the ‘good death’.[2]

1. Beware Contemporary Culture

Today death is seen as the defeat of therapy, as a frontier where medicine fights its battle to prolong earthly life. Thus birth and death are no longer seen as manifestations of the history of a person but almost as chapters of a scientific encyclopaedia, perhaps with the titles ‘procreatics’ and ‘thanatology’. As a result of this, the reasons for the fear generated by death do not concern so much the life beyond this one or divine judgement, but rather the terminal moment and the sufferings associated with it. The feeling of loneliness and dismay that is provoked by imminent separation, by the sense of the unknown and the void, is of major incidence.[3]

In addition, death is increasingly experienced in a private and institutionalised form: only a small percentage of people end their earthly existences in their families, surrounded by their loved ones. This is because the majority of people die in special structures. As a sign of the profound changes that are underway, one need only reflect that in the current mentality a ‘beautiful’ death is specifically that death which for one thousand five hundred years was feared, that is to say a sudden death. Today, almost nobody would be prepared to repeat the invocation of the litanies of the saints: ‘*A subitanea et improvvisa morte, libera nos Domine*’.

However, death remains a fact, and the attempts to remove it from personal and collective horizons is a vain one. In such a context it is of fundamental importance to propose a new cultural approach to the end of life, taking into account that our culture does not want to see death and does not want to speak about the fear that death generates because in the end death is the ‘objective’ proof of the defeat of that earthly messianism that consumer society wants to achieve.

Societies organised around the criterion of the search for material prosperity see death as a non-sense and with the intention of cancelling the question about it, at times they propose its painless bringing forward. Death, which still remains the most certain fact of the future of each individual but is so often exhibited and banalised in entertainment and the mass media, has been widely hidden and marginalised from our concrete experience.

The so-called ‘culture of prosperity’ often brings with it an inability to understand the meaning of life in the situations of suffering and limitation that accompany the drawing near of a man to his death. Such an inability is sharpened when it is expressed within a humanism that is closed to the transcendent and is often translated into a loss of trust in the value of man and life.

In the presence of death, the man of secularised Western culture finds himself, from a cultural point of view, particularly undefended and without answers: he is thus led to flee from death by excluding it from his thoughts, just as the social body already places death at the margins of his experiences. The censuring of death is one way by which to defend oneself against it, to defer the problem and distance oneself from it, almost as if it concerned only some people and any case was a particular moment of living. Instead, death remains the constant and weightiest mortgage that lies upon the whole experience of man, and in relation to which it is an illusion to imagine that one can give answers that are only consoling or directed towards the constant removal of profound questions. Amongst the inescapable tasks of being a man, there is also that of preparing oneself to address – or better to live out – one's own dying as well, given that this too is an integral part of one's own experience. This is a task that should not be limited to preparing oneself to address a future event given that, as Romano Guardini well observes, the essential moments of life, being born and dying, at all stages are mysteriously always present, always contemporary.[4] In other terms, one prepares to die every day, in all the choices of one's own life.

Then there is a philosophical and ideological dimension on the basis of which an appeal is made to the absolute autonomy of man, almost as if he were the author of his own life. In this approach, reliance is placed upon the principle of self-determination, and there is even an exaltation of suicide and euthanasia as paradoxical forms of the affirmation of one's own self. Here we should not underestimate the sad reality of hospitalised people who are often not in contact with their own families and are exposed to a kind of technological invasiveness that humiliates their dignity. Nor can we remain silent about the hidden impetus of the so-called 'culture of the useful' that governs many advanced societies on the basis of criteria of productivity and efficiency. In this approach, the gravely ill person and the dying person in need of prolonged and special forms of care and treatment come to be seen in the light of the cost-benefit ration as a burden and an expenditure loss. This mentality thus leads to lower support being given to the declining stage of life.

2. The Counterculture of Death

We have been witnesses of the advance of the 'counterculture' of death, which also emerges in other phenomena that can be attributed in one way or another to a low view of the dignity of man: examples of this are those people who die because of hunger, because of war, because of terrorism, because of lack of the control of traffic, and because of low attention being paid to safety rules at work.

In the presence of new manifestations of this 'counterculture' of death, the Church has not ceased to be faithful to her love for man, which is, indeed, the first way she is called to follow.[5] She has the task of illuminating the face of man, and in particular the face of dying man, with all the light of her doctrine and with the light of faith and of reason. The Church is aware that the moment of death is always accompanied by a particular density of human feelings: an earthly life is being completed, and affective, generational and social ties are being broken that are part of the intimate experience of a person. In the consciousness of the person who is dying and of the person who is taking care of him or her there is a conflict between the hope for immortality and the unknown, which even troubles the most enlightened of spirits. The Church raises her voice so that no offence is committed against the dying person but rather that with all loving care people dedicate themselves to accompanying him or her in dying while or she prepares, following Christ who died and rose again, 'the firstfruits of all those who have fallen asleep (1 Cor. 15:20), to cross the threshold of time and so to enter into eternity.[6]

3. Taking Care of and not only Curing

Taking care of is more than deciding to cure another person.[7] Here a certainly provocative feature emerges as regards therapeutic action, at least as it is normally understood. To take care of is to attend to another person, and for this reason placing him or her at the centre of things, beginning with him or her, listening to his or her situation, and being resistant to every temptation to objectify the person taking as a starting point his or her specific clinical condition, is something that is indispensable. To care for, in a medical sense as well, thus becomes taking care of another person, understood in an overall sense.[8] At no other time more than therapeutic action does human life come to be placed objectively in the hands of another person; it also depends to a varying but always substantial extent on the decisions of another person. We are called upon to provide an answer to the questions that the life of another person, who has been placed in our care, raises: who is the person who has reached the end of a life which, seen in a broader perspective, is not solely clinical? How can this person be helped to discover, to read and to live out his or her deepest hopes, which are often unexpressed even if they are real? How can this person be accompanied in a respectful and responsible way, in a way that does not involve mere assistance or a solely formal and procedural approach? The answers cannot fail to address this special stage of life in the earthly existence of a person who is compelled to experience a full transformation of his or her relationship with himself or herself, and thus with his or own overall life experience, with his or her own body, with her or her own freedom, with other people, within the social-institutional context in which he or she comes to find himself or herself, and with, and in, time itself.

4. A Radical Cultural Change

One is dealing with an arduous and at the same time an inescapable task: preparing oneself to live out one's own dying. If a patient, by definition, is 'he who suffers, who undergoes suffering', the patient who has come to the end of his or her life is, so to speak, a patient at the second level. He or she suffers not only because of the illness that is underway or because of its effects, which are devastating to varying degrees, but above all because he or she is aware of the irreversible nature of his or her condition and because of the consequent perception of the progressive inefficacy of the forms of therapeutic treatment to which he or she is subjected, which, whatever the case, will not return him or her to his or her previous life. Such a patient finds himself or herself faced with the syndrome of the dark tunnel: he or she does not see an end but only that it will end.[9] All of us experience this when we accompany our loved ones during this dark step, in which it is difficult to see the exit in the light of faith in Christ.

Illness and pain, and in particular in extreme cases, generate in every patient not only a request for healing and help but also a question involving meaning. Man, in fact, does not only suffer but knows that he is suffering, and this confers on his sick being a singular note of the dramatic, as Nietzsche indeed stated in a lucid way: 'the absurdity of suffering, not suffering, has been the curse that has hitherto spread throughout mankind'.[10]

An unfavourable prognosis, like, and more than, every other illness, emerges into a person's consciousness first of all as something that is foolish and wrong. The most profound and inaccessible question of a patient is the question that relates to the meaning of his or her condition. A meaning that in itself each person is called upon to rediscover in each condition of living life in times of illness emerges very forcefully and is especially acute. What makes this question even more crucial is the fact that the patient sees that he or she can do something, can have an active role in relation to the illness itself, and not only let himself or herself be taken over by it. The illness, in fact, is a threat to living in an overall sense; it cannot be seen as an evil simply because it prevents a person from doing many things that he or she previously could do. Indeed, it has the more radical countenance of an inability to want. This inability can only be resolved on the condition that once again a hope is found for the person who suffers. In this sense, the illness is a challenge to freedom. To its discouraging message it is not possible to resist in any other way than by drawing on 'moral' resources, resources, that is to say, that still allow a person to want.[11]

Our endeavour is directed towards opening up horizons that allow living, allow us to continue to live, allow us to be men and women in the time and condition of illness as well. This is because the meaning of things and life cannot be grasped by referring to intellectual categories, however persuasive and illuminating they may be, but by a keen will to go on living. To accompany the patient is to lead him or her to experience the fact that despite everything he or she remains greater than his or her illness that and his or her life is greater than what threatens it. For this reason, medicine, understood in a broad sense, cannot depart from the arduous and highest task of serving man in the fullness of his mystery. Our efforts are directed towards enabling the patient to draw upon resources that can give hope to him or her, especially affected as he or she is, and to those reasons for life that cannot be given in equal doses to everyone (nor are they even predictable *a priori*) during the course of the illness.

A form of hope that does not want to be empty or purely consolatory leads to the problem of death being looked at in the face, and not merely to it being fled from or even censured in a systematic way.[12]

To infuse a culture of hope thus means in this approach not offering the patient only accurate explanations of what is happening to him or her or of the therapies of which he or she is the protagonist. Nor does it consist only in providing him or her with intellectual arguments that are able to throw light on the moment he or she is experiencing. This is because life and dying, which are always so bound up with each other, do not need only someone who demonstrates – through rational arguments that are varyingly effective – the logic of what is being experienced. Hope, like all the great reasons for living, more than being demonstrated, should be shown, through nearness, sharing, and support.

5. A Paradoxical Challenge: Living Dying

Our task is to accompany the sick person, as far as this is possible, so that it is he or she that looks for the ultimate meaning of his or her life so as to address with truth and awareness his or own dying, which is as unique and as unrepeatable as his or her living, Dying, which is inherent in the DNA of each individual, can also be experienced not only as a terminal moment, as the final second of a trajectory that is irreversibly in decline, but also as a very personal and culminating moment of his or her own living.

A work of art, a classic text, or a film made by the author of a work should be considered to the full if they are to be enjoyed and appreciated. That masterpiece as well, which is not in the least obvious or predictable, namely the life of each one of us, without its final and ultimate scene cannot reveal the fullness of its meaning. If the whole life of a person reveals his or her identity, and a person really expresses himself or herself above all else in knowing how to face up to a trial, then specifically in the presence of dying, which is the supreme trial, a person is called upon to say, to bear witness to, what he or she really is at a deep level. Faced with dying, we are dramatically placed in a condition of extreme and radical equality. Every distinction and differentiation fades away, and the profound identity of each person is revealed in an ultimate way to oneself and others once the inessential has been dramatically removed from the fatal illness.

In this context is revealed to us an unprecedented challenge – experiencing the time of illness as well, not only in relation to the aspect of resistance, of consciously lasting during that time, but also as a possibility offered to our freedom to decide what completion we wish for our existence. Thus when on the lips of a patient at the end of life there arises the question 'how long do I still have to live?', he or she is not only posing a question of a chronological character. He or she is asking to be helped to understand and to bear the weight of what is happening to him or her, but in addition, perhaps, he or she is asking to prepare himself or herself for the encounter with his or her judge, his or her merciful judge: Jesus Christ.

6. A New Cultural Approach

a) The first step may be identified as giving an absolute primacy to the person,[13] who requires the greatest respect and must never be exploited for purposes other than his or her overall good. During this stage, the use of an appropriate pain therapy, which is the privileged way of respecting the dignity of the person during the period of his or suffering and dying and of overcoming that vision of a form of medicine directed solely towards the recovery of health by the individual involved, takes on a very special importance. This therapy too, in addition to being proportionate to the conditions of the patient and his or her ability to tolerate the treatment involved,[14] should be decided within a sort of 'pact with the patient'.

The relevance of the criterion of the quality of life of the patient, together with other criteria, emerges with singular clarity in this situation. The New Code of Medical Deontology (1998) devotes a great deal of space to the duties of the medical doctor towards terminally ill patients and observes that the relief of suffering specifically belongs to the evident tasks of the medical doctor (art. 3). In particular, articles 20 and 37 condemn the abandonment of therapy and emphasise the need, in cases of a clearly unfavourable prognosis where the patient has reached the terminal stage of his or her life, to work with the sole aim of reducing the sufferings of the patient in a way that maintains the best quality of life possible for that patient.

The way of acting towards a gravely ill person and a dying person is based, therefore, on respect for the life and the dignity of that person with the aim of making proportionate therapies available to him or her. Without indulging in any form of exaggerated treatment, it is advisable to pay attention to discerning the wishes of the patient when one is dealing with extraordinary or risky forms of treatment, always fostering dialogue and the exchange of information with the patient himself or herself. It is incumbent upon everyone to always assure ordinary forms of care and treatment – including food and liquids – and engage in the administration of palliative cures. When an inevitable death is imminent, observes the Congregation for the Doctrine of the Faith, 'it is licit in conscience to take the decision to forgo forms of treatment that would procure only a precarious and painful prolongation of life, without however interrupting the normal forms of care due to the patient in similar cases'.[15] My dear and venerated father said to me: my life has followed its natural course, joys and sufferings beneath the gaze of God. Let me die in peace, that is to say at home, with my family, a family of God.

b) The second step is in the direction of a serious preparation of the sick person by not allowing him or her to be deprived of those instruments that above all else in a prior stage but also in the terminal stage of the illness can really assure him or her of that level of information and preparation that he or she needs and that he or she normally requests. Thus, the risks and limits of 'self-information' which is obtained in a sporadic and chance fashion, perhaps using texts that are not always easily understood or even Internet, are avoided.

A real commitment to inform takes responsibility for organising not only instruments to do with knowledge but above all for offering in an accessible way the possibility of personal meetings and trusting conversations at times and in ways that are most suitable, thereby creating a culture of dialogue during the terminal stage of the illness of the patient as well. Accompanying and nearness to the sick person become in this way a space and a time in which to foster in the patient the dignity of dying, with opposition being given to the temptation to hasten the ending of the life functions. And this always prepares us for dying; we make of it a vital experience.

c) The third step of our pathway involves becoming aware of the fact that between the patient and the illness there is a third party. Illness is a personal fact but a person is not an island, indeed a person is a relationship, he or she is communication, he or she is openness. Our life is always a relationship with other people, who remain present and operate in our deepest life experiences. The way of addressing illness derives to a great extent from how we have been educated by other people (parents, family relatives) to live it, or by how others – within the society and culture we live in – have borne (positive or negative) witness in this field, helping us or otherwise in our relationship with the Other, from Whom we come and towards Whom go through death.

We are, that is to say, persons, subjects endowed with special and unrepeatable characteristics, constituted and interacting within and through a specific complex of relationships, some of which are natural and some of which are instituted.[16] Illness, therefore, also becomes an opportunity to ensure that the patient remains the protagonist of his or her communication. Although most of the aspects of human suffering remain incommunicable, careful and participated nearness, which does not take cover behind defensive attitudes, places us in a condition to receive from the sick person himself or herself authentic and unforgettable lessons about life. Although suffering cannot in itself be shared, loneliness, which is a by no means small (indeed it is a dramatically large) component of suffering, can be defeated by an exercise in otherness. Indeed, a patient who has reached the end of his or her life is not a biological residue whose life should be shortened as much as possible, but rather a person who is able until the last moment to establish a relationship, albeit in painful and dying 'passivity', and to attain his or her own completion in the extreme terminal reality of dying.

d) The fourth step leads us to see illness as an ineffable reality in time. The immediate language of experience teaches us how much time is fundamental both as regards the actual perception of one's own condition and, subsequently, when it comes to bearing the duration of the illness. That is to say, one grasps little by little what it means to be ill and this is understood by going through days of pain, of fear, and of loneliness. Once the situation has been addressed, there emerges the possibility-need to continue to choose so as to be able to go on living.[17] This is a need that is perceived with extreme lucidity by a sick person as an urgent necessity 'to be able-to have to-to want to' continue in what was the central core of his or her living, which never disappeared even if, without doubt, it has been transfigured by his or her condition. This new condition raises the problem of going on, of applying not one or more choices but of requiring continuation, a dynamic dwelling in that situation, being placed between the extremes that can be described in terms of resisting, which involves a constant search for the good that still presents itself as being achievable, or surrendering to the evil and its logic of death. In both cases, freedom is at stake,[18] that is to say the search for a meaning that alone can free and activate the autonomy of which we are constituted, so as to sustain and always launch anew an experience that is authentically human in every condition, including the end of life.

7. Witnesses to Hope

Facing this situation, which has very often been described by John Paul II in a lucid, penetrating and demanding way, is the great Gospel of life – the foundation and nourishment of an authentic culture of life. Man is called to a fullness of life that goes well beyond the dimensions of his earthly existence because it consists in sharing in the life itself of God. The nobility of this supernatural vocation reveals the greatness and preciousness of human life even during its temporal stage. Life in time, in fact, is a basic condition, the initial moment and integral part of the whole and unitary process of human existence. At the same time, it is precisely this supernatural call that emphasises the relativity of the earthly life of men and women.

We all know that this Gospel of life meets with a profound echo in the heart of every person, believers and even non-believers, because this Gospel, although it infinitely rises above people's hopes also meets them in a surprising way. Albeit amongst difficulties and uncertainties, every man who is sincerely open to truth and good, with the light of reason and not without the secret influence of grace, can manage to recognise in the natural law that is written in men's hearts (cf. Rom 2:14-15) the sacred value of human life from its beginning until its end, and to affirm the right of every human being to see this primary good of his or hers highly respected.[19]

To proclaim the Gospel of Jesus Christ is to proclaim– coherently and consequently – the Gospel of life. The life of a person is sacred because a person belongs in an overall way to the mystery of Christ, in whom and for whom the human person is for ever. Physical life is the inevitable pre-condition for a human person to live on earth and thus to live his journey of responsibility towards God the Creator during the various circumstances of his or her existence. For this reason, the life of a man is at the disposal of nobody, neither of an individual nor of the State, neither of science nor of technology, because it is a gift of God, granted mysteriously to human freedom so that a man may live out his adventure on earth as a pathway of encounter with God.

The end of life, because of physical death, does not annul the person as a perennial event in God; the conditions alone change. The intrinsic value and the personal dignity of every individual human being do not change, whatever the concrete circumstances of his or her life may be. A man, even if gravely ill or impeded in the exercise of his highest functions, is, and always be, a man.

The witness of so many men and women who make love for life, even during its gravest and weakest aspects and its most painful forms of conditioning, a privileged way by which to proclaim the culture of life, becomes for all of us a stimulus to engage in a daily commitment before the world. This is the great mission for each one of us: to open every day – with words and actions – that new path that goes from the heart of God to the world and transforms culture into a place of welcome, the place where God lives amongst men, all of whom are created in His image (cf. Gen. 1:27) and called, through the resurrection of the dead, as our Creed professes, to the life of the world that is to come.

This Christian faith of ours is the decisive new cultural approach to the end of life. In the presence of modern culture, which is soaked in that axiom of Heidegger – 'man is a being for death', to affirm that he is a being for life[20] transforms the end of earthly life into openness to eternal life and the hopelessness of modern culture into hope for life, for joy, for peace, and for light, where there will no longer be death, mourning, distress or sorrow (Ap 21: 3-4).

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Notes

[1] R. Guardini, *Le fins dernières* (Paris 1999), p. 30.

[2] We may cite those that are most famous because of the influence that they had over subsequent centuries: *De arte bene moriendi* (1618) by San Roberto Bellarmino e *L'Apparecchio alla morte* (1758) by sant'Alfonso Maria De Liguori.

[3] Reacting to this trend, the Bishops of Belgium restated in a document of February 1994 on 'the accompanying of sick people near to death' that today it is possible to prepare oneself for death that is experienced consciously as a moment of reconciliation and witness.

[4] See R. Guardini, *Le età della vita*, (= Sestante 2) (Milan, 1993^{2}), pp. 73-74.

[5] Cf. John Paul II, Encyclical Letter *Redemptor hominis* n. 14, in *Enchiridion Vaticanum* VI, p. 821.

[6] Cf. Giovanni Paolo II, 'Discorso ai membri della Pontificia Accademia per la Vita – 27/02/1999', in Giovanni Paolo II, *Insegnamenti* XXII/1 (1999), pp. 436-437.

[7] A clear and stimulating analysis from a pastoral point of view that is useful for those people involved at various levels in this field can be found in E. Monti, 'Senso e dimensioni dell'assistenza al malato terminale', in *La Scuola Cattolica* 1/2004, pp. 3-30.

[8] On 'taking care of' as an essential characteristic of man as 'being of Being', see the fundamental analysis of M. Heidegger, *Essere e tempo* (Milan/Rome, 1953) (original German edition 1927), pp. 204-213.

[9] From the very large number of possible references, we may cite a summarising text that is of great efficacy in enunciating the ethical questions and the relevant interpretational coordinates connected with the terminal stage of life: K. Demmer, 'La difesa della vita: i problemi del morire', in *Studi sociali* 26/4-5 (1986), pp. 45-66.

[10] F. Nietzsche, 'Genealogia della morale', in G. Colli and M. Montanari (eds.), *Opere di F. Nietzsche*, VI (Milan, 1968), p. 366.

[11] Cf. G. Angelini, *La malattia, un tempo per volere. Saggio di filosofia morale* (= Filosofia Morale 9) (Milan, 2000), p. 57.

[12] Chiodi, 'La morte occultata. Oltre l'alternativa tra eutanasia e accanimento terapeutico', in G. Angelini, M. Chiodi, A. Lattuada, R. Mordaci, C. Viafora, and C. Vigna, *La bioetica. Questione civile e problemi teorici sottesi* (= Disputatio 10) (Milan, 1998), pp. 101-149.

[13] For a detailed study see: P. Cattorini, *Bioetica. Metodo ed elementi base per affrontare problemi clinici* (=Biblioteca Medica) (Milan, 2000^{2}), pp. 12-14.

[14] Cf. the Declaration of the Congregazione per la Dottrina della Fede, 'L'eutanasia', in *Enchiridion Vaticanum* 7, pp. 332-351. See also Pontificio Consiglio «Cor Unum», document on 'Alcune questioni etiche relative ai malati gravi e ai morenti', in *Enchiridion Vaticanum* 7, pp. 1132-1173; and Pontificia Accademia per la Vita, 'Il rispetto della dignità del morente. Considerazioni etiche sull'eutanasia', in *Enchiridion Vaticanum*, 19, pp. 1012-1017.

[15] Congregazione per la Dottrina della Fede, *op. cit*., p. 349. Cf. *Catechismo della Chiesa Cattolica* n. 2279 (Vatican City, 1992), p. 561.

[16] On the interpretation of man and his action as a dynamic intertwining of self, others and institutions see P. Ricoeur, *Sé come un altro* (Milan, 1993), pp. 263-300; and 'L'etica ternaria della persona', in P. Ricoeur, *Persona, comunità e istituzioni* (Fiesole, 1994), pp. 77-94.

[17] On this point, the testimony of Paola Bignardi, the current National President of Catholic Action, is especially moving: *Avvenire*, 10 Feb. 2004, p. 2, with the title '*So che cosa significa essere malati*' ('I know what it means to be ill').

[18] Cf. A. Fumagalli, *Azione e tempo. Il dinamismo dell'agire morale alla luce di Tommaso d'Aquino* (Assisi, 2002).

[19] Cf. John Paul II, Encyclical Letter *Evangelium vitae* n. 2, in *Enchiridion Vaticanum* 14, pp. 1209-1211.

[20] Cf. P. Poupard, 'Aspetto la risurrezione dei morti e la vita del mondo che verrà', in P. Poupard, *La fede cattolica* (Turin, 1985^{3}), pp. 123-130.

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R. Heckel, 'Le respect de l'homme dans sa vie et dans sa mort', Pontificium Consilium pro familia, Doc. n. 83/1, March 1983.

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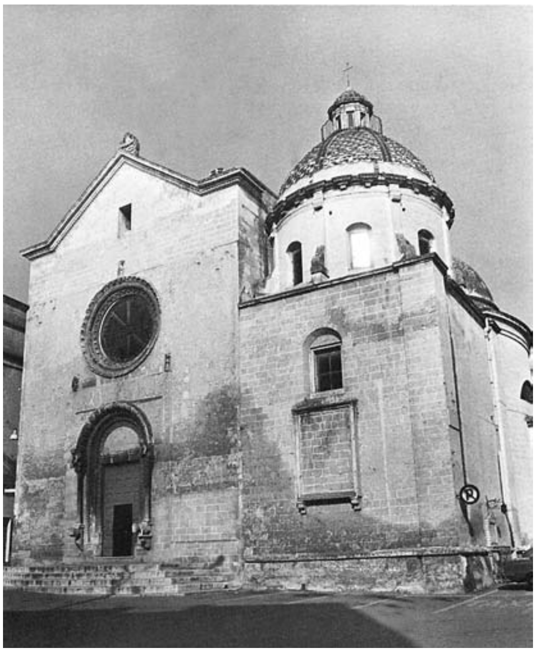

ANGELO BRUSCO

5. The Training of Staff and Palliative Care

While I was writing this paper I asked a colleague of mine to offer me some suggestions on how to present the subject that had been assigned to me, namely 'the training of staff and palliative care'. This tactic, pursued to overcome my laziness, bore its fruits.

Some Experiences

Indeed, my companion suggested that I begin my paper with an episode narrated by H. Nouwen in his book 'Creative Ministry'. Beginning with that experience, he told me, it would be easier for me to present my analysis. This is the text of Nouwen:

'One day a priest asked a group of his brothers to help him to analyse the meeting that he had had with a young woman, a parishioner of his, who was afflicted by a malign tumour and was destined to live in hospital, having only the prospect of a rather short period of survival. He described the woman as a happy woman, a woman full of life and humour. He described the conversation he had had with her and ended by saying that during the visit he had felt nervous, embarrassed, and dissatisfied with what he was doing.

The analysis of the conversation between the priest and his parishioner gave the impression of a long and painful attempt to avoid reality – the reality was that a wounded and beautiful woman was drawing near to her death. They had spoken about the female nurses, the food, the difficulties that she had in sleeping, her future plans, and when she would return home. It was clear that the pastor did not realise that he was avoiding the real question. His discussion with his colleagues made him understand that he could have helped that woman more if he had previously received better training on how to draw near to the dying.

But at this point a member of the group addressed the pastor and said: 'I wonder if you realise that you, too, will die, perhaps not this year, like your parishioner, but in a not too distant future'. Suddenly all the discussions on pastoral activity were halted and a long silence then ensued. Then the priest replied: 'Perhaps I am afraid that my patient will speak about death and it is probably the case that I do not want her to remind me of my mortal destiny'.[1]

When I observed that chaplains are *minor figures* in the sphere of palliative care, my colleague reminded me of an experience that had taken place in a hospital in New York. A psychologist, with a chronometer in his hand, who had suggested measuring the time required to respond to calls from patients, noticed that the female nurses responded rapidly to the calls made by patients who were getting better but showed no hurry to respond to calls that arrived to them from the rooms of the dying. When this psychologist told the female patients about the results of his investigation they were very surprised and refused t0 accept them. It is clear that their behaviour expressed an unconscious defensive reflex to death.

'And what about the medical doctors?', I asked. As regards this category of health care professionals, my friend invited me to read the following dialogue, which had taken place in a hospital between a medical doctor and a seventy-year-old patient with a carcinoma of the colon with hepatic metastasis:

Patient: Doctor, my liver is done in! But weeds never die…I'll win this time as well, this time as well.

Doctor: You certainly shall, you will need only a strong anti-toxin treatment for this rather wobbly liver of yours and a more suitable diet.

Patient: Listen to me. You've got to tell me the truth. I trust you. I've got liver cancer, haven't I?

Doctor: No, not at all. Your liver is just very tired. So far you have not eaten properly: too much pepper, a few glasses too many. You'll see. With good treatment everything will get better.

Patient: You know, I understand what the real situation is. But I am not worried about myself. I am sorry to leave my children and my grandchildren. I wanted to see my granddaughter get her school leaving certificate and then her degree. And the other two grandchildren as well. But it doesn't matter. I was able to enjoy them as long as I could, and with great joy. More is not possible.

Doctor: You mustn't speak like that.[2]

'Knowing how to Be'

By employing these examples my friend wanted to bring out one of the dimensions of the training of staff as regards palliative care: *knowing how to be*. It is evident, he said, that the training of those who work in palliative care must also take into consideration the dimension of *knowing* and *knowing how to do*. This is what is recommended by the European Committee for Palliative Care, which, indeed, dedicates as many as ten articles to the subject, and with the application of very high standards. However, if a choice has to be made, given the limitations of time, it must be in favour of the training dimension of *knowing how to be*.

The testimonies that are reported above, indeed, well illustrate the fact that the death of a patient can provoke deep emotions in those who are taking care of them. That death breaks the security of the medical doctor, brings out the uselessness of nursing care that seeks to achieve a cure alone, confronts a pastoral worker with arduous problems about the reasons for suffering and the end of life, which are at times without meaning, and also disrupts family relations.

In addition to being a constant affirmation of inadequacy, the patient who dies provokes a whole series of fears in those who accompany him or her. First and foremost, the unconscious desire for invulnerability and immortality is wounded.

Is the desire to always enjoy the human experience on earth, the beauty that makes it valuable, and the love that warms it, not perhaps innate in the human spirit? This desire is well expressed in the verses of the Catalan poet Joan Naragall. Turning to God, Naragall declares:

If the world is so beautiful, if it mirrors
Your peace in our eyes, can you
Not give us another life?

Because, Lord, I hold so very dear the eyes,
The face, and the body that you have given me and the heart
That beats within it; and so I fear death.

The fear that grips the patient in relation to what is deepest within him – his attachment to life – easily infects those who are looking after him, provoking in them, in addition to thoughts about their own end, memories of their past experiences of separation and of mourning.

One author has described the effects that an unconscious fear of death can have on the behaviour of workers in this area with reference to particular 'masks' and 'rituals' that are adopted by workers to distance the patient in order to protect themselves. Medical doctors and nurses can find refuge in the technical, and chaplains can take refuge in prayer and the celebration of the sacraments, thereby preventing the patient from communicating his or her own feelings, isolated as he or she is in a difficult emotional loneliness.

Entering into contact in a positive way with one's own experience in relation to death and dying is a pre-condition to ensuring that the move from *treating* to *looking after* is not a *flatus vocis*.

The phrase 'taking care of'[3] expresses the personal involvement of the health care worker with the person who suffers, an involvement that is expressed through compassion, concern, encouragement and emotional support.

This is an *act of synthesis* in which intelligence, no less than the heart, has its part and its place.

In an important book, written in the early 1980s, entitled 'In a Different Voice', the American Carol Gilligan[4] expresses in a very significant way the need for such a synthesis. The 'different voice' to which she refers consists, in the world of health and health care, of drawing near to people with an approach of participation rather than detachment, of harmony and compassion rather than abstract rationality: a voice that emphasises the primary importance of the person, the singularity of the person, because the person asks to be seen and understood for what he or she is. A voice spoken, down the centuries, in the main by women, but not only by women, even though our tradition has relegated that voice to them.

In the view of various authors, intimate emotion is the beginning of every example of real moral responsibility and thus of moral responsibility in the field of health and health care. A profound identification with those that suffer or are without means, indeed, shakes our selfishness and leads us to examine our consciences, our comforts, and our priorities.

It is this feeling of compassion, as is well observed by the French psychoanalyst Fran?ise Dolto, that achieves inter-psychic communication between humans. There is assistance in relation to the body, which requires professional skill and expertise, and is paid for, and there is emotion, which makes us human. When this is lacking it is because the service has become an institution or because the encounter is not unique but just a paid job or another engaging profession. In this case, the person who receives assistance is nothing else but an object. A human relationship no longer exists.

But practiced in the right spirit, assistance for the patient make epiphany possible, the expression of otherness, referred to by the philosopher Levinas, who defines the essence of moral experience as the experience of the encounter with another person, with the face of another person.[5]

If the move described above does not take place, there is a risk that the person of the patient is not seen, to employ the terminology of Martin Buber, as a 'you' (a subject), but as an 'it' (object), falling thereby into insignificance.

The Fruits of 'Knowing how to Be'

As you can see, my colleague said to me at this point, training at the level of 'knowing how to be' is demanding. It seeks to achieve a change that is not only cognitive in character but also one of attitude, of how to approach a person who has reached the end of his or her journey on this earth. When such training is well conducted, it produces a whole variety of positive effects.

The *first* such effect lies in the establishment of a meaningful relationship with the patient, made of respect and active listening. This relationship helps the sick person to accept himself or herself despite his or her physical and mental deterioration brought about by the advance of his or her illness. This is because he or she feels 'looked at' with respect and esteem. This relationship also makes possible an understanding of the feelings and needs of the patient (whether they are physical, emotional, social or spiritual in character) and facilitates a suitable response to such feelings and needs. In addition, it facilitates the communication of the truth to the patient, thereby helping to break the wall of silence that throws the patient into a state of loneliness. Knowing the truth about his or her own state of health is a right of the patient, but the communication of the diagnosis must take into account various factors, the first of which is the quality of the relationship.

There is a *second* effect which is very much connected with the first, and that is the capacity for self-involving and self-disclosing. This capacity allows communication to be followed up by a meaningful relationship, as emerges well from the following dialogue that took place in a hospice between a female nurse and a female patient suffering from cancer:

Patient: Nurse, could I see a specialist tomorrow? I have something important to ask him.

Nurse: I think that can be arranged, Lucia. In the meantime can I help you in some way?

Patient: Well? know that I am dying and that there is no real hope. I know that it could be in a month or in a year, and I do not want to stay here waiting to die. I want him to give me something, you know, so that I can go to sleep and never wake up again. I have heard that some doctors do this.

Nurse: I don't think our doctor would be ready to do that. You should also think about other people.

Patient: Who, for example? I don't have any relatives, or children who will weep for me. I could be beautiful dead.

Nurse: Oh, really! And what about me and my colleague? Are we not people who will weep when you die?

Patient: Oh, you, this in only your job, isn't it, only your job.

Nurse: This is my job, Lucia, but it is not only a job. I work here because I want to. I want to be a part of somebody's life, especially the lives of people like you, who do not have anyone to take care of them and to be concerned about them. And I will cry when you go, Lucia, just as I cried when Teresa died, yesterday. I am not your daughter, Lucia, I know, but I care about you. Don't neglect that fact, don't consider only my job.

Patient: Don't get sentimental. Why should you care about an old woman who is going to die in a few weeks' time?

Nurse: There are a number of reasons, Lucia. But I'll give you two. One is that I could easily be in your shoes. Cancer strikes down a large number of people and it could also strike me. The other reason, Lucia, is that on a number of occasions I have felt desperate and have wanted to die and finish everything, and somebody held my hand at the right moment.

Patient: (After a pause) Do you really care about me, I mean is it really not just a job?

Nurse: (Holding Lucia's hand) Yes, Lucia, I care about you.

As my colleague observed, this nurse correctly deciphered the question of being helped to die that had been posed to her by a patient and took account of the vulnerability of this person's condition. This deciphering allows the creation of an answer to questions such as the following: who or what is the entity that asks to be helped to die? It is the patient or the patient's environment? What is the object of the request? Is it the right to decide on one's own death autonomously, or rather the right to be assisted and looked after until death without feeling that one is a burden and without being ashamed, that has precedence? For whom is the suffering becoming unbearable?

Another effect, my colleague went on, is the way in which one approaches the reduction of pain. It is important to call into question the illusion which holds that there is only one way of addressing pain and suffering, that is to say by removing it through technical or pharmacological action. It should be remembered, in fact, that the pain of the dying person is *total* pain (fear of death, worry about separation, isolation, questions about existence, the perception of being a burden on others…). Because of this, pain is not something that can be treated at a medical level alone. It follows from this, that the efficacy of pain-killing treatment is bound up with the possibility of placing pharmacological medical treatment within a *meaningful relationship*.

'Knowing how to Be' and Spiritual Accompanying

Lastly, there is a *final* effect that requires special consideration. This involves the capacity to respond to the spiritual needs of a dying person.

Palliative care, by going beyond that organicistic orientation of medicine that led to a reductive view of the patient, has placed care for the spiritual needs of patients in therapeutic programmes for dying, and it has done this more than has been the case in any other branche of medicine and health care.

This is to be attributed above all else to a number of women of great value, women such as Elisabeth Kübler-Ross, Virginia Henderson and Cicely Saunders. In their writings, these women formulated concepts that would be of decisive importance in the practice of palliative care. The first of these, E. Kübler-Ross, brought out the mental-emotional-spiritual pathway that is followed by patients during the terminal stage of their illnesses. In the works by Henderson there is a clear statement that in order to offer nursing care that respects the person, the person's needs have to be recognised, including his or her spiritual needs. For her part, Saunders emphasised the spiritual component of *pain* experienced by patients who are nearing the end of their lives.

The paying of marked attention to spirituality in the treatment and accompanying of patients is a positive sign that reflects a living tendency in contemporary culture. But, I asked, are staff trained to understand and grasp the spiritual needs of dying people and also trained to respond directly to them or turn to suitable people?

My colleague said that rather than giving a positive or negative answer to this question what matters is the urgent need for training in this area of care so as to avoid the risk of limiting the word 'spiritual' in the texts or speeches on palliative care.

In this, as in other sectors, he went on, training begins with contact with one's own spirituality. This is an indispensable pre-condition that allows one to draw near to the questions and issues of another person with that *interior freedom* which is necessary if we want to avoid undue projections and erroneous influences.

The comments of a psychologist and a moralist are of relevance here: 'It is clear', writes the first, 'that a worker who is not in contact with his or her own spirituality cannot allow another individual to open himself or herself to that worker's spirituality, and he or she may come, through projection, to deny the presence of this interior life in the other person'. The second observes: 'the expression of spiritual needs by patients cannot but reach the personal spiritual space of every person who is engaged in accompanying. As a result, this expression will come to be fostered or impeded in varying ways'.

The project of accompanying one's fellow man until the end of his death places everyone in the truth of their condition. In spiritual accompanying, in fact, man is taken from his *divertissement* and led back to the authenticity of his own existence. He is thus confronted with his own purpose: what is he, in truth?

The observations made by Cosette Odier, a Swiss Protestant pastor, are very appropriate here: 'in order to accompany gravely ill people at a spiritual level, we must pay attention to their needs. All of us, in each one in our own way, must strive to the best to understand what is deep within us, there where we draw the strength to live, the strength to accompany those who are about to die. We must all try to be 'rooted' in order to accept the various forms of spirituality that appear in our lives nowadays and to help the patient go do down his or her own pathway (without, because of this, excluding changes), a pathway that is rooted in what he or she is. We are not there to impose a system but to discover together the roots of our being, that 'breath of life' that pervades us all, whatever the name we give to it. For me, it is the Holy Spirit, the spring of life...'

From this comes the need on the part of workers in this field to ask themselves about their own spirituality, about the system of values that guides their existence, and about the answers that are born in their hearts in response to questions about the meaning of suffering and death. Only on this condition 'can those that depart and those that accompany them together make a step forward in humanity'.

The Quality of the Therapeutic Team

At this point I wanted to take my leave from my colleague. Before leaving him, however, I asked him if what he had said to me also applied to the successful working of a therapeutic team that was engaged in providing palliative care. There can be no doubt about that, he replied. A health care team, in fact, is made up of various figures, each one of whom has their role in the organisation and provision of the forms of treatment and care that are given to the patient. The ideal is for its members to achieve that unity and that harmony which, without ignoring the diversity of tasks, allows a valid service to be offered to patients and the potential of individuals to be used to the utmost, thereby fostering their personal growth. For a team to function smoothly, attention should be paid to the principles of group dynamics, the acquisition of communication skills, and above all that ability in relationships that constitutes one of the principle features of *knowing how to be*. This is what a female nurse expressed on the matter in colourful terms:

'Each one of us would like to work in a place that we have always wished for and dreamed about: a family place where everyone knows each other and respects each other, at the service of other people, co-operating and with professional attitudes, following our heart and not only in pursuit if earnings.

Often, however, the reality is different.

We find that we work with a large number of people, of different ages, with different interests, with different motivations, with different sensibilities and with different life experiences.

The shared objective, therefore, easily becomes not the good of the person with which one comes into contact, in my case in old peoples' homes, but defending one's own interests and often one's own selfish gain.

One of the biggest problems that I come up against every day is selfishness, people closing up in themselves, and the loss of certain key values, such as readiness to help, humility, a spirit of sacrifice – in a word, people no longer know how to really love.

Our work is not simply a job, or at least that is what I think, but a calling, a life commitment to which we should always renew our 'yes' with sincerely and awareness.

Being at the service of other people, of sick people, of those most in need, requires a very strong interior richness that cannot always be sustained.

It is for this reason that colleagues should feel more united, be a force, a union, and not only people forced to spend many hours together because that is the way things must be.

It would be great if we could find people in our work contexts who were good as points of reference, on whom to draw, and recharge our batteries both at a technical level and as regards an experience made up of humanity.

Little would be needed to help nurses such as ourselves to feel more valued and more motivated, but even this small element is difficult to find, above all from those who are placed 'above' us.

I do not feel a pessimist, but the ethical, psychological and organisational problems are really many in number, but I would like to solve them, or at the least address them, feeling less on my own and nearer to responsible and satisfied people'.[6]

Some Concluding Observations

Going away, my colleague left me the task of drawing some conclusions, which I have summarised as follows:

It is important to make a distinction between information and training. Information has the task of reducing cognitive ignorance, whereas training has the task of developing attitudes and forms of behaviour. 'Speaking metaphorically, training and information are like two wheels on a cart. Unfortunately, in the health care world too much travelling is done on the wheel of information and thus the cart is very unbalanced. Unfortunately, in the health care world, as regards *knowing how to be*, there is too much travelling on the wheel of information, and the cart is very unbalanced and harsh'.[7]

As has already been pointed out in this paper, training is valid when what we learn helps us to change, and change increases our knowledge and affects the environment in which we work. If our training does not manage to transform us and at the same time to transform the environment in which we work, then our changes run the risk of lasting only a morning: the first sun will wither them and the first difficulties will suffocate them.

Training must be constantly be related to its context and find support in the structure. Otherwise, training is like teaching a person to run a hundred metres in ten seconds and then giving him or her a four by four room!

We express what we learn in what we do, but we can also learn from what we do. For this to happen, both individual and group supervision are required.

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Notes

[1] H. NOUWEN, *Ministero creativo* (Queriniana, 1981), pp. 7-8.

[2] From M. TOMAMICHEL, 'Guarirò dottore? Cattive notizie o cattive risposte', in L. PINKUS and A. FILIBERTI (eds.), *La qualità della morte* (Angeli, Milan, 2002), p. 161.

[3] Cf. M. TORALDO DI FRANCIA, 'Il tema della cura e del prendersi cura: da sponda a sponda', *L'arco di Giano*, 38(2003), pp. 81-90.

[4] C. GILLIGAN, *In a Different Voice: Psychological Theory of Women's Development* (Harvard University Press, Cambridge, Mass.), 1982.

[5] Cf. E. LEVINAS, *Totalità e infinito* (Jaca Book, Milan, 1980), p. 73.

[6] Quoted in A. DE TONI, *Salute scienza coscienza: orientamenti di etica e bioetica per i responsabili della salute* (Rosini Editrice, Florence, 1995), p. 191.

[7] A. SPINELLI, 'Il contributo delle scienze umane nell'opera di umanizzazione del personale sanitario', in AA.VV., *Per un ospedale più umano* (Paoline, Cinisello Balsamo (MI), 1985), p.

JOHN PATRICK FOLEY

6. The End of Human Life in the Mass Media

This evening, on the channel RAISAT PREMIUM, there will be the final installment of the television series, “Brideshead Revisited”, based on the novel of the same name by the English author, Evelyn Waugh.

In one of the final scenes, Lord Marchmain, the master of Brideshead, a beautiful English country home, lies dying in his ancestral mansion – and he has refused all ministrations of the Church. He was a Catholic who had been living in an adulterous relationship with a mistress in a palazzo in Venice.

The very unsophisticated pastor of the local parish, not particularly esteemed by the members of this noble family, visits Lord Marchmain – played by the great English actor, Sir Laurence Olivier – to urge him to final repentance. Finally – wordlessly – the dying aristocrat with difficulty makes the sign of the cross and receives absolution from his pastor.

My description is obviously unequal to the emotion of the moment depicted, but it is one of the most sensitive and most moving depictions of the end of human life I have ever seen.

The aristocrat’s family has provided physical care and indeed a certain reluctant loving presence in regard to a person who has – for all practical purposes – abandoned them during his life, but some of them are much more concerned about his spiritual well being, and their efforts are rewarded by one of the most memorable conversion scenes in the annals of English literature.

Would that the end of human life were always depicted with such insight and sympathy in the mass media!

Even though the end of human life is often depicted in the mass media, whether in news reports about battles or murders or the deaths of famous people, or in dramatic films or television programs, the focus is most often on the fact of death rather than on the purpose of life.

Recent reports on the terminal illness of Yassir Arafat are witness to the preoccupation with the moment of death, the prolongation of life and the physical preparation for burial, not on the preparations the individual has made for death or for eternal life.

There are many questions which can be posed regarding the end of human life and the mass media.

One of them is: what can be shown regarding the end of human life?

The film, “Saving Private Ryan”, was criticized by some because it had a long sequence regarding the Allied invasion of Normandy during the Second World War. The horrible deaths and injuries suffered by the invading force were depicted in gruesome and frightening detail and there was literally a feeling of disgust and exhaustion at the end of the sequence. I am sure it was nothing like living through that terrible day – or dying or being wounded during the course of it, but it was frightening enough for a passive viewer.

For me, that scene from the film had at least two messages: the terrible horror of war and the desperate heroism of those who faced danger and death, in this situation, in a noble cause.

How graphic, however, should be the depiction of violent death – either in dramatic presentations or in actual news reporting?

In news reporting, there is often fear that the depiction of death and dying can shock viewers – especially if families of soldiers or those involved in accidents might be offended.

While it is understandable that families should be notified before news reports reveal names of those killed, wounded or injured, it is to be feared that public authorities sometimes do not want explicit coverage of the effects of battles, because they do not want to turn public opinion against war. Also, sometimes public officials or private company officials do not want reports of the effects of certain accidents lest resentment be directed against them for not having prevented such occurrences.

Also, in all such cases – of war or accidents, there is a fear that children viewing such scenes will be traumatized.

As a former editor, I personally favor the greatest possible freedom in depicting the tragic effects of accidents or wars. In my opinion, the news should be reported accurately and even graphically; the conclusions can be drawn editorially.

Regarding spiritual care given to those who die or are injured in war, the media have most often been most cooperative, as have been military and civil authorities. It is a consolation for families to see that heroic chaplains are present to celebrate Mass for those entering battle, to administer Extreme Unction to those fatally wounded, to give absolution to those entering battle and to those who have fallen in battle. It is a tragic fact that the number of chaplains available to minister to soldiers is diminishing, but many chaplains will tell you that nowhere more than in the military is their ministry appreciated and indeed necessary.

Certainly the depiction of clergy ministering to the victims and the escapees of the disaster of September 11, 2001, at the twin towers of New York brought inspiration and consolation to many. Such tragedies often elicit the question, “why”, not only about the tragedies themselves and the meaning of such suffering, but also about the very purpose of life and our destiny and the destiny of our loved ones.

The theme of our conference, however, touches on palliative care.

Because there is a general tendency towards the denial of death, the media often avoid such questions until the appearance of critical cases, often under litigation, forces coverage of the problem.

There is the famous case of Terry Schiavo, the woman in a type of coma whose husband wants nutrition and hydration brought to a halt and whose parents wish it to continue.

Mostly because of media coverage, sympathy was at first with the husband, until allegations were made that he did not want all his wife's money to be used to maintain her life. Florida Governor Jeb Bush, the brother of the President of the United States, ordered care to be continued.

This case was widely reported in the secular media, but the Catholic media were able to use the occasion to explain to their readers the differences between ordinary and extraordinary medical care and palliative care. By the way, when I say "readers", I wish to note that it is much easier to enter into detailed explanations of moral questions in the Catholic press than it is in a radio or television report.

As we know, it was difficult enough to explain the difference between ordinary and extraordinary care – that what might be considered an ordinary surgical intervention for a 20-year-old might be considered an extraordinary intervention for a 90-year-old.

However, many – possibly under the influence of the media, having seen programs such as "ER" or even programs such as "Law and Order" or "The Practice" which might occasionally treat of medical/moral themes which have legal consequences – might think that nutrition and hydration would enter into the realm of extraordinary care, something which the Holy Father has specified is not the case.

Another question which is most current is what might be called the "Christopher Reeve case" – the apparently instrumental use of human life, in this case fetal stem cells, to treat a chronic condition. While Mr. Reeve has unfortunately died, the publicity he gave to what he viewed as the benefits of using fetal stem cells and the recent passage of a referendum in California for public funding of fetal stem cell research have made that question very pertinent. As I have noted, however, it is an instrumental view, a willingness to use what amounts to the destruction of a human being, in this case a fetus, for the benefit of another human being. But this question goes far beyond the discussion of "palliative care" – although not beyond the question of the impact of the media on moral decision making.

In both dramatic programs and in news reports, there has been a lot of coverage of "right to die" questions. Does the individual have the right to intervene directly to take one's life or to ask another to take one's life in the case of apparently terminal illness?

Because neither news agencies nor film studios have much reflected on the redemptive value of suffering or even on the intrinsic value of human life, over which only God has ultimate dominion, the prohibition of suicide in such cases is often popularly portrayed as a cruel imposition on persons in their final agony. The subsequent relativization of the value of life obviously then has an effect on such questions as the abortion of handicapped or retarded children and on the continued care of severely handicapped persons, of the victims of advanced Alzheimer's disease, or, in general, of the old, weak and sick. The worldwide revulsion at the proposals of Hitler regarding euthanasia of the handicapped is apparently fading with time – and with widespread rationalization.

What can be done to sensitize media to the needs of persons at the end of their lives?

Indeed, the Italian and English words – end and "*fine*" – have a twofold signification. The one apparently used in this conference is "terminal point". The other definition of end is purpose.

The treatment of individuals at the terminal point of their lives will be determined, however, by our concept of the purpose of human life.

If we believe that every human life has as its purpose eternal life with God and that individuals have an added opportunity for grace with every moment of their natural life and that others may also grow in grace with the exercise of Christian charity and indeed of solidarity, then there will be no concept of seeking to rid oneself or society from the alleged burden of a life which has become apparently inconvenient for the person suffering and/or for the caregiver.

The problem faced not only by the media but by society itself is not medical or sociological but anthropological and theological.

It is evident that the media strike a responsive chord when they depict chaplains ministering to the victims of war or clergy ministering to the sick and dying and to their loved ones. It is also evident that the media struck a responsive chord when they treated of Blessed Mother Teresa ministering to the sick and dying among the poorest of the poor. There was a tacit admission by the media of the precious value of each person to whom Mother Teresa and her Sisters were ministering. There was also a deliberate choice on the part of the media, especially after the biography by Malcolm Muggeridge, "Something Beautiful for God", to cover the work of a woman who so heroically cared for the most easily forgotten members of society.

Mother Teresa taught all of us the value of every human life and the importance of loving care for every person as a precious child of God.

Thus, in representing the teaching of the Church about the importance of care for every person at the end of human life and indeed about the end or purpose of human life, we need not only theological experts and spokespersons for the Church; we need the living witness of individuals who care for the sick and dying.

Therefore, I would recommend effective public relations activities on the part of Catholic health care institutions, not only to make known their financial needs or to make known the services they offer to the public, but to make known what the dedicated people who work in them are doing for the care of the poorest of the poor – naturally in a way that will not exploit the poor or that will not appear to seek to advance the careers of the health care providers involved in such care.

Catholics especially, but also all people should be reminded of the importance of pastoral care for those who are dying.

Since we believe that all does not end in death but that our true home is in heaven, greater emphasis should be given to calling a priest as death approaches so that the previously unrepentant might be able to confess their sins and receive absolution and so that all Catholics might have the consolation of Viaticum, the final Holy Communion before entering the eternal banquet of heaven, and of receiving from the priest the Apostolic Blessing, the final blessing of the Pope which carries with it full remission of the temporal punishment due to sin, in other words, a plenary indulgence.

I return again to that final scene in the life of Lord Marchmain in "Brideshead Revisited", which I believe to be the best television series ever done.

In the last moments of Lord Marchmain, who had resisted religious approaches until then, a simple, persevering parish priest reached out once again – and his reward was witnessing the struggle of a dying man to make the sign of the cross of Jesus Christ.

Continuing physical care for the terminally ill is important and its importance should be emphasized in the media, but guaranteeing spiritual care throughout a final illness and at the moment of death is of the greatest importance – and its effects are eternal in the life of the person absolved, anointed and strengthened by Viaticum but also in the lives of those who witness in news reports or even in dramatic programming the difference spiritual care can make at the end of human life and for the end – or purpose – of human life.

On the memorial cards for my late parents, I had printed the former translation of the preface of the Mass for the dead:

"In Christ Our Lord, there shines forth the hope of a blessed resurrection, so that we who are made sad by the certainty of death are reassured by the promise of immortality. Life is changed, not taken away from your faithful servants, Lord, so that when this the house of our earthly exile falls to ruin there is made ready an everlasting home in heaven."

H.E. Msgr. JOHN PATRICK FOLEY
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the Holy See.

saturday
13
november

7. The Up-dating of Health Workers in the Pastoral Aspects of Palliative Care

JACINTO GUERRERO TORRES

7.1 Priests and Palliative Care

In the presence of this select group of specialists in palliative care I would like first of all to expound what should be *the role of priests in the presence of patients who are at the terminal stage of their illness* both in hospitals and in the communities where priests carry out their pastoral activities of proclaiming, celebrating and promoting communion and brotherhood amongst the whole of the people of God and the various circumstances that are involved. Then I will dwell upon pastoral action in the world of health and health care and at a specific level I will discuss priestly action to benefit those patients who are at the terminal stage of their illness, for whom health care centers have been created which are known as '*palliative care*' centres or pain clinics. The World Health Organisation has defined palliative care as 'the treatment that is appropriate for a patient in an advanced and progressive stage of illness that does not respond to therapeutic treatment and where the control of pain and other symptoms, like the *psycho-social and spiritual aspects*, acquire greater importance'.

For priests, this involves paying spiritual and religious attention to the sick person, and even if we realise that they will have increasing numbers of terminally ill people, given their condition as persons and above all because they, too, are children of God, these sick people must be followed in a suitable and appropriate way, as indeed this Pontifical Council has stated categorically on a number of occasions (cf. 'The Rights of the Person in a Terminal situation and Hospital Work and the Role of Palliative Medicine'). Even though the patient cannot be cured, it is important that a priest be present, *and indeed 'being there' is the fundamental role of the priest*.

The patient must be assisted in an overall sense with the identification of, and attention being paid to, his or her physical, emotional, social and spiritual needs.

As a priest, it is necessary to return to history, which, indeed, tells us that for centuries care for the sick has been a responsibility of religious institutions.

This is a difficult task but it must be allocated to the projects of pastoral care in each diocese; indeed, at the present time there are gaps when we come to consider assistance for the sick.

Allow me a personal recollection that comes from my experience as a priest, and which marked my life in relation to care for the sick. They appointed me the chaplain of a hospital where I went every day to celebrate Holy Mass and give communion to the patients. The first day, after Holy Mass, at the first home where they told me that the Eucharist had been asked for, I encountered a woman who was practically a skeleton and whose skin was attached to her bones. I was afraid, I must admit, and felt repulsion. I tried to do my duty very quickly and to leave as soon as possible. That picture shook me, but I thought deeply about that encounter and I gradually changed my views: I spent more time with that person and talked to her about her family and about her illness. A month later that woman died and I accompanied her to the cemetery, to her last dwelling place, and there I established a very good relationship with her family relatives. She was an exemplary woman who during her last days was revived by the visit of a priest.

Being with the terminally ill is of

fundamental importance, being their friend, their confidant, and their servant. That is to say, as a priest one must establish human contact, be always ready to help and always kind and pleasant.

Well. *What made me change my approach to the pain of patients?* My experience in hospitals lasted for eight years, but after this there was my experience in a parish where I visited patients every eight days, and this practice of my priestly ministry made me more human. However, this took place thanks to the reflection that every priest is an 'administrator' of the sacraments and the Gospel in order to give life and light to all those who have been entrusted to his care and assistance.

We can repeat the same words of Christ: '*The Spirit of the Lord is upon me*' (Lk 4:18). Indeed, the very Spirit received from the sacrament of ordination is a source of holiness and call to sanctification not only because it shapes the priest in conformity with Christ the Head and Pastor of the Church but also because it *entrusts to him a prophetic, priestly and real mission* so that he may carry that mission out by personifying Christ and also animate and vivify his existence every day, enriching it with gifts and requests, with virtues and strengths that are expressed in pastoral charity. This charity is the unifying synthesis of the Gospel values and virtues and at the same time the force that sustains his growth and development until the achievement of Christian perfection (PDV, 27).

The same document affirms that Gospel-based radicalism is a fundamental and inescapable requirement that springs from the call of Christ to follow him and to imitate him so as to achieve communion of life with him. This requirement is even greater in the case of priests because they are the face of the Church, because they are modelled on Christ, and because they must be suitable as well as involved in the event of salvation and the well-being of our brothers and sisters, because they are modelled on Christ (cf. PDV, 27).

I believe that all this is very gratifying and above all that it is productive in ensuring that priests in their ministries enter into the field of knowing the person, the work and the teachings of Christ so that in a real sense in the world of health and health care and at a more practical level of palliative care they are like Christ, that is to say men who are near, very near to the terminally ill, and who show them that the Church is also their mother with her presence and her care and concern which foster hope and ensure that they do not live in loneliness in hospitals or their homes.

Priests Must Know How to Look at Christ

A priest must purify his gaze so as to contemplate Christ when interacting with sick people and discover what Christ would have done in the circumstances of abandonment and desperation of patients who hope only that they will finish their days.

As Paul VI declared, where there is a sick person there must be a human place in the full sense of the term where every person is treated with dignity and where he or she feels – despite his or her suffering – the closeness of brothers and sisters, of friends (Paul VI, Allocution, 24 May1974).

The Gospels very often present the love and compassion of Jesus towards sick people and at the same time they record his constant healings of the sick.

It is interesting to observe how St. Paul relates the passing of Christ through Palestine when he was at the home of Cornelius: Jesus of Nazareth…went about healing and doing good (Acts 10:38).

'He healed the sick; consoled the afflicted; fed the hungry; freed the people from deafness, from blindness, from leprosy, from the devil and from various physical disabilities; three times he restored the dead to life. He was sensitive to every human suffering, whether of the body or of the soul' (John Paul II, Apostolic Letter *Salvifici Doloris*, n. 16).

Christ drew near to pain. When he saw the paralytic at the pool who had borne his suffering for thirty-eight years he asked him spontaneously: 'Do you want to be healed?' (Jn 5:6) On another occasion Christ offered to go to the home where the servant of the centurion was ill (Mt 8:7), and he did not flee from diseases that were thought to be contagious or from those that were very unpleasant. The leper of Capernaum could have been healed from far away but Christ drew near to him and healed him (Mt 8:3).

When Christ first sent out the Apostles to preach the Kingdom of God he gave them the power to heal the sick (cf. Lk 9:1-6).

Another great motivation for priests is to know that the Holy Mother Church teaches us to visit

Christ (cf. Mt 25:36-44) because to serve those who suffer is to serve Christ himself in the suffering limbs of his mystical body, so as to be able to have the great joy as priests of hearing from the lips of the Lord: 'Come you who are blessed of my Father, I was sick and you visited me…'

In the person of Christ the Head, the priest must act as Christ himself would. This is because in his name we provide these small examples of help and at the same time behave as if we were coming to the sick Christ who needs the priestly ministry that accompanies, that cares for the sick person who very often is abandoned and discouraged. This makes the Gospel more credible.

A priest must be very conscious not only that he should reflect on the words and actions of Christ, as we have already seen in this paper, but must also take into account the spiritual dimension of palliative care. I will now speak for a short while about this *spiritual dimension*.

In his relationship with the terminally ill it is important for a priest to discover some elements of his own spiritual dimension because these determine *his vision of life, his vision of what realities are important, and the goals that should be pursued*.

Accompanying spiritual needs. Although care for spiritual needs *is the task of all professionals and not only of priests* because such professionals have to deal with these kinds of needs, it is regrettably the case that the creation of instruments for caring for spiritual needs has taken few steps forward.

Accompanying at times of anxiety and of the posing of difficult questions. Here a priest must be open to dialogue and facilitate emotional release or emptying on the part of the terminally ill person.

Accepting and integrating reactions in the face of death. This is the most difficult task that the priest faces because the death of a terminally ill person provokes profound feelings in those who have looked after him or her. It breaks the security of those who have looked after him or her and demonstrates the uselessness of forms of care that only seek a cure. It involves facing up in a severe way to the arduous problems of the reason for suffering and death. Depression must also be taken into account – this is another moment in the evolving journey of a dying person.

Reconciliation with the person's own life: the treatment of guilt and memories. This is a moment when wounds should be healed by looking backwards so that the dying person becomes aware of his or her past: it is as if at the end he or she passes in front of a mirror and sees a film of his or her own life and there is the appearance of a feeling of guilt. The sick person becomes a judge and, accused with his or her own past, is assailed by a feeling of anxiety or self-condemnation. During these moments of pacification the priest should help the sick person to introduce order into the experiences that have been accumulated during his or her life so that he or she can forgive those who have wounded him or her and openly or in a symbolic way ask for forgiveness from those that he or she has offended. At this time the sacrament of reconciliation can be very useful. It can do a great deal of good to the terminally ill person and help him or her to discover a loving presence that transcends him or her beyond the feeling of guilt.

Hope. This should not be confused with optimism. A priest must be a man of hope at a crossroads of suffering and darkness; a hope that enables the sick person to look beyond the meeting of immediate wishes and even beyond pain and death, when, that is, his anthropological vision does not end with the definite finale of death and when the patient has a transcendent vision of the world.

Hope is not suited to half-truths and is not satisfied by phrases such as 'everything will work out for the best'.

Fostering religious service. This is something specific to the priest, but it is something that should be engaged in only when the sick person wants it. The free choices of the individual involved must always be respected. It must be discovered that the illness can be transformed into a 'place', an opportunity to experience one's own faith in Christ and thus to achieve one's own baptismal vocation: to be dedicated to the Lord in every activity and situation of one's own life.

In this sense, suffering is not only transformed into an opportunity for the patient himself or herself to achieve spiritual growth, but is also transformed into salvation for those who are near to the sick person: the goodness of the action radiates around the terminally ill person.

The sick person spreads a feeling of peace, of faith, he or she makes solidarity spring forth, he or she opens up to hope; and the whole environment changes.

In this situation, the sacrament of the anointing of the sick acquires new light and a new meaning. It ceases to be the sacrament for unconscious dying people or a 'passport' to the life beyond. Here magical or superstitious interpretations of any kind must be removed so that the true meaning of this sacrament can be expressed – it is a sign of the praying presence of the community to exhort the sick person to have faith and to offer him or her the grace of sanctification so that he or she can live our her or his suffering with Christ. We know that this sacrament grants the grace of the Holy Spirit to the sick person by which the whole man is helped at the level of his health, comforted by trust in God and strengthened against the temptations of the enemy and the anxiety provoked by death so that he cannot only bear his hardships with strength but also fight against them.

The celebration of the anointing of the Sick by the Church is to be located in continuity with the actions of Jesus to benefit the sick. We know that sickness influences the whole man, his body and his spirit: without a special grace from the Lord the sick person could suffer from the temptation of shutting himself or herself up within himself or herself, abandoning himself or herself to loneliness or hopelessness, to the point of rebelling against God and His providence. Instead, the virtue of this sacrament confers on the sick person those graces that are needed in order enable him or her to trust in God of salvation and dominate the situation to hand in faith. This sacrament is a comfort, it is help.

The priest must confer a style on this celebration: he should use well-prepared liturgy with a prior catechesis. A choral participation does not only help the sick person but also develops other initiatives of assistance and closeness in death.

Christian faith also illuminates the event of death as a paschal passage with Christ to the House of the Father. The Church holds that man is created by God for a destiny of happiness beyond the boundaries of terrestrial miseries in order to be in eternal communion with incorruptible divine life (cf. *Gaudium et Spes*, n. 18).

A Christian should be encouraged to die as a Christian. This is because a baptised person does not observe what finishes but what projects him or her into the future: to die is to share in the victory of Christ over death.

The sacraments of reconciliation and the Eucharist in form of viaticum express reconciliation with the past and this is nourishment for the 'great journey beyond death'. Viaticum gives a new meaning to the death of a Christian and takes on the meaning of an offering joined to that of Christ who welcomes it in order to present it to the Father.

Lastly, in all parishes and to the extent that one can, in hospitals, accompanying does not finish. There are family relatives who have other needs. Mourning should be elaborated so that they can begin to live.

And here the spiritual and religious dimension can have a decisive importance in offering relief, courage, pleasure and the desire to going on walking through life.

Conclusion

In this paper, which I have had the opportunity to give to such a distinguished and professional audience, on the very important subject of the role of priests in relation to *palliative care*, we have not ceased to see the fundamental function of this figure whose mission is to make Christ present in the world of pain and suffering. This is an opportunity that presents itself day by day in the *priestly ministry* both in hospitals, together with the team of hospital staff, and in the ordinary ministry in the *parish context* where we constantly encounter a multitude of people who are in beds of pain in a terminal situation *because centres providing palliative care and drugs and medicines are increasingly prohibitive at the level of cost*.

Here a priest must be the voice of those who have no voice so as to offer assistance and engage in works of mercy, so as to be blessed by God the Father and express the mercy that Jesus asks of us: 'Come, O blessed of my Father, inherit the kingdom prepared for you from the foundation of the world; for 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' (Mt 25:34-36).

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7.2 The Up-dating of Health Workers in the Pastoral Aspects of Palliative Care: Medical Doctors

The concept of palliative and hospice care, which evolved in many countries, brought to our attention that there is a significant need for increased physician participation in all aspects of the care provided to terminally ill patients. Within the hospice and palliative care programs emerged four new distinct physician roles: the attending physician, the consulting physician, the medical director, the hospice team physician.

It is mandatory that the medical director and the hospice team physician should be specialists in palliative medicine. My presentation will focus on endangerments and benefits of pastoral ministry addressed especially to those two types of physicians, but certainly not limited to them.

Palliative physicians are a part of very narrow medical specialization. Their ratio to the number of inhabitants of any given country fluctuates from a dozen or so to several thousand. However, there are many countries where this medical specialization does not exist. That global situation brings a lot of challenges in establishing permanent pastoral care addressed especially to doctors and medical palliative staff. The complexity of the hospice ministry, with its holistic approach to patients, makes it even more difficult to formulate and create pastoral programs and suggestions concerning physicians and medical staff.

Social transformations. One finds numerous manifestations of the change of social context in which contemporary man is functioning. The leading processes are the following: the specialization and segmentation of social life, transformations in the social-occupational structure, socio-cultural pluralism, and specialization with regard to functions played by various social structures.

All this leads to a disintegration of local communities, and thereby to an "atomization" of the parochial milieu. This gives rise to a "social vacuum" between the parishioner and their parish, and there is no interaction between parishioners at the religious level.

The fundamental issue here is to create awareness within the Church community about what ought to be done and what conditions should be taken into consideration so that the Church can be present among the people who minister to the dying. Such awareness is rooted in the basic functions of the evangelizing Church and determining pastoral aspects of ministry to the doctors of palliative care.

The paradigm of medicine and other considerations:

– reductional concept of man: bio-mechanical – illness as a defect;

– repairable medicine: illness-defect – medicine repairs failure;

– limitations of repairable and therapeutic medicine;

– palliative medicine - the culmination point – bring changes in expectations of medical doctors in palliative care.

The basic functions of the Church: the prophetic, liturgical and charitable are stable and do not change. One may, however, seek their new forms or renew the old ones. *In the function of the prophetic* are various forms of preaching the message of salvation. At the moment it seems – taking into account de-Christianization, selective religiousness, and rationalism – that pastoral tasks are similar to those which the first Christian fellowships had. One should make preaching more essential and direct it to the establishment of ecclesial fellowships; one should stress religious instruction for adults, a more intensive commitment of the laity, and educate people for choice in the "worldview market." One postulates here discussing in ecclesial preaching the question of vocation and mission in the ministry for suffering brothers and sisters. These are charismatic elements necessary for a physician of palliative medicine. It is crucial to form a charism in a palliative care doctor. *In the regeneration of the liturgical function* one should stress the need to educate for participation in religious practices. The important point here is not only systematic participation, but also its quality and intensity. The liturgy in its fellowship-mak-

ing function should be stressed here, its role as a school of faith and a way of parochial evangelization. It is important to understand better the religious symbols, signs, and gestures. This will help to show the faithful the liturgy that is comprehended, authentic, and uniting. *The regeneration of the function of love* calls for broader perspectives of traditional charitable activity. It should be extended from its narrowly understood function (aid for the poor) towards the satisfaction of all real needs that exist in the parochial milieu.

New functions of pastoral care and parishes: developing Christian associations; non-parochial pastoral care; extraordinary pastoral care; special, specialist, and individual pastoral care.

The function of developing religious associations. Beliefs, opinions, attitudes, and behavior are to a large extent formed by the milieu. Therefore people need a Christian surrounding if they are to live a Christian life. Circumstantial factors are more than the institutional ones the elements of this development: hence the basic concern of contemporary parishes should be the establishment of such milieus. It is the task of the parish to support and stimulate initiatives, and co-ordinate small religious groups. The point is to create milieus for believers in which Christianity is accepted and manifested, in which Christians can find support for their needs. Each member of a parish has contacts with many milieus. At least one of them should be Catholic.

In contemporary societies "pastoral care for the converted," those who more or less take an active part in the life and faith of the Church, must be supplemented by "pastoral care of conversion." The latter kind of pastoral care is designed for those who partly distance themselves from faith and the Church. The need for "pastoral care of conversion" is the reason why the function under discussion has been separated.

From the pastoral point of view one should accept each Christian for the way he or she is, even if they are Christians on holidays and are selective. The point is to help them to make a step forward towards a more complete Christianity. This means that we should take an interest in the questions and problems of "those who stand far from the Church." The world today requires Christians to become more and more Christian, not in the form of conventional religiosity but crucial personal decisions. The Church becomes a kind of "spiritual homeland": I was born in it and I want to die in it. In fact all those people, and there are many of them today, are missing an essential experience, the experience of a Christian initiation. It seems that the solution is the function of the re-evangelization of the parish. This re-evangelization is taking place at three levels, all of which are important elements in Christian fellowship. They are as follows: faith, cult, and testimony. The persons mentioned above need to be re-introduced into faith, the liturgy, and the practice of Christian life.

An important value is attached to such values as participation, fellow-responsibility, and fellowship. A pastoral care that seeks to satisfy contemporary needs, including those of physicians' who administer palliative care, must take into account these, purely evangelical, values. In order to carry out this task, it seems, we need to make the traditional function of parishes more important, and realize their new functions. Fulfilling them will contribute to the development of parishes and will extend pastoral influence.

In the functions mentioned above we can point out a few important elements of the up-dating of medical doctors in the pastoral aspects of palliative care.

The pastoral tasks are similar to those experienced by the first Christian communities.

Methods: laying foundations of the faith and preparing personal acceptance of Christ as my Savior, and not only as a religious truth. To proclaim not only "what one should believe in, but also *why one should believe in it."*

Main Subjects:
– Catholic and anthropological background
– Old Testament, New Testament – Jesus Christ
– Ethics in the medical sciences

Supplementary subjects:
– Human dignity: transcendent and natural
– concern for the soul
– inform conscience
– sanctity of life

Application: seminars, workshops, bible study groups, presentations in hospitals, nursing and assistant living facilities, medical schools, printed materials, brochures, flyers, articles in local and diocesan papers

Obstacles and difficulties: political correctness, Christian values in the liberal and secular environment, a hostile media, and the culture of death, the passiveness and negligence of the medical field

Positive and affirmative:
– encouragement of Catholic medical staff;
– promoting the culture of life;
– reaching to the undecided on ethical values;
– supporting pro-life groups at a parish and regional level;
– educating the faithful in pain management and palliative care options;
– understanding of medical practice as a charismatic vocation.

Postulate: enduring need of reaching to medical doctors by pastoral ministry with emphasis on the charismatic aspects in their palliative care to the terminally ill.

Professional qualifications and requirements:

– related to personality: empathy, compassion, sensitivity, patience, spiritual virtues;

– related to values: personal beliefs rooted in the *Culture of Life, a*cceptance of the dignity of the dying person, refusing all forms of dehumanizing treatment and euthanasia, promoting a Catholic model of medical care at the end of life.

Conclusion

Palliative care changes the paradigm of medicine. Everyone who has contact with a hospice team realizes the difficulties of social, psychological and spiritual assistance that face health care professionals, especially medical doctors. Comprehensive pastoral care addressed to all physicians may also protect them from *anger* with terminally ill patients and *burn-out* or *depression* formed by human inabilities and stress. Cultural dimensions and strong pro-euthanasia movements require physicians to accept hospice and palliative treatment as a personal Christian answer to the mystery of suffering. To fight successfully the distorted understanding of human dignity and the meaning of life in the liberal environment, medical doctors and hospice physicians must be embraced by the Church community and supported by its hierarchy.

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AN VERLINDE

7.3 Pastoral Aspects of Palliative Care and Nursing

Introduction

Palliative care is implemented in many societies and has even increased.

Palliative care is in the nursing field a well developed item and along with medical doctors and health workers a recently specific domain for nursing practice.

After the overall debate on euthanasia, the attention towards palliative care increased in many western societies. In other parts of the world such as Asia, with the increase in older people, and in Africa, with the dying of patients with Aids, palliative care, too, is a hot topic in health care and particularly in nursing.

From the models in the USA (Albany) and the hospices in England, implementation of hospice work framed in an adapted model country wise started in many Western oriented societies: the USA, Europe, Australia, New-Zealand, Japan, Taiwan, Ivory Coast, Nigeria, South Africa and India; this from the reports from Ciciams-associations.

Since the mid-1980s nurses have been trained in palliative care, first in hospital wards, then in hospices and nursing homes and later in home care.

Palliative Care and Nursing

In many countries, qualified and experienced nurses are trained in palliative care at advanced programmes of nursing high schools and at university level.

Note that many nurses and religious persons practiced palliative care long before the notion of palliative care appeared.

In contradiction with the shortage of nurses in Western societies and qualified nurses, in Africa, many nurses volunteer to become experts in palliative care.

A short research among Ciciams-nurses revealed that nurses in palliative care have an average age of 45-55 and leave a career of expert nurses in intensive care, psychiatric institutions and home care.

To become a qualified palliative care nurse an advanced training of 2 to 3 years at advanced nursing level or at university level is required and essential.

Palliative Care and Spirituality

Forty percent (reported, perhaps more) of palliative care nurses are religious and help patients with spiritual needs.

Most palliative care nurses are trained in spiritual approaches and report that this is essential in their work as palliative care nurses.

In the summer of 2004 the NACN-USA (National Association of Catholic Nurses) had a conference on “A Spiritual Approach to the Basic Aspects of Health Care and Healing”. The speakers tackled the spiritual approach among terminally ill patients and palliative care. Learning moments of the conference: the effect of spirituality on health care practice of a diverse population utilizing culture care theory principles. Practical examples were given of how nurses trained in palliative care and spirituality accompanied patients, fully respecting the culture of the patients, for example: the native Americans belief in “Mother Earth and Father Son” – this has implications in nursing practices. For example: how to dress the bed in the bedroom according to morning sunshine and the evening sunset light through the window.

Palliative Care and ethics

Palliative care nurses do research their own field of practice. An abundant quantity of literature has been produced the last five years on ethics and palliative care. In literature on ethics and former literature in palliative care “death” is mostly an act of a higher sacral order.

Nurses report that in fact the dying person is concerned about daily practical problems. For example there are concerns about relatives they are leaving behind. According to Dutch research on palliative care, the dying person is sometimes less concerned about the meaning of life in the light of eternity than with daily problems and coping with relatives’ problems.

Nurses in palliative care must be aware of their personal perception of the notion of a “good death” The personal and individualistic perception of a “good death” can be in conflict with the perception of “good death” of the patient. Via dialogue nurses can learn the perceptions of the patients and their relatives about “good death”. Nurses learn that along with an objective definition of a “good death” the consequences are relevant and the recognition of diversity on opinions on this matter.

Ethical commissions instruct nurses and dialogue on the orientation of the ethical guidelines in hospitals, hospices, nursing homes and home care.

Being involved in ethical issues over the last twenty years has been major subject for health care workers and especially for nursing practice.

Although admitting that many issues in daily nursing practice are not ethical, nurses formulate sometimes daily problems and concerns in terms of ethical issues: for example, communication between multidisciplinary teamworkers, territory fights, difficulties with enormous demands of family. Urgently, palliative care nursing needs ethical guidelines in the daily practice of palliative care for hospitals, nursing homes, hospices and home care.

Nursing competences and skills in Palliative Care

Palliative care means that nurses care for the dying and that they cope with the needs, sorrow and stress of family members.

Therefore, nurses must be trained and well skilled in communication.

Otherwise this report gives room to point some important issues and situations in palliative nursing practice.

1. Comfort of the patient

Palliative care means the greatest comfort for the patient and his well-being. What does this mean?

In daily practice: bed comfort; comfortable sheets and covers, soft pillows. Helping patients to turn in their beds is a nursing skill. Handling patients without pain is nursing practice. Accompanying patients in their last life time is a matter of time-giving, experience, nearness, attention to details in the patient's environment and support of relatives.

A survey and qualitative research in Belgian Palliative Care(2004) in nursing homes and home care stated that the following nursing practices and skills are appreciated:

– in palliative care patients can make their own choices in the last phase of their live. Nurses help to turn rules, hospital regulations, etc. into an assured and trustful environment;

– nurses help the relatives to let the beloved patient pass away;

– nurses support the relatives in daily patient caring. In home care relatives can be overloaded, the burden to take care of an palliative patient can become extremely high;

– nurses give trust to the patient and the family, nurses are always available. Patients and relatives rely on the "nearness" of nurses;

– nurses through their competences and skills can create an assured, calm and confident environment;

– nurses are skilled and experienced in pain control. Mostly, the nurse is the "advocate" of the patient and helps the medical doctor in the treatment of pain;

– nurses will be more skilled in spiritual care. Nurses are, through their daily physical contacts, very "near" to the patient;

Realise that questions on death, dying and the meaning of life come at the level of about 80% to nurses.(report of the NACN-USA).

Nurses are trained in spirituality, they can give confidence to the patient, they dispatch questions to health care workers and to pastoral health workers and to relatives.

Conclusions on the above mentioned research: nurses are essential in palliative care for the following reasons: the personal attention to the patient and to the family – giving "time" and being always available; being the first health care provider and being most "near" to the patient.

2. Conflicts among practitioners on oxygen

Patients with breath difficulties are in pain and agony. Instructions on oxygen giving are not always precise. This is a domain of conflict; conflict between health care workers, conflict between health care workers and family and interpersonal conflicts in nurses.

Ethical commissions can work on daily and precise guidelines on this issue. It is felt from nursing that ethical commissions must be involved in the daily practice of palliative care.

3. Fixation of patients

Some patients must be assured in their bed and bedrooms. Palliative patients can be in great agony and try to leave the bed or pull out the needles and tubes. The nursing answer to this problem is usually remaining in bed and the doctors answer is sedative medication.

The supreme health care institution in Belgium (VVI) recommended guidelines on fixation in palliative care. New methods, and advanced materials can be used to assure the patient. Fixation can be done only in very particular situations, and with appropriate materials. A report must be submitted daily to the palliative care committee and to the ethical commission of the hospital, nursing home or the home care unit.

Nurses are involved in this dramatic but sometimes essential practice of assuring patients. Guidelines, protocols and standard nursing practices are required. The recommendation is esteemed, hopefully other countries follow the model of Belgium.

4. Feeding issues in palliative care

Feeding problems were largely debated at the FIAMC-conference of spring 2004 in Rome.

Food and hydration are palliative care nursing concerns. Palliative care nurses are trained in the problems of food and the hydration of palliative patients. Patients must be treated as full human beings until the very end of life. Advanced learning programmes for palliative care nursing deal with the practice of feeding and hydration. Dignity for the human being is essential.

Cooperation between all health care workers and families in the food and hydration issue is necessary: see the FIAMC-conference of 2004.

5. Pain-control

Palliative care nurses are highly trained in pain-control. In advanced programmes of palliative care nurses learn to recognise symptoms, differentiation in symptoms, and the circle of pain. Palliative care nurses apply the WHO pain control circle. Nurses observe patients constantly and are very near to the patient. Palliative care nurses are the "advocates" of the patients. Pain control helps the patients live their life fully to the end.

Conclusion

Reports on palliative care are more extended. Full reports are available at Ciciams headquarters, Brussels.

Palliative care for nurses is a specific field in nursing practice.

Palliative care for some nurses is the only domain where they can fulfill their vocation and where they can give meaning to their job.

Reports of Ciciams point that palliative care nurses are well trained in advanced programmes for increasing competences and skills, certainly in Western societies. In other regions, culturally adapted models in palliative care (S. Africa for Aids patients) have been established.

Nurses are essential in palliative care. Well trained and well experienced nurses, with long career behind them, make the choice to become palliative care Nurses. For many nurses, palliative care is fulfilling their vocation as nurse.

Ciciams nurses want and can debate ethical issues. On behalf of Catholic nurses world-wide, which I have the honour to represent, I plea that nurses be represented in Ethical Commissions, certainly on palliative care.

I thank the Pontifical Council for Health Pastoral Care for its lasting attention to nurses. Catholic nurses feel sheltered in the Pontifical Council for Health Pastoral Care. I humbly ask again for all needed support.

Dr. AN VERLINDE
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MARIE-SYLVIE RICHARD

7.4 Palliative Care: How does it Change Our way of Seeing Things?

My congregation, 'la Xavière', is not a hospital congregation. However, it was asked to replace a Pius Union of widows, the Dames of Calvary, which had been founded in the nineteenth century, so as to continue the work of accompanying the dying at the Jeanne Garnier Institute of Paris. We created an association of the faithful and some secular figures also joined us. Within the Institute we created a community that takes part, together with the chaplaincy, in spiritual and religious encouragement and support. Other Xavières work in it but they do not live there: two medical doctors such as myself, the person in charge of the volunteers, and a large number of voluntary workers. Two of us are members of the governing committee of the hospital. Over the last twenty years, the practice of palliative care has led me, as a female religious and as a medical doctor who exercises her profession in a Catholic institute of palliative care and in other public hospitals, to broaden my idea of what care is. Contemporary medicine requires a constant ethical questioning in order to attain a thoughtful medical approach, and this is our task in the field of palliative care, whose ethics are based upon Judeo-Christian humanism. I have also perhaps discovered the political battle that all of us, both religious and secular people, must engage in to contribute the development of palliative care. Every person whose condition requires it, should, indeed, be able to benefit from such care and be respected and accompanied until the end of his or her life.

1. The Preponderant Role of the Technical Requires that Greater Attention be Paid to the Quality of Relationships

Far from despising the technical advances in medicine from which they, too, benefit, the professionals of palliative care believe that the value and the quality of such care does not depend solely on the efficacy or wonders of the technical. They hold that their relationship with the patient and his or her family relatives is an integral part of such care and that the suffering of the patient and his or her relatives is often not taken sufficiently into account. A priority in palliative care is to create a climate of trust and dialogue between all the parties involved. This is translated into constant negotiation with everyone and within the staff responsible for such care, both as regards small things and when it comes to major decisions. For this reason, information that is sincere, well mannered and respectful of the sick person and his or her family is indispensable. Insufficient information will not allow him or her to take part in the decisions that concern him or her.

We emphasise three aspects of this relationship and these bring out all of its importance:

a. If a grave illness progressively isolates the sick person and his or her family relatives, this relationship allows them to find the words by which to express their suffering and at the same to time to find someone to listen. When shared with other people, suffering becomes less oppressive. The difficulties in communicating between the patient, his or her family relatives and the medical doctor accentuate the loneliness of the sick person, isolate him or her, and can even provoke forms of behavioural disturbance. When the burden is too great, the sick person does not have the strength that is needed to lift himself or herself up, and at times he or she expresses his or her malaise by becoming aggressive towards the staff that is looking after him or her or his or her family relatives. At times, families, as well, feel that they are isolated. Each of the members of the family hesitates before placing upon another his or her worries and troubles and at times feels alone in bearing this burden. In addition, when the illness continues over time, friends draw away because they no longer know what to do or what to say. Families then appreciate even more the welcome and the support that is offered to them by the staff providing care, by the volunteers and by the members of the chaplainry. Our communication with the families must not be reduced to providing information about the condition of the patient but must be an opportunity for discovering the particular suffering of family relatives and for the attenuation of fears.

b. Illness and nearness to death lead to a person being afraid about the laceration of his or her body and the end of his or her life. This relationship, in contrary fashion, by taking into account the various dimensions of the person and by respecting his or her singularity, restores unity and calm. Medicine, which is increasingly specialised, gives the impression to the sick person that he or is she is rarely seen in the totality of his or her being. Complementary research and forms of treatment are carried out by different teams, each one of which is expert in a specific field.

Medical advances at the level of both knowledge and technical capacities are secured at the cost of the objectification of the human body, which is what scientific rigour requires. Whereas the researcher has to abstract the individual in order to study the human being, the clinical doctor has to move from this abstraction to the individual. In palliative care, seeing the sick person as a subject is indispensable and the totality of his or her person and the complexity of his or her suffering have to be taken into account.

c. It is not rare for a sick person to have doubts about the meaning of life. The families also ask themselves about the value of this life of dependence and suffering that is at times unending, In especially difficult situations, the staff responsible for treatment and care run the risk of losing from sight the meaning of their own work. The relationship that is created between these various partners helps in the working out of meaning. Only if one passes through the trial of illness or draws near to death can one give a meaning to what one is living through. The entourage is reduced to silence even though it is tempted to imitate the friends of Job in giving the sick person rational advice or explanations. More often, the family relatives enter this search for meaning on their own and not even the members of the team are exempted from this existential or spiritual questioning, which we may locate within a religious tradition.

It is difficult to be at the side of someone who is unable to give a meaning to his or her own life – this is a challenge. Exhausted families or a staff responsible for giving treatment and care that is subjected to burn out unfortunately confirm the sick person's lack of self-esteem. This relationship, in contrary fashion, opens a breach in this situation, which is apparently without an exit door. The philosopher Catherine Chalier expresses this is a wonderful way:[1] 'listening without having answers, without knowing anything about the meaning that one wants, means having to find in oneself a sufficient readiness to welcome the words and the silences of another person without covering him or her immediately with one's own volubility and disquiet. It means finding within oneself the resources that are needed to make the person who is suffering understand that his or her unique life as an irreplaceable person is not in vain but has a value for another person, not because of its merits or its sufferings but because in it and through it the Infinite has taken a name and a face'. The atmosphere of trust and dialogue between everyone fosters this working out of meaning, which does neglect suffering or sadness.

2. The Choice in Favour of an Interdisciplinary Approach Modifies the Idea of Care by Broadening it

Bearing in mind the suffering of the sick person and his or her family relatives in relation to the various components that are involved, implies the role of a number of people. Whereas the multi-disciplinary approach pools information connected with different sciences or disciplines, the interdisciplinary approach is an interaction between these different disciplines. It depends upon an openness of spirit, an intellectual curiosity that leads people to move outside their own contexts and languages. An interdisciplinary approach is difficult. Interdisciplinary practice runs the risk of being damaged by what is at its base, that is to say the diversity, differences and multiplication of languages, points of view and methods. Another difficulty lies in the change in mentality that it requires. Lastly, health care workers still work too frequently in an individualistic way and thus the team cannot function in a healthy way. In founding the Saint Christopher's Hospice, Cicely Saunders gave rise to a broader concept of care. Indeed, she invited her co-workers to change their approach by working in teams made up of different professionals and voluntary workers.

The broadening of care brought about by an interdisciplinary approach has brought into play workers who are not professionals, namely *volunteers*, who, far from taking the place of the staff providing treatment and care, are more complementary and support-providing. As citizens, voluntary workers take the difficult decision *to take care of* sick people and their family relatives. They take part in the renewal of the social tissue. 'They take on the risks of presence near to another person who is near to death in a fundamental bond of humanity'.[11] Are not the volunteers, the staff providing treatment and care, the family relatives and partners (each according to their own role), in relation to the sick person who is near to death 'perhaps society where society no longer exists?' Always within the framework of voluntary work, but with a different function, the members of the team of the chaplainry, who belong to different religions, have their own role to play within the sphere of operations of the interdisciplinary team.

3. Dialogue at the Centre of Care: a Creative Experience

The relational difficulties between health care workers and some families are often solved after the establishment of a dialogue. At times, the intervention of a third person is required in order to re-establish a minimum of dialogue between them.

What is dialogue? I would like to take Martin Buber as a point of reference.

– Dialogue is the element at the base of the reality of people who address each other. The interlocutors benefit from an initial equality at the level of status, they are mutually responsible for each other, and their relationship is symmetrical. Very often our relationship with other people is reifying. Buber proposes a radical act of 'mutation' that involves the whole person, a true conversion of being.

– Dialogue is an experience of encounter and not of knowing. It is at the heart of speech but also of gestures and approaches. It is movement towards another person. Its aim is to create a new world in which the protagonists create each other, a mutual creation that is nothing else but an expression of love.

– Dialogue cannot be reduced to a means or an instrument of communication. Its purpose is a shared working out of meaning.

What are the conditions that are required for a real dialogue to take place? *The responsibility of each person is committed to a common search for a truth. In order to be deep and authentic, dialogue requires, at the same time, transparency and secrecy, exchange and reserve. Even though most of the time dialogue takes place between two people, it can also involve other people as well. Dialogue is the creator of meaning, the fruit of an encounter between the interlocutors. One is no longer dealing with* speaking to someone *but with* speaking with someone.

Dialogue and ethics. Dialogue and ethics are closely bound up: ethics are necessary to dialogue and dialogue is necessary to ethics. The sharing or understanding of the same beliefs are not preliminary conditions to dialogue, which is, rather, developed more beginning with the difference that exists between those engaged in the dialogue. Work in the field of palliative care requires *personal ethical reflection* and ethical reflection within the team. This involves a constant search for a suitable form of medicine that respects the human being in his or her inalienable dignity until the end of his or her life without reference to his or her physical or mental state. This presupposes a training that everyone can choose and at the same time a policy of training within the institute concerned. In our institute all of the staff, the voluntary workers and the members of the team of the chaplainry have a period of weekly training in which our common spirit is forged and in which the values upon which we base our presence and our action in relation to the sick person and his or her family relatives are remembered, discussed and analysed.

Inter-religious inter-philosophical dialogue. Our institute is a Catholic one but it forms a part of the public health service and admits sick belief of all beliefs. Amongst the members of the staff we have Christians, believers belonging to other religions, non-believers and atheists. Each one of them, however, has subscribed to the Charter of the Institute and is committed to respecting that charter. The same thing applies to the voluntary workers and the team of the chaplainry. Great attention is paid by everyone to the spiritual questioning and pathway of the sick person and of his or her family relatives. Inter-religious dialogue, which is at times 'inter-philosophical' in character, and ecumenical experience, enormously enrich us, even though at times they are demanding at a personal level.

4. Concern about the Political Aspect Forms a Part of Commitment in the Field of Palliative Care and Bears Witness to a Broad Conception of Care

How can we care for a sick person without having at a deep level the concern that everyone should be able to have access to care? Will the sick people that we cannot welcome receive acceptance elsewhere? The number of structures providing palliative care and the development of palliative care at home are insufficient in our country and this is even more the case at a world level. How can we help to improve this situation? If an action at a higher level is engaged in, it can only be carried out by some people (secular and religious), whereas, in contrary fashion, sensitisation within society as a whole is a matter for all of us and each one of us. This is a concern and/or political commitment in the broadest sense of the term. Indeed, the questions raised by caring for and accompanying people at the end of their lives, whether sick or otherwise, are not limited to health care workers or to voluntary associations but are a matter for the whole of society.

In conclusion, care based upon a relationship and dialogue is above all else a response to the appeal of a sick person and his or her family relatives. To take care of him or her means to accept the responsibility that we have towards him or her, it means to affirm the dignity of the person despite his or her appearance. This is because he or she always remains a person. This approach to care also respects our dignity as custodians of our brothers and sisters as solidarity-inspired and creative neighbours. It expands our horizons. How should we organise our concern at an individual and a universal level? Our work within palliative care is based upon solid foundations and values that we recognise as being based upon the gospel and humanism. As Christians – members of the laity, religious and priests – we want to ensure that there transpires from us the infinite and preferential love of God for every person, at the same time recognising the extreme freedom of the Spirit at work in the other person who calls on us, transforms us and enriches us.[3]

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Note

[1] C. Chalier, *La persévérance du mal* (Paris, Cerf, 1987), p.140.

[2] B. Matray, *La présence et le respect, éthique du soin et de l'accompagnement* (Paris, DDB, 2004), p 246.

[3] M-S. Richard, *Soigner la relation en fin de vie, malades familles soignants* (Paris, Dunod, 2003).

CRISTINA CALABRESI

7.5 Palliative Care: Family Relatives

I am Cristina Calabresi and I am the President of the Federico Calabresi Foundation, which bears the name of my deceased husband, Prof. Federico Calabresi, who was Consultant in Oncological Medicine at the Regina Elena Institute of Rome.

The Foundation was established in 1995. Amongst the activities that it carries out, of primary importance is the organisation of the publication of a series of information pamphlets for patients and their family relatives on various kinds of tumours.

Hitherto, we have produced seventeen pamphlets. These texts, published in thousands of copies, are distributed free in oncology departments in Italy. The purpose of these pamphlets is to provide a simple explanation and description of tumour disease and the possible treatments to deal with them, to support patients and their family relatives subject to an evil that is often not known about, and to help them in their journey of co-existing with this disease.

When a medical doctor communicates the diagnosis, provides explanations of the illness and the forms of treatment that can be given, and supplies information on possible side effects, the patient and his or her family relatives can be disturbed emotionally by the shocking news of having a tumour, which, it is generally believed, is always incurable.

It has always been the case that what is not known about generates fear. Cancer, which is often associated with death, is a word that frightens people, but a distinction has to be made between tumours that are curable and tumours that are not curable.

Having this small book, which can be consulted at any moment, can facilitate contact with the illness. Information, which is given before the emergence of side effects, helps to mitigate the worry and anxiety that arise when problems, such as those connected with chemotherapy and radiotherapy, emerge.

Using the pamphlet, the patients and their family relatives appreciate the professional care of medical doctors and associations. The fact that they find themselves in a situation that is shared by other people lowers their feeling of alarm and helps them to accept the new reality.

Such information is provided in a simple and immediate language that is accessible to everyone, and in addition the pamphlet is illustrated and made less dramatic in its impact by drawings.

In 2002-2003 our pamphlets were the subject of a research protocol called ‘Experimentation on Information for Patients and their Family Relatives’ (R. Passalacqua *et al.*, Cremona) which was carried out in thirty-eight oncological structures in Italy. The aim was to see whether giving information was of help to oncological patients and their family relatives. The results were very positive: 20% of patients informed in this way experienced a reduction in anxiety and depression, and accepted their illness in a better way.

When the illness reaches a stage when the patient does not react to conventional forms of treatment, one can and one must employ *palliative care*. The phrase ‘nothing can be done’ must never be uttered: one can go on giving pharmaceuticals to sustain the organism of the patient, engage in pain reducing therapy, and provide strong emotional, psychological and spiritual help and assistance.

Both during the natural course of the illness and even more when its deterioration has become irreversible, the patient should be seen within the context and together with his or her family circle. All the members of his or her family should be actively involved in the development and evolution of the illness.

In the past, the tendency was to isolate the sick person and see his or her family as a burden, but at the present time, in the most advanced health care structures, the family is increasingly involved and its participation is seen as being helpful.

During the period, which can also last a long time, when the patient is at the terminal stage of his or her illness, he or she needs his or family members near to him or her so that he or she can live out his or her condition in the most serene way possible, surrounded by the love and affection of his or her dear ones.

Faced with the suffering of their relative, the family members may experience increasing worry and anxiety, both because they fear that they will lose their loved one and because of the emergence of many difficulties – practical problems or at times economic problems as well.

In addition, with the deterioration of the pathology, it may happen that the patient's and family's friends, because of reticence or an inability to engage in a relationship, draw away, thereby causing the isolation of the family, which runs the risk of closing itself up in the microcosm of the illness.

For this reason, it is important to listen to the family relatives, share their pain, and free them in part from their worry and anxiety through participating and effective support, thereby establishing an atmosphere of acceptance, co-operation and relative serenity.

It is necessary to encourage co-operation between the health care staff, which should be suitably trained, and the family of the patient. It is useful to humanise to the utmost this relationship – the support and the comfort of the family are indispensable. The patient's family, if it is helped in relation to the many practical and psychological trials that it has to live with every day, will be able to be at the side of the sick person in the best way possible, thereby ensuring that he or she does not feel abandoned.

At the present time one may observe progress being made in some – the most advanced – hospital wards, where the fundamental role of the patient's family is seen as a constant factor of help, of material and emotional comfort, and as irreplaceable for the tumour patient.

In conclusion, we hope that the approach of listening and care in relation to the patient and his or her family circle will evolve and become fundamental in the treatment and care of oncological and terminal patients, that humanisation on the part of medical doctors, specialised nurses, psychologists and voluntary associations will increasingly spread; and in particular that this last category will always, with passion and commitment, fill institutional gaps and help to spread courage and hope even in the most difficult of situations.

Mrs. CRISTINA CALABRESI
President of the Federico Calabresi Foundation, Rome.

VITO FERRI

7.6 Psychologists and Social Assistants in the Field of Palliative Care

Premise

The title that was given to my paper made me reflect. I see this title as constituting a small test: psychologists and social assistants are often put together in the same category and examined together. Perhaps this is a sign that these professional roles are seen as being not very distinct and not very clearly defined. This 'test' reveals how in the field of palliative care in Italy these two roles still require a more specific categorisation and definition.

Psychologists and social assistants run the risk of being relegated to being optional when the palliative care unit is subjected to influences and pressures connected with the needs and requirements of the economic budget and by the tendency to reduce 'palliative care' to 'palliative medicine'. That the trend is to see them as being optional is also confirmed by the research carried out by the Agency Regional Health Care Services and by the Gigi Ghirotti National Foundation between 2001 and 2003 on 'the needs of palliative care' (www.assr.it). Out of a sample of 461 people working in the sphere of palliative care in 31 centres (hospices, home care, mobile clinics, day hospitals), 16 psychologists and 9 social assistants replied – a very limited number. If we exclude voluntary workers from this sample, we have a percentage of psychologists of 3.9%. This figure is confirmed by the results of a recent census (November 2004) communicated to the press by the Italian Society for Palliative Care (SICP): in Italy, out of 5,000 workers in the field of palliative care, 200 are psychologists (4%).

In this paper I will refer to my professional experience, to my role as a psychologist. I am not competent or professionally qualified to talk about the role of the social assistant. I would like, however, to express my esteem for social assistants, their valuable work of mediation between people in the terminal stage of their illness, their families, and institutions. Their activity is relevant in the process that involves the activation of resources that are present in the 'network of palliative care', which in Italy is finally beginning to spread.

My paper on the renewal of psychologists in palliative care is divided into two parts. In the first part I will summarise the technical functions that psychologists usually engage in or should engage in. In the second part I will dwell upon certain functions that are not studied very much and which should be appreciated so as to promote innovation as regards the role engaged in by psychologists.

The Technical Functions of Psychologists in Palliative Care

I would like at the outset to make some introductory observations about these technical functions. In Italy those psychologists that work in the field of palliative care may find themselves in extremely visible contexts and situations. Indeed, they may work in hospices and at the home of patients, or in consultancy centres, hospitals, mobile clinics and day hospitals. They can be the integral members of a team or external specialists who are consulted according to the situation, where their role runs the risk of being 'medicalised' if they are called to act only in moments of crisis and emergency contexts. They can be qualified only to practice the profession of the psychologist or they may also be specialised in psychotherapy. Amongst the experts in the psychological sciences that can be encountered in the field of palliative care, there are also medical doctors who are trained in psychology as well as psychiatrists. Given these different contingencies, we can identify and list seven main functions: group supervision; individual consultation for workers in the field; taking part in team meetings; conversations with the family relatives of patients; conversations with patients; on-going training; and research.

1. Group supervision: the psychologist can lead group meetings of the members of the palliative care team or volunteers in order to facilitate the expression of emotions and the sharing of experiences. In this way the psychologist helps to prevent the syndrome of burn out.

2. Individual consultation for workers: the psychologist can offer support or individual supervision to workers that belong to the team who are subjected to special stress or are in a state of crisis.

3. Taking part in team meetings: during the team meetings the psychologist can express his opinions so as to improve the assistance that is provided or tackle a situation that is problematic at the level of communications or emotions.

4. Conversations with the family relatives of patients: the psychologist can have conversations with the family as a whole or individually with a family member during the various stages of the assistance: during the initial assessment visit (usually together with the medical doctor, the nurse or the social assistant), periodically during the period of assistance, or during the period of mourning.

5. Conversations with patients: in Italy this function is giving rise to a debate. Some models of assistance see the direct role of the psychologist in the process of patient care as being of fundamental importance. Other models, however, exclude this role. Usually, psychologists intervene directly solely in response to an explicit request by the patient, but it is unlikely that this will take place in cultural contexts where the psychologist is seen as a 'doctor for mad people' or where suitable information is not provided to the patient on the functions and the role of the psychologist.

6. On-going training: the psychologist can be involved in the on-going training of professional workers and volunteers in the field of palliative care. The aim on the whole is to refine basic skills and expertise in the sphere of relations and communications.

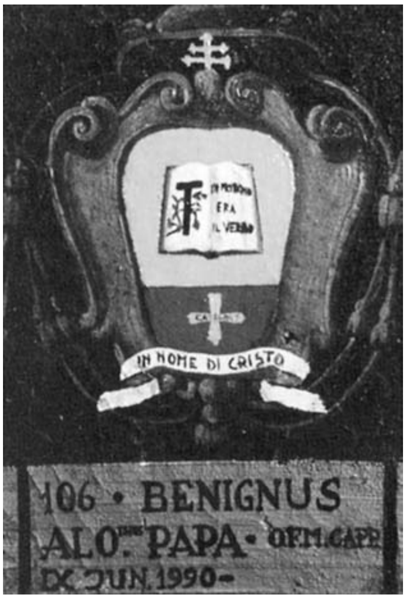
7. Research: scientific research is activity that has been held to be fundamental in palliative care ever since it went beyond the pioneering stage. The psychologist is called upon to make his contribution as a 'researcher' both from the point of view of integrating skills and expertise in order to achieve improvements in the process and outcomes of care and in relation to specific investigation of the psychological, affective and relational dynamics that characterise the terminal stage of life.

A New Perspective: the Psychologist as a 'Guarantor'

Let us now broaden the perspective. We will now consider what I define as the 'soul' of the technical functions that have just been listed, that 'added value' that makes each of the previous functions the special and exclusive responsibility of an expert on the psyche who has been trained over many years of study of the psychological disciplines, work on himself and work under supervision, in addition to unceasing learning next to those who are dying (Ferri, 2001a).

The same integrated and active presence of the psychologist in the palliative care team performs a silent function, but one that is full of 'symbolic' efficacy. The work of the psychologist thus acquires symbolic value, the value of being a dynamic vector of meaning.

We will begin by considering the psychologist as the 'guarantor of complexity'. In 2003 I had occasion to enter into dialogue with the psychologist Marie De Hennezel during her visit to the Gigi Ghirotti National Foundation. This was the first time I heard the psychologist of palliative care defined as a 'guarantor of complexity' and the definition was hers. The term 'complexity' was used because nothing can be banal in a situation of suffering and death. The experience of illness and suffering cannot be reduced or simplified. The psychologist has the task of conserving the value of complexity at a high level. He must be able to identify the dynamics that animate various situations and different contexts. 'Guaranteeing complexity' means being a sentry and a defender of complexity against reductionist and banalising tendencies, the tendencies that halt at the surface when it comes to the questions posed by a dying person; it means using one's own professional expertise and knowledge as a counterpoint to the impulses towards excessive simplification, against everything that forces the wealth of the 'qualitative' to enter the sphere of the 'quantitative', against the temptation, present in training in relation to palliative care, to minimise, and thereby secondary, the severe reality of 'knowing how to be', thereby giving way too much to the seductive standardised reproductive reality of 'knowing' and 'knowing how to do'.



Marie De Hennezel also spoke about the psychologist as a 'guarantor of the affective' within the palliative care team. He has the instruments to be able to understand when something is wrong in the team, when the pleasant emotions that follow the satisfaction of needs are eliminated by unpleasant and emotions and sentiments. Emotions and needs belong to dimensions and processes that are often underground, masked, that escape the knowledge of the workers involved. The psychologist who receives from the group the mandate to be a guarantor of the affective can play an important role in preventing the syndrome of burn out, in preventing conflicts within the group and in promoting the expression of pleasurable emotions.

I take from Marie Bernard Chicaud (1998) the idea that the psychologist is the 'guarantor of the identity' of a suffering person and his autonomy of choice. In guaranteeing the identity of the person, the psychologist recognises and respects the uniqueness of his choices, his wishes, and his personal history. In being the guarantor of identity, the psychologist fosters the expression of the authenticity of 'being' in the person, and he will help the person to protect himself against labels and identities that are constructed and imposed by the cultural context, labels and identities that want to stigmatise him as a 'terminally ill person' or 'a Karnofsky 40'. Guaranteeing identity is thus in fundamental terms a practice involving respect for the person, adaptation to his uniqueness: 'in entering into contact with the person who suffers', writes the psychologist S. Geraci when referring to his experience in the field of palliative care, 'in this attempt to "become everything for everybody", as St. Paul writes, I realise that I often make myself like water which takes the form of the contained into which it has been poured, while transmitting its vital properties, with respect and discretion' (Geraci, 2000, p.13).

The psychologist also has an extraordinary opportunity to encounter the 'reality of relief' and to act as a 'guarantor of experienced relief' (Ferri, 2003; 2004). Palliative care is not only able to cancel out all suffering, it can also 'suspend it', 'alleviate it', and avoid so-called 'useless' pain. Palliative care, therefore, must be able to guarantee relief. Each one of us during the course of our existence have more than once experienced such relief, but during care at the end of life the experience of relief acquires a more relevant value than in other circumstances and takes place much more often than could appear at first sight. Great and evident examples of relief exist but they are rare. Small, discreet, intimate examples of relief are many in number. More than securing the achievement of relief (for example the alleviating effect of a pain-killing pharmaceutical), the psychologist can guarantee 'experienced relief' by fostering in the sick person and his family relatives an awareness that they are in a state of relief because they are experiencing such relief. The psychologist offers a person an opportunity to recognise and live such relief in a full way so as to enjoy it while experiencing it now and hereafter. Relief that is fully enjoyed and experienced becomes a fertile terrain to welcome seeds of hope: 'if I have experienced relief now, I can experience it again in the future'. Relief opens up the road to hope and it is the responsibility of the psychologist to be vigilant and perceive this road in its early state and share it: 'hope, in fact, cannot be given, only shared' (Brusco, 1995, p. 127). In my clinical experience I have observed that the more the person is aware of, and takes part in, his own relief, the more he is able to experience hope and express an approach of 'mental openness' and a confident state of mind.

Basing myself, lastly, on the thought of Viktor Frankl (1977), I believe that a psychologist who works in the field of palliative care may also define himself as a 'guarantor of meaning'. The psychologist who 'knows how to be' a guarantor of meaning activates in himself a skill or better a 'talent' that should be transversal and shared by all those who offer palliative care: sensitivity to the spiritual dimension of *homo patiens* (Ferri, 2001b). To be a guarantor of meaning does not mean being 'people who suggest meaning' but accepting it without prejudices or rationalizing filters when the assisted person discovers it or tries to grasp it.

I remember the history of Maria, aged sixty-eight, a simple women, physically very small, alone, who had left her village in Sardinia when she was very young to come to Rome and do humble jobs. For years she lived accompanied by the suffering due to her illness, to nineteen operations, and to who knows how many cycles of chemotherapy. It was a gift of my professional and human life to have the opportunity to accompany her during her last three years until she died. On more than one occasion I asked myself what meaning life had for this women, but I posed the question in silence, after every visit to her home or after every telephone call. Maria complained about her pains during the first five minutes of the meeting and then addressed other subjects; she always had caring questions about those who were looking after her. She said that she loved all her 'angels', all the professionals and voluntary workers that surrounded her. Pain, which it was difficult to control with drugs and medicines, tormented her day and night but her balanced groans reminded her of much loving human warmth which she repaid with an infinite series of 'I love you, you are angels, my angels'. For the first time in her life Maria felt surrounded by people who were taking care of her. It was a totally new experience for her. It was specifically from her grave condition of illness that Maria drew the fact that she 'felt important'. In being taken into consideration as a cancer patient she found a new meaning to her life, I was with her to steward this meaning with respect that was sacred, new, and valuable, so as to legitimate it, keep it alive, and guarantee it.

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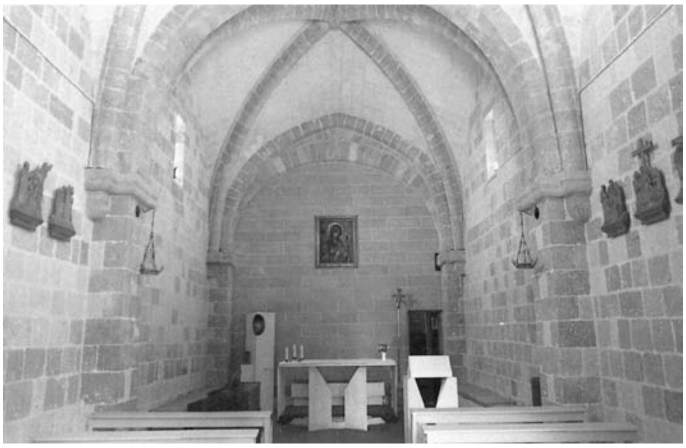

RAYMOND ZAMBELLI

7. 7 Voluntary Work: a New Approach to Pastoral Care in Relation to Palliative Care

'Lourdes: you mean the sick!'. This is a phrase that is often heard. And immediately people then add: 'the sick are the responsibility of male and female nurses'. It is true that the Sanctuaries of Our Lady in Lourdes are perhaps the only place of pilgrimage in the world to receive eighty thousand sick and disabled pilgrims every year, as well as the two hundred thousand male and female nurses who accompany them, welcome them and serve them. With this very high level of pilgrimage, Lourdes is at the same time a lighthouse of voluntary work at the service of those who suffer.

One cannot fail to observe that when a man or a woman is struck by illness and goes on a pilgrimage to Lourdes, this is an initiative that is not directly linked to a policy of palliative care. This is an evident point. And thus one should not forget that at the end of the nineteenth century the initiative of the first sick pilgrims who went to Lourdes was an extraordinary practice. All forms of treatment and care were stopped, the person who suffered was only advised to engage in those forms of treatment and care that was needed for his or her comfort, and he or she was left in the hands of volunteers whose only forms of care were to enable that person to engage in the experience of a pilgrimage to the grotto of Massabielle. Thus, in studying this rather unknown aspect of Lourdes, can one not see a practice that prefigured those forms of palliative care that we know today? But to follow this line of inquiry would lead us outside the parameters of the subject that I have been asked to address in this paper.

In the light of what has been experienced at Lourdes, I will now outline the profile that could be that of a voluntary worker in a palliative care unit with reference to the question: 'who is a voluntary worker?' I will then attempt to define the action of such a volunteer in a palliative care unit by answering the question: 'what does this voluntary worker do?' Lastly, and always basing myself on what I have witnessed and experienced at Lourdes, I will propose a few guidelines which will allow each volunteer who works in a palliative care unit to deepen his or her knowledge and practice of his or her service.

Who is a Voluntary Worker?

The wise communications that you have listened to over the last three days allow me to state at the outset what a voluntary worker in a palliative care unit is not.

This volunteer is neither a medical doctor nor a member of the staff that provides care and treatment. And if this volunteer has some expertise in the sphere of medicine, this is not the qualification that lies behind his or her presence within the palliative care unit. Therefore, he or she is not a part of the staff that provides care and treatment, by any qualification whatsoever, and yet the physical health of the sick person to whom he or she is near directly concerns him or her. The voluntary worker is not a psychologist and yet the psychological health of the person that he or she is accompanying is important for him or her. He or she is not a medical-social assistant and yet what these special actions on behalf of the sick person involve are important for this voluntary worker.

In the same way, the volunteer under discussion is not a priest. And yet this voluntary worker attends to the spiritual health of the sick person and that person's ultimate purpose. This voluntary worker is not a male or female religious and yet he or she wants to help the sick person by implementing a Christian approach to the end of life.

The volunteer who is present within a palliative care unit is not necessarily a member of the sick person's family; he or she is not necessarily or a friend or a neighbour of the patient. And yet he or she cares about the affective health of the sick person to the point of wanting to do everything that is in his or her power to foster a relational climate in the best way possible.

Thus the voluntary worker is not a specialist in one of the aspects of the sick person's condition. On the contrary: he or she is more a generalist who is interested in the sick person considered as a whole.

Indeed, the voluntary worker is present within a palliative care unit because a man who suffers and whose days are threatened is also present in that unit. At the moment when death inexorably advances in the body of the sick person, the voluntary worker is next to life. He or she is an apostle of life and recalls with his or her person the mystery of life, its beauty and its value.

A voluntary worker is what the term means in French (*Bénévole*),[1] that is to say a person who wants the good of another person. He or she wants what is best for other people. And this takes place with total self-giving and in a selfless way. He or she receives neither a salary nor a wage nor a payment. He or she is there to give his or her time, his or her person, in order to give of himself or herself by accompanying the sick person.

In order to define a voluntary worker who is present within a palliative care unit in positive terms, one may say that he or she is a person of a relationship, a relationship based upon the choice in favour of 'life' that is anchored in the defence of 'man' and the wish to help man to live until his last breath. The relationship of accompanying the person who suffers thus also becomes a relationship with the other people who surround the sick person.

The person of the relationship of accompanying, the voluntary worker, is not, however, only the service that he or she provides. Indeed, the voluntary worker is to begin with a member of a team of volunteers who accompany, a team that can be replaced by an association or a service of the Church.

And yet it is under this heading that the voluntary worker most often acts. He or she thus has a life that is bound up with voluntary work. He or she is motivated by faith, guided by ethics, and is at the service of a belief. Prayer, reflection, training, and sharing help to make him or her what he or she is. Then, in his or her capacity as a voluntary worker, he or she forms a part, in varyingly explicit ways, of the team that surrounds the sick person who is receiving palliative care. Next to the medical doctors, to the staff involved in providing care and treatment, and other forms of intervention, the voluntary worker is there because of what he or she is.

What Does the Voluntary Worker Do?

In a palliative care unit, therefore, the voluntary worker is someone who accompanies a sick person who has arrived at the end of his or her life – the voluntary worker thus accompanies a person who suffers. He or she dwells in that person's company. He or she keeps that person company. In a certain sense, he or she shares bread with the person who is his or her companion: the bread of suffering, the bread of need, and the bread (very often) of anxiety.

In order to do this with the person that he or she is accompanying, the volunteer enters into the rhythm, the step, and the level of the sick person. The voluntary worker is careful to reach the other person in that person's reality, in that person's capacity, and in that person's expectations. The voluntary worker imposes nothing; he or she accompanies. The voluntary worker does not impose himself or herself; he or she is a presence. He or she does not dispose of the other person; he or she gives the sick person pride of place.

This accompanying is made up of readiness to help, of respect, of discretion and of listening. *A priori* this makes the sick person feel more important than the voluntary worker.

In this approach, the voluntary worker ensures a quality in the relationship whose every moment is valuable because life itself is priceless. Thus accompanying does not only involve a form of assistance that would lead to a unilateral relationship. One is not dealing, therefore, with a relationship in which one person is active and another person is passive, but rather of a relationship that is an encounter between two people. But it is certainly the case that this relationship is not easy to initiate given that the lack of symmetry between the two figures is more than evident. Indeed, one of these two people is characterised by the strength of the other rather than by his or her weakness. Thus the accompanying of a person who is living out the last period of his or her life in a palliative care unit can be like a part of the relationship that exists between a parent and a small child or between a teacher and a young pupil. This is a relationship that should be seen from the perspective of time, a relationship where the person who is in a dominant position should be concerned to apply to the present (but transitory) situation the words of John the Baptist 'He must grow and I must diminish'.

This encounter between the voluntary worker and the sick person is itself inscribed within a history. Time rediscovers its importance because each visit refers to the previous visit and already determines the next one. Duration allows trust to become established. Each party can then begin to be what he or she is beyond his or her own weakness, weakness, fragility or precariousness, for the other person and beyond his or her own necessary reserve, in a relationship that involves indispensable modesty and immense respect for the other person.

Thus slowly but truly entering into the reality of his or her own humanity that is wounded to the point of bringing about death, the sick person can live in a better way the present moment in the light of the last moment. This is because, at this stage of the relationship, the prospect of death is no longer what hinders, what neutralises, what paralyses, in a word what inhibits living. On the contrary: this ineluctable date of death is in a certain way what makes the person live by appreciating the present moment in its right and infinite value. For his or her part, the voluntary worker then enters the stage where he or she, too, can give the best of himself or herself.

Thus, at this stage, the relationship of the accompanying of a living person until the end of his or her life in a palliative care unit can take on a new dimension. Indeed, the encounter that the voluntary worker and the sick person experience opens up to each one of them the capacity to experience still other encounters.

The voluntary worker will find his or her place in the accompanying team reinforced and this role will take on all its weight. He or she is now a member to the full of this team. The same voluntary worker will be appreciated by the family entourage of the sick person not only because of his or her readiness to help, his or her devotion, and his or her kindness, but also because of what he or she really is. By now the voluntary worker will form a part of their history and when death has done its work he or she will still be remembered and they will feel and manifest gratitude and kindly feelings towards that voluntary worker.

For the sick person, this stage of the relationship, which opens up to encounter with other people, will allow him or her to have another look at the people that surround him or her as well as all those people that have been important during his or her life. Another kind of relationship can then begin. This is the moment when the forgiveness to be given and to be requested becomes possible. This is the moment when the sick person who has arrived near to death can engage in truth in relation to his or her life. This, for that matter, can be given practical expression in a simple way: some special gesture, some precise words, can be sufficient to experience a real liberation that is a relief for the conscience and peacefulness for the depths of the heart.

As the relationship between the voluntary worker and the sick person grows deeper, the sick person becomes unified. His or her past, his or her present, and his or her future, can be taken on in God. This is because they are taken on by Christ who is present in the relationship.

Because of his or her relationship with the voluntary worker, it will be less difficult for the sick person to consider the future, that is to say to speak about his or her death as an encounter with God. Thus, because of the character of the relationship that he or she has formed with the sick person, the voluntary worker can prepare the sick person for his or her encounter with God. The relationship with the sick person for the voluntary worker is openness to Christ and thus Christ himself can prepare for that great passage the person who, in his or her death, will experience the encounter for which God created him or her.

This is the special place for a voluntary worker who belongs to a palliative care unit and knows that within it he or she is never alone. Indeed, each person, in his or her own way, with his or her own means, and with his or her expertise and implications, is near to the person who suffers.

But in a certain sense a volunteer is a person who captures all the good intentions of the other people who are involved in looking after and caring for the sick person. In this, the role of the voluntary worker is unique and necessary.

How Can the Service of the Voluntary Worker be Improved?

It is the communal dimension of his or her service that allows the voluntary worker to make progress. He or she will never cease to receive a necessary training from the Church. From his or her group the volunteer will receive unceasingly a touch that must always be refined. From the palliative care unit to which he or she belongs the voluntary worker will increasingly learn about the truth and the humility of his or her action.

But this is only possible through the personal life of the voluntary worker. The relationship of the voluntary worker with Christ and the authenticity of his or her Christian life conditions all of his or her action. The relationship of the voluntary worker with life, which is made up of amazement and the work of grace, will allow him or her increasingly to be a loving and zealous servant of life. Lastly, the more his or her desire for holiness grows, the more he or she will be able to make present He who is Holy. The voluntary worker will also allow the person who is sick and is preparing to die to enter – when God so wishes it – that experience of healing and true sanctification that Christ came to bring us – the Resurrection.

Conclusion

I am grateful to one of my brothers of Lourdes, Padre Régis Marie de la Teyssonnière, the chaplain general of the Hospital of Notre-Dame of Lourdes, for having provided me with some incisive notes on the subject that I have addressed here before you.

In speaking about the relationship of the voluntary worker with the sick person in a palliative care unit, I also think of all those male and female nurses at Lourdes who accompany the sick pilgrims to the end of their lives with so much generosity, devotion and self-denial. This is true of the context of the French pilgrimages, of the 'Lourdes Cancer Hope' of the Italian pilgrimages, and of the pilgrimages of UNITALSI. Indeed, the voluntary workers of Lourdes live out the following words of Bernadette Soubirous: 'It is such an honour to look after a sick person that one does not expect any other reward'. These are words that can help every voluntary worker who is active in a palliative care unit.

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Note

[1] The French word '*Bénévole*' cannot be translated into Italian. The literal translation from the French is 'he who wants good'.

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