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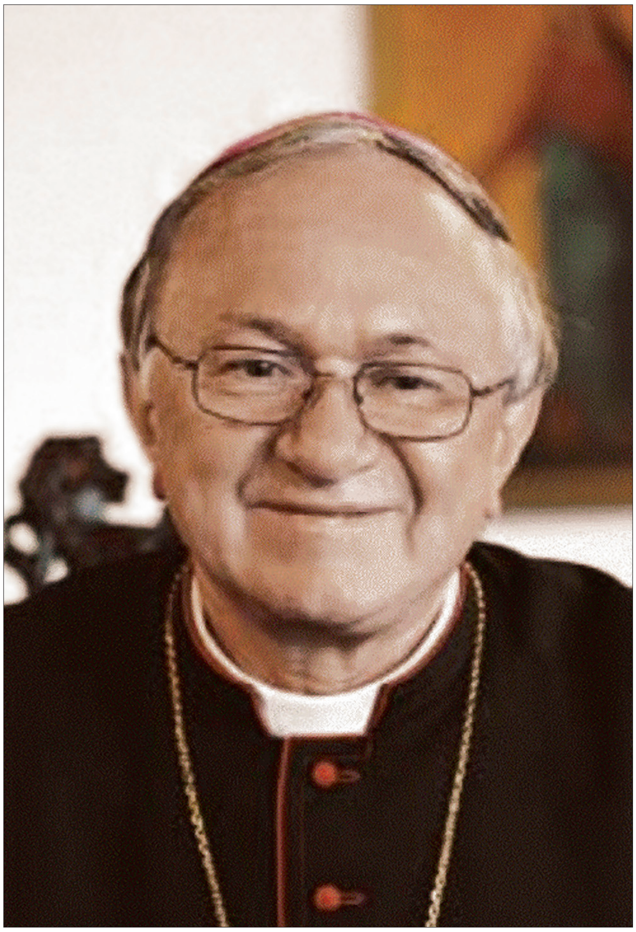
On 12 July 2016
the Lord Called unto Himself
Archbishop Zygmunt Zimowski



ARCHBISHOP ZYGMUNT ZIMOWSKI

- Born in Kupienin in Poland on 7 April 1949
- Ordained a priest on 27 May 1973 in Tarnów
- Licence in theology at the Catholic University of Lublin
- Doctorate in theology at the University of Innsbruck in Austria
- Official of the Congregation for the Doctrine of the Faith 1 February 1983
- Appointed Bishop of Radom in Poland on 28 March 2002
- Consecrated a Bishop by Cardinal Joseph Ratzinger on 25 May 2002
- President of the Polish Episcopal Commission for the Doctrine of the Faith
- Member of the Polish Episcopal Commission for Ecumenism
- Delegate of the Polish Bishops' Conference for Pastoral Care for Migrants
- Appointed President of the Pontifical Council for Health Care Workers and raised to the office of Archbishop on 18 April 2009
- President of the 'Good Samaritan' Foundation
- Member of the Congregation for the Causes of Saints
- Member of the Congregation for Bishops
- Knight's Cross of the Order of the Restored Poland
- Commander with Plaque of the Equestrian Order of the Holy Sepulchre of Jerusalem
- Commander's cross with plaque of the Order of the Restored Poland
- Honoris Causa degree in theology of the Christian Theological Academy of Warsaw 30 June 2008
- President of the Ethics Committee of the St. Lucia Foundation IRCCS in Rome

SEGRETERIA DI STATO

TO THE MOST REVEREND GENTLEMAN
MSGR. JEAN-MARIE MATE MUSIVI MUPENDAWATU
SECRETARY OF THE PONTIFICAL COUNCIL
FOR HEALTH CARE WORKERS
00120 VATICAN CITY

I HAVE LEARNT OF THE SAD NEWS OF THE DEATH OF HIS EXCELLENCY THE MOST REVEREND MSGR. ZYGMUNT ZIMOWSKI, THE PRESIDENT OF THE PONTIFICAL COUNCIL, AFTER A LONG AND PAINFUL ILLNESS WHICH HE LIVED IN A SPIRIT OF FAITH AND CHRISTIAN WITNESS. I WISH TO EXPRESS MY SPIRITUAL PARTICIPATION IN THE MOURNING THAT AFFLICTS THE DICASTERY AND, WHILE REMEMBERING HIS GENEROUS MINISTRY EXERCISED FIRST AS A PASTOR IN THE DIOCESE OF RANDOM AND THEN AT THE SERVICE OF THE HOLY FATHER, I RAISE UP FERVID PRAYERS OF SUFFRAGE TO THE LORD FOR HIS SOUL, ENTRUSTING HIM TO THE MATERNAL INTERCESSION OF THE BLESSED VIRGIN MARY, QUEEN OF POLAND. WITH THESE SENTIMENTS, I INVOKE FOR OUR MUCH LAMENTED FELLOW WORKER THE ETERNAL PRIZE PROMISED TO THE FAITHFUL SERVANTS OF THE GOSPEL AND I WILLINGLY BESTOW ON YOU, THE OFFICIALS AND WORKERS OF THE PONTIFICAL COUNCIL, AND ON THE FAMILY RELATIVES OF THE MUCH LAMENTED PRELATE, MY CONSOLING APOSTOLIC BLESSING.

FRANCISCUS PP.

From the Vatican, 13 July 2016

Personal Memories of H.E. Msgr. Zygmunt Zimowski

FATHER JÁN ĎAČOK SJ
Prelate Theologian of the Apostolic Penitentiary, the Holy See

I met His Excellency Msgr. Zygmunt Zimowski for the first time in February 2010 in St. Clement's Basilica in Rome. We were celebrating the feast day of St. Cyril and St. Methodius, the patron saints of Europe. After the solemn celebration, I asked who one of the concelebrants was because I had never met him. That person was Zygmunt Zimowski, the new President of the Pontifical Council for Health Care Workers. After being introduced to him, he invited me to visit him in his office. Thus was born our cooperation and our friendship which offered numerous opportunities for us to get to know each other well. In this paper, I will take the liberty of referring to some of those opportunities.

On the occasion of my first visit to the Pontifical Council, he suggested that I accompany him on his trip to Vitebsk, in Byelorussia, in May 2010, a trip he was making in response to an invitation of H.E. Msgr. Władysław Blin, the then bishop of that city. Each one of us gave two papers: one for the students and the lecturers of the Faculty of Pedagogy of the state University of P.M. Masherov in Vitebsk, and the other at the international conference on contemporary problems of medical ethics for the medical doctors and researchers of the Faculty of Medicine of the same university.

Msgr. Zimowski so much appreciated the activity of health-care workers in Slovakia that he visited that country twice. I had the honour of being able to accompany him on those two visits. The culminating point of his first visit (which took place in June 2011) was his participation in the solemn academic meeting of the Faculty of Theology of the University of Trnava in Bratislava when he gave the keynote magisterial paper entitled 'The Current Trends in Pastoral Care for Health-Care workers and the Role of Bishops' Conference in the Achievement of the Culture of Life'; his *laudatio*; and the award of the medal of the Pontifical Council of Health Care Workers to H.E. Msgr. František Tondra, the Bishop of Spiš, the President Emeritus of the Bishops' Conference of Slovakia and the first chairman of the sub-committee of bioethics of the Bishops' Conference of Slovakia (BCS), on the occasion of this last's seventy-fifth birthday, because of his distinguished contribution to the development of the culture of life and the protection of human dignity and human life. Msgr. Zimowski greatly appreciated that occasion and the giving of that award because Msgr. F. Tondra was to die the following year. After receiving the news of his death, Msgr. Zimowski repeated: "We did well, we did well!" His visit was a great enrichment and encouragement for the priests, religious and lay faithful who worked in the field of health care, a field in which they had to address very many problems and challenges. The bishops of Slovakia appreciated the meeting with Msgr. Zimowski who left in them profound and inspiring impressions.

In June 2014, during his second visit to Slovakia, he took part in the international conference held in Bratislava on contemporary biomedicine and care for health and human dignity. On that occasion he visited some institutions dedicated to care for the sick and the suffering and he met health-care workers of Slovakia and representatives of the European Federation of Catholic Doctors (FEAMC). During this trip he also visited the Faculty of Medicine of the University of P.J. Šafárik in Košice in Eastern Slovakia where he met the dean of the Faculty and his colleagues, gave a *lectio magistralis* for the medical doctors, health-care workers and students of the faculty, and visited the university hospital, the centre for heart disease, and the chapels.

Because of other engagements I was not able to accept his invitations to accompany him on his trips to Croatia and the Czech Republic.

I am deeply grateful to Msgr. Zimowski and those who worked with him for being able to represent the Pontifical Council for Health Care Workers, together with Msgr. Dariusz Giers, an Official of the dicastery, at the conference on pastoral care in health organised by the Ecumenical Patriarchate of the Orthodox Churches in Rhodes, Greece, in October 2011. From my point of view, I am able to state that gradually good and promising cooperation was established between the two institutions. I was able to get to know Msgr. Zimowski better thanks to two visits to the Holy Land in October 2013 and in particular in February 2016 when the twenty-fourth World Day of the Sick was celebrated in Nazareth. His participation, so much wished for, and its success, despite his illness, encouraged everyone.

After his second visit to Slovakia, H.E. Msgr. Viliam Judák, the Bishop of Nitra, invited him to a pilgrimage to a holy place associated with Saint Andrew and Saint Benedict, the patron saints of that diocese, in Skalka near to Trenčín, for the renewal of the historic ties between the diocese of Nitra and the diocese of Tarnów in Poland, the diocese of his birth. Msgr. Zimowski had very much wanted to go to that place as early as 2015, but his state of health prevented this. When we spoke about this invitation at the beginning of the year 2016, he repeated his wish in emphatic fashion: "we'll go there, we'll go there". He confirmed this in May 2016 as well when he was already in Poland, to which he had travelled before Easter. The medical doctors, because his health had got worse, advised him not to return to Rome. I spoke to Msgr. Zimowski again on the telephone on 24 June when he had been admitted to hospital again near to his place of birth in Kupienin in the diocese of Tarnów. On that occasion, he appointed me his delegate for the pilgrimage to Skalka. Later I was unable to talk to him because his state of health was deteriorating rapidly…

I felt greatly moved and honoured to have been appointed his representative at the solemnity of St. Andrew and St. Benedict, to preside over the celebration of the Eucharist on Sunday 17 July 2016, and at the first pilgrimage of the health-care workers of Slovakia which had taken place on the previous day. His letter, addressed to H.E. Msgr. Viliam Judák, in which he informed him that he was unable to take part in the events of the pilgrimage and told him about the appointment of his representative, was dated 1 July 2016, a few days before he was called to the Lord… During those events we remembered Msgr. Zimowski with great esteem and gratitude.

Together with H.E. Msgr. Milan Lach, the chairman of the then sub-committee for bioethics and of the committee for pastoral care in health of the Bishops' Conference of Slovakia, and Prof. Jozef Glasa and Fr. Jozef Mydla, I took part in his funeral as a sign of gratitude for a great personage who loved Slovakia and its people and appreciated everything that had been done in that country for the cause of human dignity, in particular in the field of health care.

I knew Msgr. Zygmunt Zimowski as a cordial, friendly and generous man who loved Jesus Christ and the Church which he served with all of his energies. He not only proclaimed the gospel example of the Good Samaritan but also embodied it during his meetings with the sick and with health-care workers. With his patience, and in a special way during the period of his worsening illness, he demonstrated his deep personal union with the suffering and risen Christ who strengthened him in his personal journey until the end. I am profoundly grateful to the Lord that I knew him, for everything that, under his guidance, could be done for the universal Church, for Slovakia and for all the other countries of the world. I am convinced that already in the house of the Lord he is accompanying, and will accompany, the efforts of all those who continue, and will continue, in the mission that he outlined. ■

Remembering H.E. Msgr. Zimowski

PROF. DOMENICO ARDUINI
Director of the Department
of Obstetrics and Gynaecology,
the University of Rome
Tor Vergata – the Holy Family

To meet His Excellency Zimowski was certainly a moment that it was difficult to forget. His capacity to attract people put every interlocutor at their ease. I remember perfectly, even though ten years have passed since that time, the first occasion that I had the honour to be able to speak to him. It was in his office.

The question was a rather important one and his experience and his capacity to go immediately and rapidly to the heart of a problem could have been of vital help. I remember that my anxious wait in that little room was immediately forgotten when he come right up to me with that smile of his which I would always remember, until our last meeting when his illness had already weakened him but had not been able to eliminate that smile.

On that first occasion, he took me right away into his office and he had me sit down on the small sofa, with him beside me. I immediately understood that he was no ordinary person, and above everything else he behaved like an old and patient friend. From that moment onwards, I began a slow and constant drawing near to the mission of his Pontifical Council, which was never to leave me.

Each time that I went to see him and proposed some idea about work, he listened to me patiently, he corrected me in a kindly way, and said goodbye to me like a father, with his answer already in my pocket. It was often in the affirmative, at times involved doubts, in rare cases it was negative, but it was always accompanied by an exhaustive explanation about the negative or positive reasons for his response.

When my family and I myself personally had to go through the anxiety-inducing journey of illness, the first person in whom I confided and from whom I sought comfort was Zimowski; the first chapel in which I asked the Lord to point out to me the pathway to take was the little chapel of the Pontifical Council. Zimowski always comforted me and was for all of us a real point of support, a rock to hang on to, to resist the unforgiving torrent of illness.

When he spoke to he about his Cross, smiling, I reminded him of the words that he spoke to me in similar circumstances when he saw that I was ill. He smiled back and we held each other in the silence of understanding.

Now, when thinking about those years when I was near to him, I cannot imagine how fortunate I was to know him and how much he gave to me as an example and as an impress of charity and of faith.

As you will have noticed, I have always used verbs in the present tense because, not only as a Catholic but also as a man, I cannot believe that everything finishes with death and that one should use the remote past tense in Italian. I am certain that his teaching is, and will always remain, with us, and this is the finest gift that Zimowski is giving us. ■

The Last President H.E. Msgr. Zygmunt Zimowski

MS. MARISOL CARPINTERO
Director of
'Secretariado Diocesano
para la pastoral de la salud',
Diocese of Avila,
Spain

A gift was present in the mystery that surrounded the life of John Paul II with the assassination attempt on his life in 1981 that took place shortly after the beginning of his pontificate – the gift of his life which lasted until the year 2005. The creation of the Pontifical Commission for Pastoral Assistance to Health Care Workers (1985), which later became the Pontifical Council for Pastoral Assistance to Health Care Workers (1988), participated in this gift. This was a journey that lasted thirty-one years. The greatest beneficiaries of this journey were the sick and, amongst them, the poorest and the most discarded of the societies of the five continents of the world.

Following its creation, this institution had three presidents: Cardinal Fiorenzo Angelini, an Italian; Cardinal Javier Lozano Barragán, a Mexican; and Archbishop Zygmunt Zimowski, a Pole. They in their turn were able to rely upon the cooperation of two Secretaries: H.E. Msgr. José L. Redrado, a Spaniard, and Msgr. Jean-Marie Mupendawatu, from Lubero, in the Democratic Republic of the Congo, formerly Zaire. This diversity of nationalities expressed a vision of the universality of the Church.

As we celebrate the thirty-first international conference of the Pontifical Council for Health Care Workers, we know that this dicastery will end its activities on 1 January 2017, following the wishes of Pope Francis. It will form a part of the new Dicastery for Promoting Integral Human Development, but this does not mean that what has been done hitherto will be forgotten about since the Church follows the same Lord in her various institutions.

Almost without wanting it, the thirty-first international conference has been pervaded by a feeling of sadness and remembrance, with the sensation of being an orphan, because on 12 July last Msgr. Zimowski took the final step from life to Life because God saw him as being worthy of Him. For this reason, the general chairman is our Secretary, Msgr. Jean-Marie Mupendawatu. The pious meditation and prayer in his memory encourage me to offer you the memories of him that I keep in my heart.

A few months after Pope Benedict XVI had appointed him Archbishop-President of the Pontifical Council for Health Care Workers (2009), Msgr. Zimowski visited Spain on the occasion of the National Meeting of Delegates of Pastoral Care in Health. He was a kindly man, approachable, intent on knowing about the realities and development of pastoral activity in our country. I spoke about my admiration and veneration for his countryman, Pope John Paul II. He listened to me carefully and agreed with the good things that I said about that Supreme Pontiff. For me that appointment was a present of John Paul II who promoted within the Church the pastoral task of bringing light, comfort and hope to all people who have to face up to the trial of illness and suffering.

My subsequent meetings with him took place in Rome on the occasion of the international conferences. He greeted me with affection and he had already identified me as a faithful follower of John Paul II. His ability to listen always struck me. I had the perception that he was a pious bishop and a good pastor who loved sick people. I told him about the way in which we provide pastoral care in the pastoral plan of our diocese; our projects, our concerns and our hopes.

Within a short time, it also fell to him to experience suffering and illness, a situation that many of us could not live with him in his daily life. But we certainly accompanied him with our prayers. Everybody prayed for him to be relieved and comforted by Jesus. I should say that the 'gift' about which I spoke at the beginning of this paper found its way into the life of Msgr. Zimowski and the way in which he lived his illness, following the example of his fellow countryman, St. John Paul II. He said this to me personally in his office exactly a year ago when in November 2015 we celebrated the thirtieth international conference, the last that he was to lead. "I have been very ill, but I want to be strong as he was strong". This strength and vitality of his soul were very evident to those who had the grace to live the World Day of the Sick in the Holy Land together with him in February 2016. He was the Delegate and Special Envoy of the Holy Father. We could observe the frailty of his body and the greatness of his soul. The way that he dealt with people; the spirit with which he overcame difficulties; his wish to be present and to take part in all the events of the programme; the way in which he experienced the liturgical celebrations; his piety and concentration in receiving the sacrament of Holy Anointing; his action of welcoming the sick; and his humble approach when he allowed himself to be helped by priests, were all exemplary.

I remember, in particular, the homily that he gave during the celebration of the Eucharist in the Basilica of the Holy Sepulchre: very moved, he recalled the visit of Pope John Paul II to that holy place. I remember the effort that he made to climb the stairs that go up to where the body of Christ was buried. Msgr. Zimowski tried to imitate the courage of Pope John Paul II. There, more than in any other place, we could feel in our hearts that suffering, illness and death do not have the last word because the Resurrection of Christ is the final triumph. The Basilica of the Holy Sepulchre became for us a symbol of light and of grace which helps us to accept and offer up our suffering. I believe that this is how our President Msgr. Zimowski lived that moment and today we feel grateful for his witness, his strength and his love for Jesus Christ; this was truly an experience of faith lived in the best of settings – the Holy Land. He made real the words of St. John Paul II: 'do good with suffering and do good to those who suffer'. He truly did a great deal of good to us.

It remains to me to express a special reason for gratitude. The section for pastoral care in health in our diocese of Avila published the Messages of John Paul II and Benedict XVI published on the occasion of the World Day of the Sick: 'Messages Starting from Love for Suffering People'. I asked Msgr. Zygmunt Zimowski to write the conclusion to the second part which was dedicated to the Messages of Pope Benedict XVI. Shortly after I made my request, however, his situation got worse and thus I had doubts about whether he would be able to make this contribution because everything suggested that this would not be possible. But to our great joy Msgr, Zimowski made a great effort and gave us the present of his conclusion. Today I see it as his spiritual testament. With gratitude I reproduce the following section which brings out the heights of his spirit: 'The subject of suffering is a difficult subject, both to live and to explain. More than a challenge it is mystery that we address very day personally or indirectly because a friend of ours or a family relative is going through a moment of physical or moral difficulty… Suffering should always be faced up to in the light of faith, which is also, during moments of misfortune, subjected to a great trial. Faith, however, is not only useful – it is even indispensable. Suffering experienced in communion with the Saviour is not only easier to bear but also, in reality, it can be – paradoxically – a reason for especial joy. There are two reasons for this: firstly, when I suffer I can rely upon the special nearness of the Christ who identifies above all else with those who bear the cross of illness; secondly, my suffering becomes an opportunity for a sort of mission, of evangelization. Through my witness of interaction with suffering, I can, after a certain fashion, make it happen that other people, seeing the extraordinary strength that springs from my faith, are attracted and want to strengthen their relationship with God, the source of spiritual strength. In this way, suffering becomes a kind of challenge, but also an opportunity to take part even more fully in the missionary activity of the Church'.

I thank the Lord for the good that the Pontifical Council has done during its thirty-one year journey; the good done by its Presidents, the last one of whom, Msgr. Zimowski, is present in a special way at this thirty-first international conference, by its Secretaries and Under-Secretaries, by the workers of this vineyard of the Lord, workers and volunteers. All of them have helped us to discover in a small diocese the greatness and the universality of the Church; they have helped us feel that we are not alone, that pastoral activity is unique, inherited and learnt from Jesus who during his life privileged the sick, curing, healing and saving everyone. May God be blessed! ■

International Symposium

Towards Holistic Care for People with Hansen's Disease, Respectful of their Dignity

Organised by

The Pontifical Council for Health Care Workers
The Good Samaritan Foundation
The Nippon Foundation

In Cooperation with

The Raoul Follereau Foundation
The Sovereign Order of Malta
The Sasakawa Memorial Health Foundation

9-10 June 2016

'Padre Agostino Trapè' Auditorium
The Patristic Institute Augustinianum
Vatican City

THURSDAY 9 JUNE

Message of H.E. Msgr. Zimowski

H.E. MSGR.
ZYGMUNT ZIMOWSKI
President of the
Pontifical Council
for Health Care Workers,
the Holy See

I warmly greet all those taking part in this international meeting entitled 'Towards Holistic Care for People with Hansen's Disease, Respectful of their Dignity' which the Pontifical Council for Health Care Workers (for Health Pastoral Care) through its own Good Samaritan Foundations has organised together with the Nippon Foundation, to whom, indeed, I express my thanks. Similar thanks go to the Raoul Follereau Foundation, the Sovereign Order of Malta, and the Sasakawa Memorial Health Foundation who have cooperated in making this meeting a reality.

To all those present and all those who are involved every day in the fight against Hansen's disease and against all 'even more contagious diseases', as Raul Follereau repeatedly said, that injure the dignity of human beings, I express my great and keenly-felt gratitude and also my admiration.

Unable to take part in this initiative on 'doctors' orders' because they want me to conserve my strength, I greet with especial affection all people with Hansen's disease or afflicted in some way by it. I feel particularly close to all of them and my prayer is that suffering will never manage to be stronger than hope and that we can offer up all our tribulations to the Lord, to those people who have most need of comfort and care.

I hope that this symposium will be successful, indeed very successful. I personally took part in its organisation. As will emerge from the subsequent papers, this is a very important appointment because Hansen's disease, despite the notable decrease in cases of contagion following the advanced development of therapies for it, continues to be a challenge that has to be addressed at three levels. They are a reduction in the incidence of this disease; helping people who are afflicted by it and their families; and reintegrating people who have been cured of it into society. In addition, leprosy has a deep connection – starting with Holy Scripture – with Mercy, and providing a contribution to the fight against this ancient and still today frightening malady belongs in a very appropriate way to this Jubilee Year of Mercy.

In preparing for these deliberations, we can draw inspiration from many exemplary people and entrust our activity to saints who marked themselves out by their encounter with people with leprosy or in caring for them, to the point of sacrificing their lives in their mission for them. We may remember St. Francis of Assisi, St. Damian de Veuster, St. Marianna Cope, the Blessed Jan Beyzym, the Venerable Marcello Candia, the Servants of God Raoul Follereau and his wife Madelaine Boudou, and the Blessed Mother Teresa of Calcutta who will be canonised by Pope Francis on 4 September of this year as a model of mercy.

Our meeting is to be placed in this context and it wants to highlight that Hansen's disease cannot be a pathology of which we should be afraid and that it cannot be forgotten about, in the same way as the people who are afflicted by it cannot be forgotten about. In my *Message* written on the occasion of the sixty-third World Leprosy Day of 31 January 2016 I made an appeal for a shared effort to expand activities involving information and prevention and above all to foster, as a gesture of true 'compassion', the social and occupational reintegration of those people who have been cured of this disease and who, despite bearing signs of it impressed on their bodies, have conserved intact their dignity as persons.

When announcing the Extraordinary Jubilee of Mercy Pope Francis expressed the hope 'that this Jubilee year celebrating the mercy of God will… eliminate every form of closed-mindedness and disrespect, and drive out every form of violence and discrimination' (Bull of Indiction for the Extraordinary Jubilee of Mercy, *Misericordiae Vultus*, n. 23). Adopting the words of the Pope I hope that there will 'be ever more abundant goodness in us. Let us be infected by goodness and let us spread goodness' (Pope Francis, Prayer of the *Angelus*, 15 February 2015). I believe that too many of our sick brothers and sisters still await a gesture of tenderness, of sharing, and believe that this will help to remove all social stigmas. In accepting the invitation of the Holy Father, the Pontifical Council for Health Care Workers has wanted to celebrate this international meeting as an immediate preparation for the Jubilee of the Sick and the Disabled which will be celebrated next Saturday and Sunday, and which will have an especial relevance because of the Holy Mass celebrated by the Holy Father Pope Francis. I hope for all of you that this experience of the Church immersed in mercy will make all sick and disabled people, as well as their family relatives, health-care workers and those who work hard in the world of voluntary work, increasingly joyous and effective witnesses to mercy, in particular in relation to people marked by Hansen's disease. This jubilee appointment, therefore, should be a stimulus to act because, as Rauol Follereau said, 'to love without acting means nothing!'

I wish you fruitful work and I look forward to seeing you all soon! I accompany you with my blessing! ■

Introduction

MR. YOHEY SASAKAWA
Chairman of
the Nippon Foundation,
Japan

I am truly grateful to the Pontifical Council for Health Care Workers for graciously co-organising this symposium, and I would like to thank the Good Samaritan Foundation, the Foundation Raoul Follereau and the Sovereign Order of Malta for their cooperation.

I believe that we cannot talk about leprosy without listening to those who have experienced it. But there have not been many who have heard their voices directly. Today, I would like to express my special appreciation to those who have come from so far to share their experiences with us.

Let me begin by acknowledging the role that the Roman Catholic Church has played in caring for those who suffer from leprosy. Many in the Church have devoted their lives to helping leprosy patients.

Among them have been Saint Damien whose care for leprosy patients in Hawaii in the nineteenth century was very much recognised, or Mother Teresa, a Nobel Peace Prize laureate for her dedicated services to the poorest of the poor and for people with leprosy and other diseases. I myself was fortunate to meet Mother Teresa in India. When I visited a home for leprosy patients run by the nuns of the Missionaries of Chastity, she showed me around herself. My visit and my experience of joining her in prayer for the patients is a memory that I shall never forget.

Wherever I travel, many who have been cured of leprosy have told me how grateful they are for the devoted care of the Church.

The Nippon Foundation of which I am the chairman, and its affiliated organisation, the Sasakawa Memorial Health Foundation, have been committed to eliminating leprosy since the 1960s, in addition to diverse humanitarian programmes in many parts of the world.

In 1983, my late father, Ryoichi Sasakawa, was invited to meet and talk with His Holiness Pope John Paul II in his office, and I accompanied him on that occasion. During the audience, His Holiness wrapped his arms around my father and expressed deep gratitude for his work to eliminate leprosy and he encouraged him to continue.

In the 1990s we at the Nippon Foundation decided to make available the effective treatment for leprosy that had been developed in the 1980s, the multidrug therapy, free of charge, globally. With the cooperation of the WHO and many others, we were able to achieve a dramatic decline in the number of patients.

I was granted a second audience with His Holiness Pope John Paul II in 2003. At that time I was delighted to be able to report that I had travelled and could confirm that the medicine was always in stock even in the remotest districts of all the endemic countries, and as a result of this successful distribution of the medicine the number of patients had undergone a significant decline.

Thanks to the medicine, the number of leprosy patients declined. Yet, while there was an improvement on the medical side, the social problem of discrimination remained unchanged. Many people continued to suffer from the discrimination and stigma associated with leprosy.

In other words, although they had been cured of leprosy, they still continued to be stigmatised as former 'leprosy patients'. They were discriminated against, unable to return home or go back to work. They had no other choice but to live in the leprosaria or leprosy colonies where they had lived as patients.

This is a problem that cannot be solved by medical treatment. It is a problem of awareness. The problem of public awareness stems from deep-rooted misperceptions of leprosy that lead to discrimination. In many cases, leprosy is still misunderstood, and is seen as a hereditary disease or as a curse or punishment of God.

To rectify these misperceptions, the Nippon Foundation engages in activities that promote a correct understanding of leprosy. For example, every year since 2006 we have continued to launch a message that we call the 'Global Appeal to End Stigma and Discrimination against People Affected by Leprosy' to coincide with World Leprosy Day in January. This is one of our key advocacy efforts. This annual appeal is made in cooperation with leaders who represent different sectors of society, such as medicine, business, academia, to name a few, in order to try to reach out to a broader public.

I would like to acknowledge, and once again express thanks for, the support that we received from the Pontifical Council for Health Care Workers at the time of Global Appeal of 2009. We sent out a message, together with the world's religious leaders, 'to eliminate discrimination against leprosy and let the healing begin'.

These activities seek to correct misunderstanding and to encourage the general public to learn more about the disease. I believe this is one of the steps towards creating a world without discrimination and stigma associated with leprosy.

There is another awareness that must be addressed. This is the self-awareness of people who have themselves been affected by leprosy. I realised that many of them also had misperceptions of the disease. They had lived with discrimination so long that they had even given up all hope of returning to society. They chose to live isolated from society because they feared further discrimination, never realising that they, too, have their rights as human beings.

Religious leaders touch the hearts and minds of so many people. Your words teach us compassion, give us courage, heal suffering, and bring us together. Last year, His Holiness Pope Francis graciously received a delegation of people affected by leprosy from Brazil at the Vatican and they told me how meaningful and rewarding it was for them.

Today, this symposium is attended by representatives of the Roman Catholic Church as well as of other faiths, whom the Holy See has cordially welcomed. We have come together to discuss holistic care and to share awareness of the need to eliminate social discrimination against leprosy.

The ladies and gentlemen who have experienced what it is to be afflicted by leprosy are also here with us today. They are courageous people who have stood up to bring to the attention of the entire world the situation that all people affected by leprosy are now going through. They are the dynamic leaders who are actively guiding others to follow.

By joining forces, we can more effectively ease the suffering of those affected by leprosy. By working together, we can enable them to recover their dignity.

In closing, let me share the words of a friend who was cured of leprosy. He was afflicted by leprosy when he was a young boy. Since then he had lived in a leprosarium for over seven decades. Now he is 89 years-old and active in sharing his stories and experiences. He often tells me: "Although I have suffered discrimination, I choose to forgive those who have discriminated against me, and in doing so, my life has been enriched". Hearing his words, I was struck by the strength and tolerance that human beings are capable of. He is one of many who have courageously stood up to speak out against discrimination and change these conditions.

The voices of those affected by leprosy resonate powerfully for they have experienced discrimination first-hand and suffered its pain. By listening closely to their voices, we can learn what should be done. ■

Message of the Right Honourable Beatrice Lorenzin

RT. HON.
BEATRICE LORENZIN
Minister of Health,
Italy

To H.E. Msgr. Zigmunt Zimowski
President of the Pontifical
Council for Health Care Workers

I thank you for your courteous invitation to take part tomorrow, 9 June, in the inauguration of the international symposium 'Towards Holistic Care for People with Hansen's Disease that Respects their Dignity'. I truly would have liked to have been able to bring my personal greetings to all those present. Unfortunately, institutional engagements that cannot be postponed prevent me from take part.

I am certain that the meeting will constitute a fruitful opportunity to call people's attention to a disease that is neglected, namely leprosy, but one which still causes a great deal of suffering to patients and their families. I am also certain that this meeting will generate general awareness about this disease and its medical, mental and social consequences.

The role that the Church plays in addressing leprosy, and discrimination in relation to it, is an expression of the great commitment and profound sensitivity that the Church has towards the sick. This is particularly true of the Pontifical Council for Health Care Workers which wanted to celebrate the Jubilee of the Sick and the Disabled within the context of the Jubilee of Mercy called by Pope Francis in the current Holy Year.

I am certain that your event will have the success that it deserves, creating the right support in spreading correct information about this disease as well as a message of tolerance and inclusion. Therefore, in wishing you fruitful deliberations, I renew my thanks to you for your invitation and I send my most cordial greetings to all those present. ■

Speech of Mr. Récipon

MR. MICHEL RÉCIPON
President of the Raoul Follereau Foundation,
France

Your Eminences, Your Excellencies, Reverend Monsignors, Reverend Sisters, Reverend Fathers, Ladies and Gentlemen, it is a great honour for me and for the Raoul Follereau Foundation, of which I am the president, to have been asked to cooperate in the organisation of this symposium and to speak to you today. I would like to thank the Pontifical Council for Health Care Workers, the 'Good Samaritan' Foundation, and the Nippon Foundation for this initiative which provides us with an opportunity to remember that still today 200,000 people contract leprosy every year. This is a scourge that the Raoul Follereau has fought since its own beginnings, following its founder Raoul Follereau, the Wanderer of Charity.

That engaged Christian was above all else an intellectual, a poet and an orator. The first part of his life was therefore an intellectual struggle in the footsteps of Father de Foucauld and the religious who had been expelled from France at the beginning of the last century. His first public lecture, which he gave at the age of fifteen, already pointed out the direction that his life was to take. In this lecture, which was entitled 'God is Love', he was already observing that 'living means helping others to live'. The Second World War was a time of conversion for him: after being an intellectual, his battle now took shape. He no longer defended ideas; he defended men, above all those afflicted with leprosy. He made his life into a struggle to restore dignity to man; a struggle for charity.

There thus began the second part of his life which commenced with fund gathering for the building of the first village for leprosy patients, Adzopé, in the Ivory Coast, in response to a request made by the Sisters of Our Lady of the Apostles. From his first encounter with a leper in 1936 until his death in 1977, for his leper children, as he loved to call them, he went round the world thirty-three times offering service to them. Everywhere he was accompanied by his wife, Madeleine. On behalf of his children he appealed to the 'Great and Powerful' of the world, Presidents of the United States of America and of the Soviet Union, the Secretary General of the United Nations, and young people throughout the world. Above all else, he wanted people afflicted by leprosy, those people who had been excluded from society since the dawn of time, to be once again welcomed into those societies that had rejected them. This wish took practical form in the kiss that he gave to people with leprosy: he embraced them to restore human dignity to them, like St. Francis of Assisi before him, like St. Damian of Molokai, and like Pope Francis in Sardinia. This wish was also expressed in the first World Leprosy Day which was celebrated on the last Sunday of January 1954. A day of celebrations and joy, it still today brings together sick and handicapped people. In countries spared this scourge, it now represents for the sixty-third time a day of solidarity.

This today is the legacy of the Foundation of which I am the president. We want to continue with this legacy because it nourishes our future and our determination. We have a modern message that was bequeathed to us by Raoul Follereau; we must bequeath it in our turn because our world needs this message.

This commitment at the side of the excluded of our time, of those who are afflicted by 'leprosy and the other leprosies of ignorance and poverty', has brought us to Africa, to Asia and to Europe with over three hundred projects. This is a commitment that has four causes: integration through employment in France; help for the victims of the conflict in the Middle East; help for children; and help for those with leprosy.

It has been in the context of the fight against poverty that we have developed our support for integration through rural employment in France. In a context of lasting unemployment, situations of great precariousness have been increasingly numerous. Carrying on the Hour of the Poor that was launched by Raoul Follereau in 1942, we have accompanied almost five hundred people in re-acquiring their freedom and dignity through work. As regards the Middle East, our presence developed to begin with in the Lebanon through a large number of schools that were supported by our Foundation. But with the worsening of the situation in the Middle East we could not be indifferent to the suffering of uprooted people who were forced to abandon their homes in a condition of absolute poverty.

Our third cause – that of children – forms a part of a very special link that existed between Raoul Follereau and young people. He addressed many appeals to young people and they always answered 'present'. Since ignorance is one of the scourges of our world, and one of the leprosies condemned by Raoul Follereau, we have tirelessly followed in his footsteps.

We thus come to our fourth cause – that of helping people with leprosy. This is something that today is of especial interest to us. Raoul Follereau and the Foundation have taken part in all the relevant battles and in all of the advances of a medical, legal or human character. Thanks to the experience and the advice of its medical and scientific committee, the Foundation helped to develop the first effective treatment for leprosy, poly-chemotherapy, and to distribute it to all people with the disease, and has implemented national programmes which our medical consultant Dr. Johnson knows about extensively, thereby treating since the outset fourteen million patients. What fecundity this has been for Madeleine and Raoul Follereau: a couple that could not have children!

I will not dwell upon the advances of medicine that the Foundation has fostered since then – others will do this better than me. I will confine myself to citing the sequencing of the leprosy genome and the genome of Buruli ulcer achieved by Professor Cole, the current chairman of our medical and scientific committee, as well as the implementation in Mali of tests for a new potential treatment for this disease. In simple terms, at the heart of our activity, there is always the wish to raise man up, to restore to him the place that is his in society: a place that far too often, unfortunately, is taken from him by these diseases. We thus seek to go beyond the elimination of suffering or malady. This overall response involves access to hygiene, to health in general, but also to instruction, to formation and to an improvement in living conditions. This has led us to fight against the spread of neglected tropical diseases such as Buruli ulcer. All of this belongs to a process involving the development of the autonomy of patients who are cured and their reintegration into society, something that Dr. Chauty in Pobé, Benin, and Sister Dolores, who is present at this symposium, have been able to put into practice.

Raoul Follereau had the insight that this disease could not be defeated without a coordinated effort. For this reason he worked to create the ELEP (the European Federation of Anti-Leprosy Associations) which in the year 1975 became the ILEP (the International Federation of Anti-Leprosy Associations). In making the various actors of civil society work together to distribute countries amongst them so as to avoid the duplication of efforts, enabling thereby them to share successes and disappointments, the ILEP has been without doubt a decisive factor in pushing back leprosy throughout the world. This year is its fiftieth birthday and during this year we want to emphasise the effectiveness of this institution, which is one of a kind, in the fight against this disease, and I greet its president who is with us here today.

Together with the members of the ILEP, the Order of Malta, the World Health Organisation and naturally with all our partners on the ground, who are often religious Congregations, we have constructed a more just world. More just because patients can now obtain treatment and rediscover their social lives; more just because people in the world open their hearts and give their time or money so that we can accomplish our mission. But we know that the struggle is not yet over and we remain mobilised.

While His Holiness Pope Francis this year has invited us to explore Mercy, in particular through the practice of acts of charity, I would like here to recall some words of our founder. “But do not believe, above all and first of all, that giving some of our surplus, even if it is a small sacrifice, dispenses us from the duty of loving’. He wanted to warn us about the possible inclination to appropriate the poor, providing them with charity almost without thinking – automatically, only for our consciences. Almsgiving without the heart is counter-witness and an approach that is against charity itself.

Raoul Follereau also said that ‘Charity is not money. It is an act of love. Money is a means – amongst many others – to bear witness to this love. It is an instrument and nothing else’. ■

Speech of Mr. Narsappa

MR. VAGAVATHALI NARSAPPA
President,
Association of People
Affected by Leprosy,
India

Namaskar! I thank the Pontifical Council for Health Care Workers and the Nippon Foundation for arranging this symposium in support of a dignified life for leprosy-affected people who face discrimination on a daily basis. I thank you in the name of the Association of People Affected by Leprosy (APAL) and the many thousands of leprosy-affected people across our land.

As you will know, over half the number of new cases of leprosy reported worldwide occur in India. In many places you will still find leprosy-affected persons segregated from their families and the community. This is because of lack of knowledge and misconceptions about the disease. Rejected by society, they live as outcasts in leprosy settlements, colonies, Ashrams, sanatoria or rehabilitation homes.

I come from a remote village in Karnataka, South India and I developed leprosy when I was nine. It was a huge crisis for my family and the local community. The village elders declared that I could not remain in the village. My family was ordered to send me away. I became an outcast. My father took me to a leprosy hospital in Andhra Pradesh and left me. I felt entirely alone during the two years of treatment. In the process, I lost my fingers.

After I was discharged, I went home. But my family would not take me back. Rejected by my family, I realised that my true family was other people affected by leprosy. I went to live in a rehabilitation home where I also did my schooling. In order to take my exams, I had to go to the government school. They made me sit outside in the hot sun. I felt the heat and I felt the discrimination.

Later, my life changed for the better. I was educated and trained by the home as a medical assistant. I met Ms.Nirmala who came to the home for treatment. We got married. My wife and two daughters have since given me great support and inspiration in my work for the rights of people affected by leprosy.

I travelled across my State and began to understand the needs of people living in leprosy colonies – for education, sustainable livelihoods and basic infrastructure. Some were denied ownership of land. Some children were refused admission to schools. They are not aware of government schemes and benefits. I recognised that people faced discrimination but could not get their voices heard.

I decided to do something to change this situation – so I started the Society of Leprosy Affected Persons (SLAP) involving more than 20,000 people in more than 90 leprosy colonies in my State, Andhra Pradesh, with the support of many friends among leprosy-affected people. It was the first platform in the State to fight for the rights of people affected by leprosy. Politicians began to take notice.

Now I am president of the Association of People Affected by Leprosy – APAL– which covers 800 leprosy colonies in India and unites affected people in different parts of the country. We work for socio-economic empowerment, promote respect and dignity, and educate our community about government schemes and benefits. We have much work to do.

I am honoured to be here at the Vatican representing people affected by leprosy in India. We humbly look to His Holiness the Pope for his blessings and support in helping to end the stigma and discrimination that people affected by leprosy and their family members face, so that we may live in this world with dignity.

Thank you all for your understanding and support. ■

PROLUSION

Care for People with Leprosy: a History of Mercy and Holiness

HIS EMINENCE CARDINAL ROBERT SARAH
Prefect of the Congregation for Divine Worship and the Discipline of the Sacraments, the Holy See

I wish to begin this paper of mine by referring to an example in history that took place in France in the year 1321 and which indicates the climate that has often been created around leprosy. Strange rumours began to circulate in that year. Hundreds of lepers who lived in public refuges had organised a plot: they were going to poison wells, fountains and rivers in order to infect the people of France with leprosy and thus seize power and take over the kingdom. The hysteria generated by the discovery of this imaginary plot led Philip V (1317-22) to promulgate an edict in Poitiers against lepers. A series of trials were immediately begun. Lepers were interrogated and tortured and those presumed to be guilty were immediately sent to the stake. These included men and women. The persecution of the lepers ended with an authentic massacre. In addition to the workings of the judicial system, some people, overcome by terror, independently engaged in the summary execution of entire families.

This episode was symptomatic of a climate that has always surrounded – as far back as *Biblical times* – the disease of leprosy, a bacteriological malady that takes various forms and has different consequences (ulcerations, the degeneration of nerves, a decrease in sensitivity and in movement of the muscles, paralysis). It should be remembered, first of all, that whereas for us the term 'leprosy' (in Hebrew '*zara'at*' and in ancient Greek '*lepra*') refers to classic leprosy (the bacillus of which was discovered by Hansen in 1871), for the Bible it covered a broad series of afflictions and diseases of the skin: mycosis, psoriasis, leukoderma, leukoplakia, dermatosis, eczema, etc.[1] In essential terms, these were maladies that were highlighted on the skin and became a sort of visible brand not only of the malady itself but also of the shame connected with it.[2] Indeed, for the Bible leprosy was a divine punishment that punished people for sins that had been committed. The Egyptians were struck by it (Ex 9:9ff); Mary, the sister of Moses, became a leper following her sin of defamation (Nm 12:1-10); and the same happened to Uzziah (2 Chr 26:19-23). David invoked leprosy on the house of Joab as a punishment for the murder that he had committed (2Sam 3:29). In Deuteronomy 28:25-27, Israel itself was threatened by this disease given that leprosy was listed amongst the maledictions visited on the People of God if it did not obey His voice. Leprosy was thus the quintessential scourge that God inflicted (*vaga*') on sinners. It was, therefore, to begin with, a sign of sin.

For the Torah, in addition, leprosy is also a contagious impurity and thus a leper should be excluded from the community until his or her cure and ritual purification. This last requires a sacrifice for the sin that has been committed. This is because it was thought that there was a very close connection between leprosy and personal guilt. The laws of the Torah on leprosy are to be found in Leviticus 13-14. The Lord when addressing Moses and Aaron explains the manifestations of leprosy and the way in which a priest has to judge whether the disease exists. The text ends in the following way: 'he is unclean; he shall dwell alone in a habitation outside the camp' (Leviticus 13:46). This verse is further explained in the commandment given to Moses: 'Command the people of Israel that they put out of the camp every leper…you shall put out both male and female, putting them outside the camp, that they may not defile their camp, in the midst of which I dwell' (Numbers 5:2). As one can well see, leprosy involved exclusion from the community. A priest had the task of judging whether it was present and it was constantly associated with the idea of a divine punishment for sins that had been committed. In these texts, furthermore, the idea is also sustained that to promote the worship of YHWH the physical integrity of a person was indispensable and this was something that lepers did not possess. As a consequence, they were forced to live outside the city, to wear rags, and to have long hair and unkempt beards.[3] Even objects, homes and clothes were held to be capable of infection and thus protective legislation was required.[4] The priest was the person who had to ascertain the presence of the disease. If he thought that the person had leprosy, the stage of isolation was immediately begun whereas when there was a doubt he or she was placed in quarantine for a week or two before establishing whether he or she had to be isolated and purified or otherwise.[5] The purification envisaged a rite with two aspects: purification against the forces of evil (the disease was seen as a demon that had to be exorcised) and sacrificial rites.[6]

As can be seen, the leper, in addition to the suffering caused by the disease, also suffered pain and shame because of the guilt involved – his or her leprosy declared publicly that he or she was a sinner and had been struck down by God. He or she was not only a victim of the disease – he or she was also guilty! Leviticus declares that 'The leper who has the disease shall wear torn clothes and let the hair of his head hang loose, and he shall cover his upper lip and cry, 'Unclean, unclean'' (Lev 13:45). A leper generated fear – he or she could infect other people and was thus abandoned by his or her family, avoided by other people and marginalised. He or she was expelled from society and forced to live in places distant from inhabited centres. Normally a leper lived in caves or huts and feeding him or her was entrusted to the charity of relatives or merciful people who brought food and clothes to those places, always remaining, however, at a good distance from those who had been infected. Relationships with a leper were prohibited and he or she was afflicted in all relational areas. Expelled from his or her family, every contact with him or her was taboo. Distanced from society, from work, from participation in the life of the village and communal activities, a leper was adjudged a sinner and held to be guilty, and excluded from the cultural life of the people. To sum up, because for the Bible life is relationships, a leper, whose relationships were compromised or prohibited, was one of the living dead. He or she, the Book of Numbers declares, was like one whose father spat in his face (Num 12:14). In definitive terms, for the Bible leprosy constituted the utmost social and personal disqualification.

To bring matters up to the present day, we may think of cases of people who are HIV-positive. Perhaps AIDS constitutes a good contemporary and pregnant parallel with the situation of lepers in antiquity. In both cases the belief is that a terrible disease is caused by a sin. A regards those who had AIDS, in the majority of cases it was a sign that they had had a disordered life and at least at the beginning of this terrible epidemic people were wary about coming into contact with individuals who were HIV-positive. As ignorance about the disease diminished, things, however, improved. There was the same approach to lepers as to AIDS patients: one had to keep clear of them because they were highly infectious and sinners.

However in the *Old Testament* there is a text which should make us reflect a great deal. The suffering servant is afflicted by God and people draw away from him as though he were a leper. However innocent he may be, he bears the sins of men who will be healed because of his wounds (Is 53:3-12; cf. Ps 73:14). With this text we come to *Jesus* who, when *he heals lepers* (Mt 8:1-4 par.; Lk 17:11-19), is shown to be the one who triumphs over the scourge to the utmost; he heals these men and takes their illnesses upon himself. (Mt 8:17). In purifying lepers and reintegrating them into the community, Jesus abolishes the separation of the pure from the impure. The offerings laid down by the law are still prescribed and this is done in order to provide testimony: the priests in this way will observe his respect for the law, and his miraculous power, at one and the same time. But in reality Jesus is the new temple and the new priest. This is why the Samaritan leper who is healed by Jesus in Luke 17 does not go to the priests of the temple but goes back to Jesus to thank him because by now he recognises that he is the true Temple and the true priest. This is what the nine Jewish lepers healed by Jesus do not do. Their failure to go back and thank he who had healed them becomes a tragic prophecy of what would happen a little time later when Israel does not recognise its Messiah; indeed, will reject him in Jerusalem, having thereafter to listen to foreigners proclaiming his messianic salvation.

The healing of lepers, together with the other healings, is therefore a sign that Jesus is really 'he who has to come'. Indeed, such healing is classified and offered as a messianic sign of Jesus for the disciples of John the Baptist (Mt 11:5 and Lk 7:22). The same takes place in other accounts of healings (Mt 8:1-4; Mk 1:40-45; Lk 5:12-16; L 17:11-19)[7] where Jesus is portrayed as the Holy One of God who breaks the cultural mould and reintegrates lepers into the human community with love. In the various accounts of healing that make up the gospels, the lepers always stop at a distance and say in a loud voice "Jesus, teacher, have pity on us!". They stop at a distance because according to the law they are impure and therefore they have to live on their own, outside the camp, without being able to enter into contact with other people. They stop at a distance and shout out so as not to contaminate anyone; they feel that they are impure, guilty and sinners. The only acts of kindness that they receive is from good men who leave them food at a good distance. But the lepers of the gospel are also a little special. They shout out: "Jesus, teacher, have pity on us!" Whereas the first thing they should have shouted out according to Leviticus 13:45 is "Unclean! Unclean! (that is to say Impure! Impure!), and this is perhaps a sign that they already had a certain knowledge of Jesus. They knew that he was an *epistatês* (a man who watches over sheep and takes care of them.[8] This is a term peculiar to the Gospel of Luke that is always used in the vocative to ask for care).

In the passage of Luke 5:12-16, as well, the leper, when coming to the city, seems to be disobeying the ritual law and to be plucking up courage. And Jesus responds to his presence by touching him, that is to say by entering into contact with his impurity and healing him – this is an action that indicates Christ's care and concern, goodness and power.[9] Mt 8:1-4 and Mk 1:40-45 present two episodes that involve the healing of lepers where it is once again evident that Christ enters into contact with their impurity without any fear (in *Mark*, indeed, the leper asks to be declared to be pure by Jesus, a decision that is the task of a priest – a sign that by now that leper recognises Jesus as being the true priest). However, the Lord ask them to go to the temple, that is to say to respect the cultural laws envisaged in cases of healing.[10] Jesus is therefore he who 'saves from illness and reintegrates people into the human consortium. In him it is possible to rediscover the fullness of human wholeness'.[11] It is interesting to observe how Jesus in his relationships with lepers is always seized by a movement of great compassion: he allows himself to be wounded by the suffering of the sick person and enters fully into that person's situation. He touches the leper and in this way he not only runs the risk of being infected but he himself becomes contaminated – contracting at the same time ritual impurity, that impurity that excludes a person from taking part in cultural gestures. Jesus the Holy One of God breaks the barriers that separate the pure from the impure and reintegrates the lepers into the human consortium. But this exclusion is the price to pay for going up to an excluded man and tearing him away from his mortal solitude. And Jesus is not afraid of being contaminated. Charity is never innocent – it contaminates and it compromises. The man whom nobody could touch, or wanted to touch anymore, finally feels touched by somebody. And this contact is affective language which transmits the sense of a friendly presence. That skin which no one had touched for a very long time now returns to the circuit of relationships. The skin is not only the most extensive organ of the human body: it is also a place of experiencing, and interchange with, the world.

The fact that Jesus touches lepers (with them Jesus almost never performs miracles at a distance) means that they can return to contact with themselves and with other people; that their situation of isolation is about to finish. The encounter with Jesus and with this impairment of their sense of touch helps the leper to welcome himself and to look at himself with new eyes. The healing advances with giant strides. But at a heavy price as well. Now, indeed, it is Jesus who finds himself in the situation of being a leper, as Mk 1:45 observes: 'Jesus could no longer openly enter a town, but was out in the country'. Jesus has taken upon himself the suffering of the leper; he has contracted impurity in his place and can no longer enter the villages. In this way, Jesus truly emerges as the suffering Servant who has taken on, and borne, our illnesses and infirmities. It is no accident that the text of Is 53:4, to which reference has already been made in this paper, in the Latin text of the Vulgate speaks about the suffering Servant as a leper: *'Nos putavimus eum quasi leprosum'* ('We consider him on a par with a leper').

As one can see, *leprosy has had a strong impact on social reality* and has generated a very powerful approach at the level of the imagination which has sanctioned terrible forms of behaviour that involve separation. During the *medieval* period, the laws of a state followed, from many points of view, the Biblical model: total exclusion because a leper was 'like a dead man'. The greatest diffusion of this disease during the medieval period took place between the end of the eleventh century and the fourteenth century. This was a period when lepers, on a par with heretics, witches and Jews, were made the targets of systematic and ferocious persecution. The third Lateran Council of 1179 decreed that all lepers should be segregated from the rest of society and that churches, with their own cemeteries, should be created exclusively for lepers. At the fourth Lateran Council of 1215 it was established that lepers, like Jews, had to be made recognisable to the community by wearing special clothes. Other signs of recognition were a yellow star sown onto their clothes, a bell that they wore around their necks, and a characteristic stick that was used to indicate what they wanted to purchase. The segregation of, and discrimination against, lepers fostered the proliferation in the whole of western Europe of places for the reclusion of lepers outside the walls of the cities, the so-called leper colonies, institutions which usually had six to twelve lepers in them. Roundabout the year 1220 there were at least 19,000 leper colonies in Europe.

It was in this context of great exclusion of lepers that *Francis of Assisi* made himself the agent of a gesture which for that epoch was scandalous. We are told about it by the *Legend of the Three Companions*: 'Francis, while one day he was riding in the area around Assisi, met a leper on the road. He usually felt overwhelming repugnance for these unfortunate people. But this time, engaging in violence against his own instincts, he dismounted from his horse and offered money to the leper, kissing him on the hand. And after receiving from him a kiss of peace, he mounted his horse and continued on his way. From that day onwards, he began to separate himself from his own selfishness, to the point of knowing how to overcome himself, perfectly, with the help of God. After a few days had passed, he took money with him and went to the leper colony. He gathered them together and gave alms to each one of them, kissing them on the hand. On his return, that contact which beforehand had been repellent, that is to say seeing and touching the lepers, was truly transformed in him into tenderness. He himself made clear in private that looking at lepers had been so unpleasant that not only did he refuse to see them but he could not even bear to draw near to their dwellings. It happened that when he passed near to their homes or saw one of them, although compassion stimulated in him almsgiving by way of another person, he always turned his head the other way and held his nose. But by the grace of God he became a companion and friend to the lepers, so that, as he himself stated in his Testament, he spent time amongst them and served them humbly'.

Starting in the middle of the fourteenth century, leprosy gradually disappeared from the map of Europe and this movement went from the South to the North of the continent. But leprosy continued to remain an endemic problem in the South of the world, at last until the nineteenth century. A very famous episode here is the case of the King of Hawaii, Kamehameha, who at the end of the nineteenth century, conforming to the Western model of exclusion, decreed the need for a rigid policy of segregation and established a concentration camp for lepers on the Island of Molokai. Surrounded on three sides by the sea and separated from the rest of the island by a gorge, a strip of the Island of Molokai was thus transformed into a leper colony which the lepers could not escape from and in which the living conditions (food, hygiene and health care) were at the limit of what was human. The natives of the place considered leprosy to be an incurable illness and this was why segregation in the camp was equivalent to a sentence to life imprisonment. But it was precisely to Molokai that a Belgian priest who belonged to the Congregation of the Sacred Hearts, *Father Damian de Veuster*, decided to go and live. To read the history of this priest, who was proclaimed a saint by Benedict XVI on 11 October 2009, is balsam for the soul. Father Damian landed at the 'colony of death' of Molokai in the year 1870 and found in front of him an incredible spectacle of dirt and degradation. He was thirty years' old and began to care for the lepers there, building huts, schools, farms, a church, refectories, orphanages and dormitories. From being an open-air living cemetery, Molokai became an exemplary town where the lepers began to live not as rejects but as human persons who worked, prayed and led dignified lives. After eighteen years of direct contact with these sick people, Father Damian himself fell ill and died of leprosy in the year 1889, at the age of forty-eight.

Father Damian, however, was one of many Christian missionaries who associated care for lepers with the goal of evangelisation. Care for lepers, indeed, following the gospel example of Jesus, was seen as one of the highest expressions of Christian charity. Thus it was that given the lack of sufficient medical personnel, many religious took care of these sick people, uniting the figure of the evangelising priest with that of a person who cares for the sick.

Mother Teresa of Calcutta deserves a special mention. Her love and care for lepers constitutes one of the greatest examples that this extraordinary woman bequeathed to our century. Unfortunately, we do not have enough time here to speak about her but you all know that she will shortly be proclaimed a saint – significantly enough during the Holy Year of Mercy. Just as we are also obliged to make only one reference to the great apostle of lepers of the last century – *Raoul Follereau*. A brilliant journalist of *La Nation*, in 1935 Follereau was in Africa to write a piece on Charles de Foucald when, while he was on a safari, his jeep broke down near a pond. Forced to stop, he saw coming out of the forest a group of lepers with their bodes destroyed and fear on their faces. They looked at him and they asked him for food because they were dying of hunger. This was an encounter that changed his life. Follereau went back to France and decided to help his 'buried alive' lepers, but because of the war and the persecution of Hitler, against whom he had written violent articles, he was forced to hide in a religious house in Lyons. The strong words of Mother Eugenia, the Superior General of the Missionary Sisters of Our Lady of the Apostles, who had been greatly shaken to see a leper colony near to the lagoon of Abidjan in the Ivory Coast, shook him out of his fear and made him leave his hiding place. Follereau began to go round France and Europe, Asia and America, to speak about the problem and collect funds. Over about thirty years of activity, Raoul Follereau travelled millions of miles, collected millions of dollars, and managed to cure a million people who had contracted leprosy.

At the present time, leprosy has been eliminated in Western countries but it remains a problem of public health care in many countries in Africa, South and South-East Asia, and South America. In 1985 there were still ten million lepers in the world. But thanks to the results achieved by the LEP (the 'Leprosy Elimination Programme') sponsored by the World Health Organisation, the number of recorded victims of this disease has fallen dramatically. The latest survey of the WHO, of January 1999, limited the number of people suffering from leprosy to 800,000.

Unfortunately, there persists, still today, the ancient stigma of being a leper and its consequent forms of behaviour at a social and health-care level. Right up until the end of the twentieth century people afflicted by leprosy were the victims of social exclusion, with the loss of their jobs and their distancing from their families and communities, to the point of being compelled to be shut up in leper colonies. For many people belonging to populations afflicted by leprosy, the moral stigma and the practices that involve social exclusion belong to a background that it is still difficult to eliminate. Paradoxically, today it is easier to eliminate the disease than it is to eliminate the social prejudice that still surrounds this disease, to which Christ in person, and some very great saints such as Francis of Assisi, Father Damian and Mother Teresa of Calcutta, dedicated special attention, fighting against both the physical signs of this malady and the terrible fears and ideas with which leprosy has always been connected.

And this is the teaching of Jesus: we should generate encounter with the other in order to bring to everyone the possibility of knowing God, of having an experience of God, through His person. It was Jesus himself, who through his incarnation, came amongst us to save and to purify those who are sick. Pope Francis has said on a number of occasions that charity, love of God, is to touch in suffering people the flesh of the suffering Christ. This seems to me to be a very fine image with which to begin to reflect together on the relationship between illness and salvation. ■

Notes

[1] Cf. J.L. McKenzie, *Dizionario Biblico* (B. Maggioni ed.) (Cittadella, Assisi), p. 536; Aa.Vv., *Nuovo Grande Commentario Biblico* (R.S. Brown, J.J. Fitzmyer, R.E. Murphy, eds.) (Queriniana, Brescia, 1997), pp. 90, 782.

[2] X. Léon-Dufour, *Dizionario del Nuovo Testamento* (Queriniana, Brescia, 1978) p. 325, defines leprosy as a term which, in addition to the disease which bears this name, refers to various kinds of afflictions of the skin which involved such a legal impurity that the person was excluded from the community.

[3] Cf. Aa.Vv., *Nuovo Grande Commentario Biblico* (R.S. Brown, J.J. Fitzmyer, R.E. Murphy, eds.) (Queriniana, Brescia, 1997), p. 90.

[4] Cf. *Ibidem*.

[5] Cf. *Ibidem*.

[6] Cf. *Ibidem*.

[7] Cf. *Ibidem*.

[8] G. Kittel, *Theological Dictionary of The New Testament*, vol. II, Michigan; WM. B. Eerdmans Publishing Company, Grand Rapids).

[9] Cf. *Ibid*., pp. 902-903.

[10] Cf. *Ibid*., pp. 782-783.

[11] *Ibid*., p. 925.

Hansen's Disease: Epidemiological Data and Future Scenarios

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Part 1: Epidemiological Data

Prevalence, prevalence rates and trends in prevalence

Dr. Cooreman first described the disease burden of leprosy in terms of "registered prevalence". This means the number of patients on treatment at any given point of time. The World Health Organization typically requests countries to count this number at the end of each year. This indicator may reflect the true number of cases in a particular setting, especially when a strong control program is in place. However, in other settings, there is a gross underestimate of the true burden, with many cases remaining hidden and untreated.

Worldwide there were almost 175,000 patients on treatment at the end of 2014, which corresponds to a rate of 0.24 per 10,000 population. The highest burden was found in the South-East Asia Region,[1] which accounted for more than two-thirds of the global burden. Countries in Europe did not report to the World Health Organization. It is believed that leprosy is a rare disease in this region. The number of patients on treatment is likely underestimated as some countries in Africa and Latin America did not submit reports. From previous reports, we know that these countries have a significant number of undiagnosed (and therefore unreported) cases as well as cases on treatment but not reported.

The World Health Assembly had passed a resolution in 1991 calling for elimination of leprosy. This did not mean zero leprosy. It was defined as less than one case per 10,000 population under treatment and was a benchmark for considering leprosy as no longer being a public health problem. This target has been reached at national level by all countries, except for three small Pacific Island countries, the Comoros islands and South Sudan.

The focus now is on reaching elimination at sub-national level (state, province, district, etc.).

Between 1985 and 2000, we notice a 90% decline in registered prevalence. This is explained by the introduction of multidrug therapy or MDT, which allowed to shorten treatment. Prior to this, monotherapy with dapsone was given, usually lifelong. With MDT which includes dapsone, rifampicin and clofazimin (the latter drug only for the multibacillary cases), treatment was shortened to two years, later to one year and to six months for paucibacillary cases. A six-month uniform treatment with three drugs is now being evaluated for all patients, irrespective of their bacillary load. If proven safe, it is expected that this will further improve programme management: a shorter regimen enhances treatment compliance while a uniform regimen makes classification of patients redundant. Once patients complete the prescribed treatment, they appear no longer in the treatment register and are thus no longer included in the prevalence, from there the decline.

It could also be that the number of new cases of Hansen's Disease has reduced during the same period. This is likely the case in some countries but cannot explain this major decline globally.

Incidence, incidence rates and trends in incidence

The number of new leprosy cases detected is a proxy indicator for incidence or the number of people who develop the disease during a particular period. In well-functioning programs, this indicator may provide a good measure for the true incidence, though there are settings where new cases are not immediately picked up by the health systems and remain undetected, showing an artificially low case notification. The case notification will not reflect the reality when diagnosed cases are not reported (e.g. in some private clinics) or when a patient is registered more than once, in which case there will be an inflation in the case notification.

During 2014, almost 214,000 new cases were notified to the World Health Organization. Compared to flu or diarrhea, this number is small. In Hansen's Disease, even small numbers are considered significant for two reasons: firstly, we aim to remove the disease from this world and hope that future new cases will be less and less; secondly, leprosy carries in many countries a big social stigma and thus every new case is not merely a disease but a person who may be ostracized from his or her community. From this angle, every new case is one case too much.

The highest burden is again borne by the South-East Asia Region (especially India and Indonesia) with over 150,000 new cases in 2014, corresponding to 8.3 per 100,000 population. This is followed by Americas where Brazil accounts for 90% of the regional burden. The numbers are much lower in the Eastern Mediterranean and Western Pacific Regions.

The global leprosy burden is not uniformly distributed but concentrated in only a few countries. Three countries constitute "Group A" and contributed 81% of the new cases worldwide in 2014. These countries are India (more than 125,000 new cases), Brazil with more than 30,000 new cases and Indonesia, reporting 17,000 new cases.

Countries in "Group B" reported between 1000 and 10,000 new cases annually and included Bangladesh, Myanmar, Nepal, Philippines and Sri Lanka in Asia; and the Democratic Republic of the Congo, Ethiopia, Madagascar, Nigeria and the United Republic of Tanzania in Africa. Mozambique reported more than 1000 new cases in previous years but did not submit a report to the World Health Organization in 2014. This second group of countries collectively contributed 12% of the global burden.

Group C consists of 83 countries that reported at least one case.

The above-mentioned grouping of countries is based on absolute numbers of new cases notified, which highlights immediately where the highest disease burden is located. However, this gives less information about the intensity of transmission. Notification rates – new cases per 100,000 population – are a better measure for transmission. The highest case detection rates are found in the Comoros islands (and especially in Anjouan island) and three Pacific Island countries (the Federated States of Micronesia, Kiribati and the Marshall Islands). These countries have small populations (a few hundred thousands) but report between 100 and 250 new cases each. When we examine the details more carefully, these countries have relatively more children and more paucibacillary cases, both pointing towards intense ongoing transmission.

High rates are also found within other high burden countries such as in India, Brazil, Indonesia and sub-Saharan African countries.

The trend in notifications of new cases during the last decade shows a very striking feature: a dramatic and sudden decline in new case detection of over 60% over a short period of time (2001–2005). Understanding the possible explanations for this dramatic fall is very important. One explanation is that this represents a true fall in the incidence of leprosy following reduction in transmission of *Mycobacterium leprae* infection. Disease modeling work has suggested that the long-term underlying trend in leprosy incidence in a good scenario including infant immunization with *bacille Calmette-Guérin* is a slow, gradual decline of around 4.5% per year. A large, sudden fall in transmission seems biologically implausible given the long and variable incubation period in leprosy and the evidence of continuing, significant rates of new cases in children. A second explanation is that there was substantial overdiagnosis of leprosy prior to 2001, which has inflated the previous levels of new case detection. This may be a factor to explain the peak of new case detection between 1996 and 2001, a period of intensified case detection activities, when intensive leprosy elimination campaigns were implemented. However, the new case detection trends between 1985 and 1996 are remarkably stable and sustained overdiagnosis seems unlikely over this period. The third and most probable explanation is that the dramatic fall in new case detection is a result of a decline in leprosy activities following the declaration of elimination as a public health problem globally, and in individual countries. This decline resulted in several countries in a reduced intensity and coverage of case detection activities, community awareness, and training in the diagnosis and treatment of leprosy often associated with the move from vertical leprosy control activities to integrated approaches. The recent rise in disability in new cases detected and the increasing delay in diagnosis reported by many countries supports this explanation.

A country example from Indonesia was provided of long-term trends in number of patients on treatment (proxy for prevalence) and new cases detected (proxy for incidence). The fall in prevalence was completely attributable to the introduction of MDT and shortening of the duration of treatment. The number of new cases did not change dramatically during the same time period. A slight increase in absolute number of new cases was even observed, though the almost doubling of the country's population during this time period also has to be taken into account. While elimination as a public health problem was achieved around the year 2000, it should be clear that this does not mean that the leprosy problem is solved. At the community level, the leprosy burden is constituted by the number of new cases as well as old cases that we call cured but that live with irreversible deformities.

Another (regional) example was given from the Western-Pacific Region. This region includes countries such as China, Viet Nam and the Philippines. During the period 1990-2014 showed a trend that was very consistent with the natural evolution of the epidemic, accelerated by sound control programmes and economic growth. There was a decline of about 6% per year, pretty consistent over the past 25 years.

Part 2:
Global Leprosy Strategy 2016-2020

Development of the Global Leprosy Strategy

The Global Leprosy Strategy 2016-2020 was built on the rich experience and contributions of many actors. It is a logical next phase after the three most recent strategies, each encompassing a period of five years: (1) the Final Push Strategy for the Elimination of Leprosy, 2000-2005; (2) the Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities, 2006-2010; and (3) the Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy, 2011-2015. It also builds on the Roadmap to address neglected tropical diseases (2012-2020).

The process to develop the current strategy took one and a half years and included multiple consultations rounds with national program managers, partners and representatives from affected communities. Though the development took a long time, the fact that many stakeholders were involved and took ownership will let us hope that the strategy will be more easily accepted and implemented.

The World Health Organization had received a grant from The Nippon Foundation, which allowed the Organizations to organize the consultations and develop the strategy.

The Global Leprosy Strategy is not a mere strategy of the World Health Organization or a country strategy or a strategy of a non-governmental organization or a donor. It is all of these. It is comprehensive and inclusive and aims to cover all important aspects of leprosy control in today's world. It expands approaches with proven success and introduces innovative actions.

Though the main focus is on high burden countries, in order to have maximum impact globally, other contexts are also considered. Leprosy is not uniformly distributed across and even within countries: there are hot spots in countries reporting few cases while there are also silent zones in countries still reporting a large number of cases.

The strategy is linked to the broader context in health and development, including the agenda of universal health coverage and the sustainable development goals. Leprosy control does not only contribute to Sustainable Development Goal 3 (related to health and well-being) but to a variable extent also to other goals such as poverty reduction, gender equality, decent work and economic growth, reduced inequalities, peace and justice and partnerships.

Vision, goal and targets

The vision is a leprosy-free world. It is a long standing dream of a world without Hansen's Disease, without transmission of infection or disabilities due to leprosy, a world without stigma and discrimination linked to leprosy. While one would wish this to be realized soon, this will unlikely happen before the end date (2020) of the current strategy.

A realistic goal has been agreed to further reduce the global as well as local leprosy burden and go for elimination at sub-national levels. The Operational Guidelines that accompany the Global Leprosy Strategy contains a list of indicators that further elaborate this goal.

Three principal targets have been singled out of the many targets. The first one is zero children with leprosy and visible deformities by 2020. It is a shame that in the twenty-first century children are still diagnosed with leprosy and deformities. This reflects our collective failure of not detecting these children early as most of them are contacts of known leprosy cases. Addressing it requires cutting the transmission in household settings. The second target is to reduce the rate of newly diagnosed leprosy cases with deformities to less than one per million population. And the third target focuses especially on the human aspect of leprosy by aiming for a repeal of all laws worldwide that provide a legal cover for discrimination of leprosy patients. While such laws may already have been repealed or become obsolete in many countries, there are still instances where leprosy patients are divorced, loose their job or are deprived of an inheritance, only because they are diagnosed with a curable disease.

Guiding principles

While developing the strategy, five principles were identified that are underpinning the strategy components and are of cross-cutting nature.

National governments have a key role to play. This is because targeting a disease of elimination requires a nationwide coverage sustained over a long time period. While partnerships with other actors in the field are of utmost importance, elimination cannot be dependent on time-bound or geographically-limited projects.

There is the need to sustain leprosy expertise in a context of a dwindling number of leprosy experts and challenges of becoming acquainted with leprosy with less cases around.

Any service for leprosy should be of good quality and also take care of children and other vulnerable populations. This includes also availability of anti-leprosy drugs. Novartis has committed to donate MDT for all patients worldwide till at least 2020.

Persons affected by leprosy should be involved in all stages of the strategy development and subsequent implementation. They are not just mere recipients of services but, having gone through or coping with the disease, know better than anybody else what is needed.

Lastly, the protection of basic human rights, reduction of social stigma and restoration of dignity of leprosy affected people has received a prominent role in the Global Leprosy Strategy.

Pillars and components

The Global Leprosy Strategy is centered around three strategy pillars, each with a set of components. There is an overarching pillar, linked to governance, stewardship and overall program management, which should be led by a national government entity, in collaboration with partners based on comparative advantage. Government buy-in is necessary in order to cover entire countries territories and populations for many years to come. The second pillar is the more medical pillar, focusing on interrupting transmission of leprosy and averting or addressing complications. The third pillar focuses on stopping discrimination and promoting inclusions of persons and communities affected by leprosy.

The first pillar is overarching and linked to governance and programme development. It encompasses:

– Ensuring political commitment and adequate resources for leprosy programmes: funding, human resources, drugs, guidelines, etc.

– Contributing to Universal Health Care with a special focus on children, women and underserved populations including migrants and displaced people. Leprosy is known to disproportionately affect marginalized populations.

– Promoting partnerships with non-state actors and promoting intersectoral collaboration and partnerships at international level and within countries. This refers not only to the traditional leprosy agencies but also other community-based organizations or agencies in other sectors such as the press, lawyers, maybe some private companies interested in developing corporate social responsibility schemes for leprosy, etc.

– Conducting basic and operational research on all aspects of leprosy and maximizing the evidence base to inform policies, strategies and activities. Though leprosy is an age-old disease, there are still many fundamental questions unanswered, e.g. can infected people (without the disease) transmit the infection? Is resistance against the drugs spreading?

– Strengthening surveillance and health information systems for program monitoring and evaluation. This will become even more important when leprosy becomes a more rare disease.

The word that summarizes this first pillar is "accountability". The leprosy community (in the broad sense) will be held accountable for achieving what the Global Leprosy Strategy aims to. Five years from now, there should be a significant further reduction in burden.

The second pillar focuses mostly on the medical and control aspects of Hansen's Disease and is the traditional domain of national leprosy programs. Most components are linked to case detection and management. Important is the renewed emphasis on case finding.

An increase in awareness in the community about the signs and symptoms of Hansen's Disease, importance of early detection (before deformities occur), treatment and curability should prompt patients to seek care earlier and reduce stigma. In leprosy, early detection and passive detection, i.e. waiting till patients self-report, are pretty contradictory. Some forms of active case detection have to be pursued. While campaigns were regularly organized many years ago, this had become taboo with integration, assuming that all patients would self-report in a decentralized and integrated setting. This assumption did not come true in many settings. Especially in areas of known high endemicity, some forms of campaigns should again be undertaken. How this is done, through skin camps, door-to-door surveys, or combined with other diseases or other campaigns, is to be decided based on the local situation. Campaigns are generally very labour intensive and costly. They should thus be judiciously designed. Checking family or social contacts of known leprosy patients should yield more new cases than examining general community members, especially in lower burden countries, where almost all cases can identify an index case in the family.

Following diagnosis it is important that treatment is promptly started to reduce the duration of infectiousness and also to improve adherence since many patients do get lost while waiting for treatment. The current treatment regimens, lasting for six or twelve months, are being reviewed with the possibility of adopting a uniform regimen of six months for all forms of leprosy. While resistance in leprosy has been documented, it is a very small problem. However, vigilance is required and capacity must be built for monitoring resistance against anti-leprosy drugs.

While leprosy experts are getting older and are insufficiently replaced, opportunities should be availed of introducing new methods and technologies for transferring the knowledge and skills to the next generation of health service providers. New methodologies including e-health or mobile apps can provide sustainable avenues.

Prompt diagnosis and early treatment is considered as the principal way of preventing leprosy. However, prophylactic treatment and maybe immunotherapy may also be useful in preventing breakdown of disease in infected people. This is an area still under study but that has the potential of becoming a game-changer in global leprosy control.

The second pillar can best be summarized in one word: "Action".

The third pillar is entirely devoted to the human, social and economic aspects relevant for leprosy. This is crucially important, more than for any other disease, as it is exactly the stigma associated with leprosy that hinders effective control of the disease. Hence, this piece of work has been elevated to a full pillar of the strategy.

There are two important aspects underpinning this pillar: eliminating stigma and promoting inclusion. While addressing stigma and its underlying causes is important, it was felt that this is not sufficient. A pro-active approach is required to restore the dignity of affected persons and communities.

This pillar includes all activities related to participation of affected people in leprosy services, including policy formulation, planning service delivery and evaluation. The mantra is "nothing for leprosy affected persons without them". The strategy aims to build bridges, coalitions with affected people and communities and abandon the practice of segregating them. This includes social rehabilitation particularly for those who are otherwise most negatively affected. It is paramount that abolishing laws that sanction state-based discrimination are repealed, but also that steps to positively advance the role of leprosy affected people in society are promoted.

This pillar may not be the immediate responsibility of ministries of health. But it is important that national leprosy programs understand the importance of this pillar and play a role of advocates with the relevant ministries as well as with partners who may be much better placed to take the lead in implementing necessary activities under this pillar.

This third pillar can be summarized in the word "inclusion".

A bicycle was unanimously chosen as logo for the Global Leprosy Strategy and will also be used for other documents that will be published linked to this. The bicycle has three main features: two wheels, which represent pillars 2 and 3 (the medical and social arms of the strategy) and the frame, representing pillar 1, which holds the two other pillars together and is the frame on which the other two pillars are anchored.

Part 3: Conclusion

The future of leprosy control looks very positive from epidemiological viewpoint. We are at a crossroad where disappearance of a dreadful disease is not a utopia but a realistic goal for the next generations.

The current downward secular trend is likely to continue. Appropriate interventions can accelerate this trend. Transmission of the leprosy bacillus has halted in many countries and can stop in the remaining hot spots. This should first be visible in absence of children with leprosy, since they are recently infected. Reactivations may continue for many more years in older people who have been infected long time ago during a time that active transmission occurred in their community.

Unfortunately, the visible deformities and disabilities that cannot be corrected through reconstructive surgery and are the main cause of stigma will remain, even when we say that a patient has been cured. There is thus a continued need for "care after cure" programmes for this group of people.

Call for action

Partners are expected to continue to play an active role in this changing context. Contributions to leprosy control by nongovernmental and community-based organizations merit special credit. Hosting the International Symposium on holistic care for people with Hansen's Disease in Vatican City, the heart of the Roman Catholic Church, draws additional attention to the efforts of faith-based organizations in leprosy control. Agencies such as the Catholic Health Association of India and similar organizations in Africa, Asia and Latin America are providing a range of services in a very professional fashion, including administering MDT, providing ulcer care, offering counselling services, reconstructive surgery and rehabilitation. Nuns, priests, brothers and lay people offer dedicated services in the care and management of leprosy.

All partners are expected to continue supporting community mobilization activities to improve early detection of Hansen's Disease and transmit messages to further reduce the stigma against the disease. We also count on governments and partners alike to further take care of the unfinished agenda of providing care after cure and promote the integration of leprosy-affected persons in the communities to which they belong.

Future support and adequate funding will remain paramount for successful Hansen's Disease programs for many more years to come. ■

Note

[1] The South-East Asia Region of the World Health Organization consists of the following countries: Bangladesh, Bhutan, Democratic Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste

FIRST SESSION

MEDICAL-SCIENTIFIC ASPECTS:

1. The Fight against Leprosy: Current Challenges and Strategies

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Introduction

Recently, archeological studies have revealed absolute evidence for leprosy in an Egyptian skeleton of the second century BC, although the earliest written records of the disease come from India and date back to 600 BC. These findings make leprosy one of the oldest diseases known to mankind.

Certainly, the fight against the disease started as long ago as its history. Methods for this are difficult to confirm. However, social restriction was probably adopted when the first cases appeared, due to a mixture of disagreeable skin lesions, a sense of impurity, dreadful disfigurement, nauseating odors, and the lack of effective treatment.

In this context, when the advances in medical science are considered, it is intriguing that in the twenty-first century this disease continues to affect large proportions of the world's population.

In fact, the time line of the history of leprosy shows only a few major landmarks that are worth mentioning. These are as follows:

a) The identification of the causative agent by G. A. Hansen in 1874.

b) The introduction of sulphones, including dapsone, for treatment in the late 1940s.

c) The *in vivo* growth of *M. leprae* in mice and later in armadillos.

d) In this sequence, last but not the least, the introduction of the WHO-recommended multidrug therapy in the middle 1980s and its consequences.

e) At the end of the year 2000 the sequencing of the entire genome of *M leprae*.

The MDT Era

It was obvious by the mid-1970s that the efforts to control leprosy using long duration, even lifelong, dapsone monotherapy were failing due to increasing resistance to the drugs involved.

In 1981 the World Health Organization convened the Study Group on Chemotherapy for Leprosy Control. This Study Group recommended combined drug regimens based on the supervised intermittent administration of rifampicin for both MB and paucibacillary (PB) leprosy.

Due to the substantial progress in leprosy control achieved by implementing MDT, the World Health Assembly (WHA) in 1991 called for the "elimination of leprosy as a public health problem by the year 2000", defining elimination as attaining a level of prevalence below 1 case per 10,000 members of the population. The figures and trends at the time suggested that this ambitious goal was feasible.

Its implementation had a marked epidemiological impact. The prevalence of active cases declined dramatically all over the world. Initial figures showed that within two decades there had been a marked decrease in the estimated of leprosy cases worldwide: from 10 to 12 million in the mid 1980s to 0.51 million in 2003.

Another important achievement of the elimination strategy with MDT, sometimes neglected, was the improvement in the organizational aspects of leprosy control services, that is to say the improved quality of care and a new sort of relationship of the health team with patients.

The WHO elimination strategy may thus be seen as the most remarkable and controversial event in leprosy control since the adoption of the compulsory isolation of cases.

However, despite the relevant achievements with MDT and the elimination strategy, we reached the twenty-first century with leprosy still affecting people in many countries in the world. Indeed, besides the reduction in the prevalence of the disease, the detection rate of leprosy remains almost stable in the principal endemic countries of the Americas, Africa and Asia.

To cope with this problem, the World Health Organization and its partners organized broad and important meetings to review strategies and renew the commitment to a world free of leprosy. One of them was in the year 2009 and it launched the “2010-2015 Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy”. Another meeting that was remarkable because of its political aspect was the Bangkok Summit in 2013 which produced one of the most relevant documents of this century, the Bangkok Declaration, which was signed by Health Ministers from the seventeen high-burden leprosy countries of all the WHO regions.

Nowadays, leprosy still poses further challenges and new strategies are required to cope with the remaining burden of the disease.

Current Challenges and Strategies

1. The potential lack of governmental commitment

After the encouraging results of the MDT elimination strategy, some partners and governments tended to perceive the leprosy problem as relatively small and this produced a reduced political commitment, with a lack of priority being given to the disease, and reduced resources in dealing effectively with this still relevant public health problem. A shortage of funds for research in leprosy was also observed.

Therefore, we have understood that it is time for leprosy-endemic countries, as well as their international and national partners, to reaffirm their commitment and to strengthen their participation in addressing leprosy in order to ensure a leprosy-free world.

The primary responsibility for leprosy control rests with governments. Governments should act through partnerships with international organizations, including WHO, the private sector, local and international NGOs, CBOs, as well as people affected by leprosy. To achieve this, governments and all involved parties should allocate increased resources in the coming years in a sustainable manner.

In this context, the 2013 Bangkok Summit was a landmark in stressing the need for governmental authorities to avoid complacency in fighting leprosy and making the commitment to a world free of leprosy a high-level priority.

2. The lack of clinical expertise

Leprosy is a clinical entity, the diagnosis and management of which is mostly based on clinical examination. The adequate management of cases, including a correct classification, is based on clinical realities integrated with laboratory findings.

With the introduction of MDT and its shorter regimen duration leading to an important reduction in prevalence, the medical interest in leprosy now seems to be progressively fading away.

A probable reason for this is the idea that leprosy is being eliminated, and even eradicated, as a clinical entity, and, therefore, that it is no longer a health problem of concern.

The consequence is that leprosy has little space in the agenda of medical schools throughout the world and the expected result of this is misdiagnosis or a delay in diagnosis (which are both detrimental to the patient and to the control of the disease) during the elimination or post-elimination periods.

Therefore, one of the present challenges is to maintain a considerable degree of leprosy expertise. In those countries with a notable past prevalence and a relevant detection rate, leprosy should be part of medical courses, at least in the disciplines of dermatology, tropical medicine or infectious diseases. Authorities in the Ministries of Health should be in charge of contacting medical societies and medical schools to promote the inclusion of leprosy in the curricula of medical studies.

Another important need is to give full support to maintaining international centers of excellence in leprosy studies around the globe to serve as a reservoir of knowledge on leprosy and to provide teaching and training to doctors from countries where leprosy is no longer a significant problem, although present to a notable degree.

3. Interrupting transmission

I dare to say that the main challenge of this century is to interrupt the transmission of leprosy. If MDT can cure people, it is rational to assume that MDT, together with early diagnosis, will be paramount in interrupting the chain of transmission. However, data so far indicate that MDT has not had a striking effect on the reduction of leprosy transmission. Indeed, the transmission of *M. leprae* still appears to be occurring at a relatively consistent rate in many countries.

Therefore, new strategies should be designed to interrupt the transmission of *M. leprae*. A key point here is the long duration of the incubation of the disease and infection that is difficult to detect. Furthermore, transmission that takes place before the detection of the case is likely to result in many more new cases in the future.

Research in this area is mandatory in order to develop practical diagnostic tools to detect levels of infection that can lead to transmission. It is important to stress that basic control measures, such as early diagnosis and complete MDT treatment, are essential components in interrupting transmission. However, control of transmission is not solely dependent on the identification of subclinical infection by appropriate diagnostic tools, or on early treatment of cases, improved housing conditions, sanitation and education. We are not quite sure if man is the only reservoir for *M. leprae*.

Of great importance is the fact that patient contacts and neighbor contacts are an important category in the transmission of leprosy. They can be healthy carriers of the disease and/or they can carry a definite sub-clinical infection. For such a sensitive group, preventive measures are of striking importance.

The recent LPEP strategy – Leprosy Post-Exposure Prophylaxis – is an effective answer to this need. The Leprosy Post-Exposure-Prophylaxis (LPEP) project is a collaboration between the Novartis Foundation and its relevant partners that seeks to test the feasibility and effectiveness of single-dose rifampicin as a leprosy post-exposure prophylaxis. Rifampicin is given to contacts of newly diagnosed leprosy patients to decrease their risk of developing leprosy.

As regards measures to interrupt transmission, the LPEP seems to me the most relevant and innovative proposal to modify the relative monotonous epidemiological course of the disease over the next decades.

4. Vaccine

Those who have studied leprosy control measures agree that having a vaccine with a high protective capacity and with few side effects would greatly reduce the transmission of leprosy.

So far, the most common vaccine strategy has been to immunize individuals with *M. bovis* BCG. The degree of protection against leprosy provided by BCG vaccination, however, has varied dramatically between studies and the clearest indication that BCG is not perfect is the indisputable fact that leprosy remains endemic in countries where BCG immunization is extensive, such as Brazil.

A vaccine for leprosy has for long been on the agenda of many researchers and we have reached the twenty-first century without any concrete results that produce an effective vaccine to be used in the context of controlling leprosy. Recently, a project from the INDRI in the USA has been working on a new proposal of a vaccine against leprosy and this is showing promising results.

Although difficult to attain, the availability of an effective vaccine would support the interruption of the chain of transmission of the disease. Therefore, constant technical and financial support should be secured for initiatives in this field.

5. Early diagnosis and adequate treatment before the onset of disabilities

Despite the technological and scientific advances in the field of leprosy, the most effective way to prevent leprosy related disabilities and to interrupt transmission is still to provide early diagnosis and adequate treatment.

However, late detection is a multifactorial issue.

– Scarce or unavailable health services.

– A lack of knowledge and skills.

– A lack of drugs for treatments.

– Ineffective referral systems.

– Accessibility of services (social, cultural, economic, mobility).

– Lack of awareness.

– Stigma and discrimination.

6. Research

There is a clear picture among leprosy workers that leprosy is not going to disappear anytime soon. Many challenges remain unsolved in different fields of the disease. Just to mention one, the causative agent is still not cultivable *in vitro*, although with limited success this has been achieved *in vivo*. Besides that, the precise mechanism of the transmission of *Mycobacterium leprae* is not clearly understood and extensive studies have not yet produced any practical and effective tool for early diagnosis. Furthermore, a highly effective vaccine has not yet been developed. Therefore, in the case of leprosy we face great limitations in the usual research approach adopted with most infectious diseases, for example:

(1) It is not easy to obtain great amounts of the viable causative agent; (2) it is not possible to devise effective preventive measures due to gaps in the understanding of the transmission of the disease; and (3), lastly, it is difficult to protect populations due to the continuing unavailability of an effective vaccine.

In conclusion, these reasons support the need for continued research and increasing funding for research into leprosy.

7. Stigma and discrimination

Stigma and discrimination have been historically linked to leprosy. From the patient's perspective, they can affect individuals and their families. From the medical point of view, stigma and discrimination are potential factors in preventing the presentation of cases for diagnosis and adequate treatment, and this leads to increased opportunities for transmission of the disease. Furthermore, some patients may interrupt their treatment prematurely due to a fear of stigmatization because of an uneven darkening of skin due to the use of clofazimine.

Worse than this perceived stigma is the institutional discrimination imposed by archaic legislation that still exists in some countries. A survey conducted by the ILEP revealed that in 63 countries, persons affected by leprosy are subject to discrimination because of the law. This legislation includes the segregation of leprosy cases, the right to divorce, refusal of access to public places, deportation, and the refusal of entry visas in a few countries.

It is amazing to see that in the second decade of the twenty-first century legislation such as this is still present in some countries.

Therefore, fighting stigma and discrimination is an urgent need that has to be addressed by governments, national and international societies that work with leprosy, including scientific associations and organizations of people affected by leprosy, in close contact with other organizations that address similar discriminating conditions such as HIV and tuberculosis.

Concluding Remarks

M. leprae seems to be a bacterium of this earth whose presence in the world is unavoidable. Despite the enormous accumulation of knowledge about its behavior in relation to the environment and man, the disease it causes seems to be approaching a stable condition.

If one studies the burden of leprosy from antiquity to the twenty-first century one cannot deny the tremendous improvements that have been achieved in the treatment and control of the disease.

However, in the centuries to come if the social condition of the populations of the world improve due to a political improvement in access of these populations to new technologies in the fields of agriculture, health and social sciences, leprosy will only find space in medical museums as a terrifying disease that threatened humankind for many millennia. Therefore, leprosy will be, finally, a disease that will have been truly eliminated and eradicated from the surface of the earth.

However I am quite convinced that in this distant (faraway) scenario, scientists will continue to be intrigued by many aspects of the biology of *M. leprae* which will remain unsolved. ■

2. The Elimination of Leprosy and Neglected Diseases as a Problem of Public Health Care

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of the General Department
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Hansen's disease is a bacteriological infectious disease which has a sub-acute-chronic development and is caused by a micro-bacterium*, mycobacterium leprae*, which multiplies slowly. It has a period of incubation that lasts about five years, although the symptoms can require up to twenty years to emerge. This disease provoke lesions of the peripheral nerves, of the skin, of the mucous of the upper respiratory tract, and of the eyes, and has effects that often involve invalidity when it is not diagnosed swiftly and a correct multi-drug therapy is then administered.

Although it is not highly infectious, transmission of this disease takes place through drops that come out of the nose or mouth during close and frequent contacts with patients who have not been treated.

Thus the carrying out of a correct diagnosis and subsequent treatment are of primary importance. Indeed, an untreated infection can cause gradual and permanent damage to the skin, to nerves, to limbs and to eyes, and this can lead to grave forms of invalidity.

It should be emphasised that leprosy can be treated. In addition, if the treatment is administered during the first stages of the illness it is possible to avoid forms of disability.

Throughout the world multi-pharmacological treatment has been offered free by the World Health Organisation to all patients since the year 1995. This therapy is a simple and effective cure for all kinds of leprosy. Over the last twenty years, it is calculated that throughout the world over sixteen million people with Hansen's disease have been treated with multi-pharmacological therapy.

At a world level, we have been witnessing a steady reduction in cases of leprosy. Ever since the year 2000, a prevalence has been achieved of less than one case in every 10,000 people. It is therefore believed that leprosy no longer constitutes a grave problem for public health.

The data of the World Health Organisation, which come from 103 countries in five regions of the world (excluding the region of Europe, given the low number of cases in that region), show that at the end of the first quarter of 2014 the prevalence of the disease was a little more than 180,000 cases throughout the world, whereas during the year 2013 215,557 new cases had been recorded.

The areas where the disease is most endemic, with over 1,000 new cases a year over the last five years, are limited to certain countries. In Africa, those countries are Ethiopia, Madagascar, Nigeria, the Democratic Republic of the Congo and Tanzania; in Asia, Bangladesh, the Philippines, India, Indonesia, Myanmar, Nepal, and Sri Lanka; and in Latin America, Brazil.

The strategy of the World Health Organisation for the elimination of leprosy has been called 'Final Push' and this strategy is based upon the following points:

– Increasing the availability of multi-pharmacological therapy to all health-care institutions.

– Ensuring that all cases, both those that already exist and those diagnosed in the future, receive appropriate multi-pharmacological treatment.

– Educating patients so that they receive the treatment regularly and in a complete way.

– Spreading information about leprosy in communities, at a grassroots level, so that individuals with suspected lesions feel supported by their communities and notify them about it of their own accord.

– Monitoring the effectiveness of the implementation of strategy by establishing beforehand chronograms and objectives.

– Documenting all activities that are promoted in the field of the implementation of the strategy for the elimination of leprosy in order to assess their progress.

In Italy, the epidemiological situation as regards leprosy has changed profoundly over the last ten years. Indeed, new cases of leprosy have been ones that above all else have been imported from abroad. If we analyses the data of the last ten years, we can see that in Italy 'home-grown' cases have been between 0 and 3 every year, whereas, during the same period, the imported cases have varied between 2 and 20 a year. As regards the autochthonous cases, we have witnessed the disappearance of centres of infection on the Ionian coast of Sicily and Calabria, on the west coast of Sardinia, and in the west of Liguria.

The provisional data for the period 2014-2016 confirm this trend, a trend linked to the importation of cases from countries where leprosy is highly endemic.

One can thus state that this pathology, which seemed destined to disappear given the constant reduction in autochthonous cases, has instead experienced a worsening because of imported cases. Specifically because of the new epidemiological characteristics of this disease in Italy, it should be emphasised that the cases of it are no longer confined to a few centres of infection limited to a few areas but can appear throughout the national territory of Italy. Here two factors should be referred to: on the one hand, the heavy medical and social consequences of this pathology which can become highly disabling, and, on the other, a low level of knowledge about this disease amongst health-care personnel.

Amongst the factors that foster the appearance of this disease, we should remember both individual characteristics, such as chronic nutritional deficiencies, and unfavourable living conditions, and, lastly, factors linked to access to socio/health-care services, which themselves are increased by language barriers.

Italian legislation on Hansen's disease is a little dated and is made up of three measures:

– The ministerial decree of 15 December 1990 which sets out the system of information about infectious and widespread diseases.

– The guidelines for the control of Hansen's disease in Italy which were issued in June 1999.

– The official guidelines and arrangements for the coordination of regions and autonomous Provinces in relation to Hansen's disease which were issued in May 2001.

As regards the system of information, it should be remembered that Hansen's disease is placed in the third class and has a differentiated information flow that includes the compilation of an epidemiological form.

The guidelines constitute the document of reference for the diagnosis, treatment and management both of people with the disease and their family contacts. In particular, I would like to observe that the principal source of infection is patients who are infected with leprosy but who have not been treated. Italian citizens with Hansen's disease must have periodic controls in order to receive the financial payment envisaged by the law. The domestic contacts of these patients must also receive periodic controls and especial attention is paid to children. In contrary fashion, in the workplace and schools controls are not carried out and this is done to avoid stigma. Where a diagnosis is carried out in reception centres or centres of voluntary service of cases for people where the presence of the disease is suspected, it is recommended that patients be sent to specialised public institutions. I will speak about this shortly. These services are a useful resource by which to educate patients and their family relatives. However, the training that is provided at both a university level and during refresher courses on this pathology should be intensified.

The diagnostic-therapeutic pathway, as I pointed out, is implemented at the regional reference centres as envisaged by the guidelines of the year 2001. In these guidelines, the institutions responsible for this are listed, with a differentiation made between local centres established at a regional level and national reference centres. There are four of these last in Italy and they are to be found in Genoa, Cagliari, Gioia del Colle (BA) and Messina. The laboratory in Genoa also performs the role of being a supra-regional institution.

The local centres have, in particular, the task of sending patients suspected of having leprosy to reference centres for the confirmation of the diagnosis, implementing protocols of treatment and rehabilitation, and carrying out periodic controls on patients and those who live with them.

The national reference centres, in addition to confirming the diagnosis, establish protocols for treatment and the end of the treatment, give notice of confirmed cases, and attend to the ongoing training of health-care personnel in this field.

The notification flows are two-directional and designed to inform all the individuals and institutions involved both in the local areas and at a regional and central level.

To end this paper, I hope that in a short time an updating of the guidelines will be achieved, reviewing the definition of a case of leprosy as well as laboratory methods on the basis of the most recent available information. Last but not least, data in the literature in the field, although anecdotal, have reported in some clinical cases the beginning of the appearance of examples of resistance to anti-leprosy medical products with some strains of the bacterium. This is a phenomenon that should be carefully followed. ■

3. The Modern Challenge of an Ancient Disease

DR. ANN AERTS
Head of the Novartis
Foundation,
Belgium

In the small village of Dana Toc in Myanmar, community organizers are engaged in the task of gathering all their neighbors to be tested for one of the oldest documented diseases: leprosy.

In Dana Toc, 72-year-old widow Daw Khin Thein was diagnosed in the same way that people have been diagnosed for centuries – with a feather. As there is no existing reliable diagnostic test for the disease, a feather is run over the skin to detect areas of numbness, which is indicative of the nerve damage caused by leprosy.

Commonly thought to be a disease of the ancient past, leprosy continues to affect thousands of people each year. Between 200,000 and 250,000 new patients are diagnosed annually.

Thanks to medical advances, leprosy can be treated with multidrug therapy (MDT) once diagnosed. Not only is MDT effective at curing leprosy, it helps reduce transmission and prevent permanent disability. Since this therapy became freely available worldwide, there has been a dramatic decrease in annual diagnoses of leprosy. Yet it can only be administered once a diagnosis has been made, and as it can take up to 20 years before patients become symptomatic, during this time leprosy can be unknowingly transmitted.

In the absence of a better diagnostic tool, the most effective way to interrupt transmission and eliminate leprosy is contact tracing.

Contact tracing identifies and diagnoses people who may have come into contact with an infected person, which helps toward earlier diagnosis. This is one of the approaches the Novartis Foundation is taking to help work toward final elimination of the disease.

In 2014, the Novartis Foundation and its partners launched the leprosy post-exposure prophylaxis (LPEP) program. This program focuses on interrupting the transmission of leprosy by ensuring all those who may have been exposed are examined and offered a post-exposure prophylaxis, which can reduce the risk of developing leprosy by 50-60%.

Since its launch, LPEP has been expanded to Indonesia, India, Nepal, Myanmar, Tanzania and Sri Lanka, while Brazil and Cambodia have introduced similar approaches. We are excited to see this program expand, making progress toward interrupting leprosy transmission.

In April 2017, the Neglected Tropical Diseases Summit, five years after the London Declaration, gave us new momentum to meet the goals outlined by the WHO's Roadmap on Neglected Tropical Diseases (NTDs). These goals include continuing to work together to make leprosy history. This is an ambitious goal, but it is one the Novartis Foundation is committed to, and one I believe we can achieve.

To cover the last mile toward leprosy elimination, we must leverage and scale proven solutions, while also investing in research for improved diagnosis methods. The LPEP program is an excellent example of a program that can be scaled and taken to other leprosy-endemic countries, and we are proud of the success it has had.

The Novartis Foundation is also working to develop a diagnostic tool, by collaborating with research partners to develop a leprosy molecular diagnostic test. The hope is that, once this test is developed, leprosy can be diagnosed before significant nerve damage has taken place and before it is unknowingly transmitted to others.

Cases of leprosy have plateaued in the past few years: it is increasingly difficult to make significant reductions when diagnosis is so difficult. Without an effective diagnostic test, we are left to work with the centuries-old technique of using a feather.

But by leveraging interventions that work and continuing research into developing effective diagnostic tools, I am certain that we can reach the final elimination of leprosy together. ■

SECOND SESSION
ASPECTS OF HUMAN RIGHTS

1. Dignity and the Right to Protection of Health of People with Leprosy

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I would like to extend my thanks to the organizers of this important Symposium on Holistic Care for People with Hansen's Disease. We are grateful especially to the Pontifical Council for Health Care Workers, and the Nippon Foundation, and its Chairman, Mr. Yohei Sasakawa, for their organization and support for this important forum.

I am honored to be invited to speak today on the Dignity and the Right to Protection of Health of People with Leprosy. From 2012-15, I served as a member of the International Working Group on Leprosy and Human Rights, an independent body of experts representing various geographical regions and expertise, including persons affected by leprosy. The purpose of the International Working Group (or "IWG") was to develop a plan for effective protection of the human rights and human dignity of persons affected by leprosy and their family members. Today I would like to briefly describe the international standards, and present you with our Group's findings concerning the most effective way to implement those standards. I will then explain what these findings mean for states, civil society and religious organizations, and individuals.

The Principles and Guidelines

In December 2010, the General Assembly of the United Nations endorsed the "Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members" ("Principles and Guidelines") and encouraged "Governments, relevant United Nations bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions to give due consideration to the principles and guidelines in the formulation and implementation of their policies and measures concerning persons affected by leprosy and their family members."

The Principles and Guidelines represented a truly critical achievement in affirming the human rights of persons affected by leprosy and their family members. The international instrument consists of two parts: *the Principles*, which restate and recognize the most basic human rights that extend to all persons affected by leprosy and their family members. The second part consists of *the Guidelines*, which elaborate in concrete terms the responsibilities of States to promote, protect and ensure the realization of all human rights of leprosy-affected persons and communities.

Regrettably, as the need for these Principles and Guidelines demonstrates, and as many persons affected by leprosy and their family members testify, there continues to be widespread discrimination worldwide, in schools, work places, communities, public places, religious sites, restaurants, hotels, and buses, trains and other forms of public transport.

To address these violations of human rights and human dignity, the Principles and Guidelines confirm and build upon the core international guarantee of non-discrimination, a right based on the notion of the equality and dignity of each human being, which is deeply embedded in human rights law. The Principles and Guidelines set forth the standards of behavior that have been deemed necessary for States to achieve their responsibility to prohibit all forms of discrimination against persons affected by leprosy and their family members.

The Principles and Guidelines have their roots in the UN Charter, by which each Member State has acknowledged its common faith in "fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small." The global commitment to human rights cannot be achieved if the rights of any particular group of people are not fully respected and protected. The centrality of the principles of equality and non-discrimination in international human rights law and the adoption and endorsement of the Principles and Guidelines by the UN Human Rights Council and the General Assembly mean that these standards carry authoritative weight in international law. The P&G can be therefore used as a measure to assess State practice.

The IWG

After the adoption of the Principles and Guidelines, the Nippon Foundation undertook further action to disseminate and ensure the effective implementation of these critical standards throughout the world by organizing five regional symposia to learn about the experience of leprosy-affected communities and to hold consultations regarding the most effective means of ending stigma related to Hansen's Disease. The first regional symposium – for the Americas – took place in Rio de Janeiro, Brazil in 2012, where the participants recommended the creation of an International Working Group to study and recommend ways to ensure the implementation of the standards of non-discrimination so clearly set forth in the P&G.

The International Working Group was chaired by Dr. Yozo Yokota, distinguished professor and internationally-recognized expert of international human rights law. The twelve additional members of the IWG, represented various geographical regions and expertise, including persons affected by leprosy. The members were from Brazil, Bulgaria, Ethiopia, India, Japan, Jordan, Kuwait, Philippines, Sri Lanka and the United States.

The IWG held four working sessions over the next three years:

– October 2012, in New Delhi, India

– March 2013 in Tokyo, Japan

– August 2013 in Gunma, Japan

– October 2014 in Rabat, Morocco

The IWG presented its final report at a regional meeting in Geneva, Switzerland, one year ago.

In conjunction with our substantive meetings, members of the International Working Group also had the opportunity to engage with leprosy-affected communities in most of these sites. We toured leprosaria in Japan and Morocco, and held deeply moving conversations with people who had suffered the health and social consequences of the disease over the course of their lifetime. They talked to us about the effects of being separated permanently from their family, friends and pre-disease identities.

We visited the National Hansen's Disease Museum in Higashimurayama, Japan, which vividly demonstrated the day to day life for residents of the leprosarium where since 1909 persons with leprosy had been removed from society permanently, resulting in a form of social death. As an example of this, the museum featured the distinct monetary currency and fire-fighting equipment that was required in the leprosarium as a means to prevent any intermingling of persons with leprosy and the outside world.

At the National Sanatorium Kuryu Rakusen-en located in Kusatsu, Gunma, we spoke with the president of the sanatorium residents' association, 87-year-old Sanshiro Fujita, who had lived at the sanatorium for 67 years. We also toured the remains of an inhumane prison where leprosy patients had been incarcerated before and during the Second World War for their alleged crimes. The prison was being excavated by a team of archeologists who were reconstructing the experience of the detainees there. A member of the excavation team explained how there had been no roof and in winter it was like a freezer, so that many detainees died from exposure.

In Casablanca, Morocco, we were allowed to visit the site of the leprosy hospital and meet with many of its current and former residents, who live difficult lives afflicted by stigma and poverty because of the disease. Despite these conditions, the leprosy-affected community in Morocco, as in other countries, continue to be passionate advocates for their own dignity.

The IWG's Final Report

Based on our study and observations, the International Working Group drafted its final report, proposing that all actors -- states, civil society actors, and persons affected by leprosy – work together to eliminate discrimination associated with Hansen's Disease, more commonly known as leprosy.

Our report emphasized the many actors who must be involved in ensuring that the standards in the PRINCIPLES AND GUIDELINES are carried out. First and foremost are *States*, which have the primary obligation to respect, protect, fulfill and ensure human rights for all. As such, States are called upon to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members. All parts of government, including the executive, legislature, and judiciary, as well as local governments, and institutions under the control of governments, must act in conformance with the Principles and Guidelines. Governments should also take steps to ensure that the rights of persons affected by leprosy and their family members are protected in the private sphere through appropriate regulations related to the actions of individuals, groups and private enterprises. The International Working Group recommended that States, therefore, adopt and carry out their own national plans of action and collect information regarding the actual status of implementation of the Principles and Guidelines.

To assist with that process, the International Working Group prepared a "Suggested Framework for National Plans of Action" for States to use in their own domestic contexts. The elements of this suggested framework include the following:

– A clear statement of objectives

– A timeframe for achieving the stated objectives

– Cooperation with stakeholders, most importantly with persons affected by leprosy

– Law reform, including repeal of laws that directly or indirectly violate the rights of persons affected by leprosy and their family members; and the removal of discriminatory and offensive language;

– Provision of remedies, including judicial remedies

– Special attention to women, children, the elderly and other vulnerable populations

– Rights related to the family, including the right to marry and raise children, and support for reunification of family members separated as a result of past policies and practices;

The Framework for National Plans further includes:

– An emphasis on inclusion and participation in the community,

– The rights to political participation, to work, education and training.

– The right to health, including early diagnosis and prompt treatment for leprosy, free medication, counseling and rehabilitation.

– The right to an adequate standard of living and social security.

– And a plan for awareness raising to foster respect for the rights and dignity of persons affected by leprosy and their family members.

In addition to States, the International Working Group considered the resolution of the UN General Assembly which also encouraged *other actors* to give due consideration to the Principles and Guidelines in implementing policies with regard to persons affected by leprosy, including relevant UN bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions.

In considering the role of non-state actors, the IWG highlighted, in particular, that *persons with leprosy themselves* must be central actors in implementing the PRINCIPLES AND GUIDELINES. The right of persons affected by leprosy to be *actively involved in decision-making processes* is underscored in the Principles and Guidelines with regard to policies and programs that directly concern their lives and the lives of their family members. The affected individuals are powerful agents of social change who should act, individually and collectively through their respective local, national and international organizations to claim and implement their human rights.

To ensure effective implementation, the International Working Group further emphasized the importance of *awareness-raising activities* to be carried out by *all sectors of society*. In addition to state actors and the affected community, the IWG noted that civil society groups, including religious institutions, have a critical role to play in eliminating the stigma and raising up the dignity of leprosy-affected persons. States are encouraged to work together with national human rights institutions, NGOs, civil society and the media to foster respect for the rights of persons affected by leprosy and their family members. Civil society organizations and social institutions, including schools, religious communities and centers of art and culture are critical partners in helping to remove the misconceptions associated with leprosy and in raising public awareness about the disease and its impacts.

The IWG noted, in particular, the critical need for civil society and religious communities to raise up the dignity of persons affected by leprosy by modeling positive language. We noted that old perceptions of the disease of leprosy continue to be reinforced by stigmatizing language. The offensive term “leper” used to describe someone with the disease connotes an outcast, sinner or a person who is rejected by others for moral or social reasons. Such terminology contributes to the discrimination that people affected by leprosy face and discourages those in need of treatment from seeking help. The IWG, therefore, invited religious leaders and all supportive communities to consider ways that we can model language that conveys our respect for persons with leprosy.

Next steps for international action

In addition to these domestic-level activities, the International Working Group concluded that the P&G are most likely to be given effect if States are called upon to take specific implementing actions, including conducting studies, collecting and analyzing data, bringing these instruments to the attention of various governmental offices and reporting back to a specified international body. To ensure these measures were taken by governments to implement the P&G, the International Working Group further recommended the establishment of a *follow-up mechanism* at the international level that would have the authority to monitor the actions of States. Drawing upon the experience of independent committees of experts that have functioned to monitor the implementation of international human rights treaties in the UN as well as the International Labour Organization’s Conventions and recommendations, the INTERNATIONAL WORKING GROUP specifically recommended that the UN Human Rights Council request its Advisory Committee to study and recommend an appropriate follow-up mechanism at the international level. We were pleased that, in 2015, the Human Rights Council indeed took this important step, as you will hear from our next speaker, the Chair of the UN Advisory Committee on Human Rights, Dr. Obiora Okafor.

The IWG further recommended that whatever follow-up mechanism was created be empowered to distribute a questionnaire to States in order to collect data regarding the actual practice of States in implementing the P&G. To assist with this data gathering, the International Working Group prepared a model questionnaire calling for information with regard to the following topics: (i) basic epidemiological and clinical management status of leprosy, (ii) healthcare, (iii) abolishment of discriminatory laws, (iv) establishment of a national committee, (v) awareness raising, translation and dissemination of the Principles and Guidelines; (vi) reporting to international human rights bodies, and (vii) adoption of a National Plan of Action.

Conclusion

In sum, the 2010 endorsement of the Principles and Guidelines by the UN General Assembly represented a significant turning point in the recognition of the full human rights of all persons affected by leprosy and their family members. These standards have been welcomed by tens of millions of persons who have endured the stigma associated with this disease. The Principles and Guidelines provide the international community with a solid base from which to work together to ensure the full realization of immediate and effective elimination of discrimination resulting from leprosy. On behalf of the IWG, I thank you for your support and participation in this historic process. ■

2. Stigma and Prejudice: the Role of the Nippon Foundation in Tackling Leprosy Discrimination

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Japan

Hansen's Disease in Japan: Isolation and Discrimination

This year marks the twentieth anniversary of the abolition of Japan's Leprosy Prevention Law. To put it another way, up until twenty years ago a law existed in my country requiring leprosy patients to be taken from their families and forced to live in sanatoria. Long after the notion that it was necessary to isolate people with leprosy had been discredited, we continued to enforce our isolation policy, cutting them off from society. Patients changed their names to avoid exposing their families to the stigma surrounding the disease; families carried the secret that one of their relatives had leprosy.

Lives were destroyed by a diagnosis of leprosy. Even today, twenty years after the law was abolished, there are still people who are unable to return to their hometown, whose relatives refuse to acknowledge them, because of the stigma this policy helped to entrench.

Let me be clear. Since the abolition of the law, there have been changes: the state has formally apologised; a court ruled that the law had violated patients' constitutional rights; and the government agreed to pay compensation.

Nevertheless, we must not forget that this policy continued for far too long, that people are still living with its consequences, and that society, through ignorance, indifference, fear and prejudice, was complicit in allowing an injustice to stand unchallenged for decades.

The Nippon Foundation and the Fight against Leprosy

How does this concern the Nippon Foundation? We have already heard this morning from our chairman, Mr. Sasakawa, but let me add a few details. Founded in 1962, we are one of the largest not-for-profits in the world. The foundation is active in many humanitarian fields, but from the beginning our founder, Mr. Sasakawa's father Ryoichi, was passionately interested in eradicating leprosy. His interest stemmed from a childhood experience: seeing a young woman in his village forced to leave home because she was diagnosed with leprosy. He determined that one day he would rid the world of this disease.

Starting in 1974 we have been the principal donor to the WHO's Global Leprosy Programme. Between 1995 and 1999, we underwrote the free supply of multidrug therapy (MDT) – the cure for leprosy – worldwide. We are committed to supporting efforts to cure leprosy and eliminate the disease from the world.

In step with this, in recent years we have been placing more emphasis on addressing the stigma and discrimination that blight the lives of people affected by leprosy. We believe this to be an essential component of our mission to achieve a leprosy-free world.

In particular, we raised leprosy as a human rights issue with the then UN Human Rights Commission in 2003. With support from the Japanese Government, this initial approach to the UN led eventually to a 2010 UN General Assembly resolution on 'Elimination of Discrimination against Persons Affected by Leprosy and their Family Members'. Work now continues to see that the set of principles and guidelines accompanying the resolution are fully implemented .

We also sponsor an annual Global Appeal to End Stigma and Discrimination against People Affected by Leprosy, which Mr. Sasakawa mentioned in his remarks.

In these efforts, we believe it is very important that the voices of people affected by leprosy are heard. For a number of years now both the Nippon Foundation and Sasakawa Memorial Health

Foundation have been supporting the empowerment of people affected by leprosy in different parts of the world and providing platforms for them to make their views known.

I am thus very pleased that representatives of people affected by leprosy from some ten countries are attending this symposium and that we shall be hearing directly from them.

I said at the start of my remarks that we must not be allowed to forget the consequences of our past policy. One of the outcomes in Japan of the abolition of the Leprosy Prevention Law and subsequent legal action was the establishment of a National Hansen's Disease Museum.

In fact, a museum begun by people affected by the disease already existed. As part of the national effort to erase the stigma associated with leprosy, this was enlarged with state funding and reopened in 2007 as a national museum.

The purpose of the museum is to increase public awareness of leprosy and of the struggle waged by people affected by the disease for the restoration of their dignity. It also encourages respect for human rights in general and promotes an end to discrimination and prejudice.

There is now a growing movement around the world to preserve the history of leprosy for what it teaches about the issue of stigma and discrimination and the lessons we can learn from efforts to combat it. The Nippon Foundation, which has been entrusted with operation of Japan's National Hansen's Disease Museum, is now heavily engaged in this movement and we believe this history is worthy of world heritage status.

Why do people discriminate against other people? Leprosy teaches us the answer to this universal human problem. Stigma and discrimination are born of misconceptions about others based on ignorance and fear. That is why we need conferences such as this one to dispel mistaken notions about the leprosy and tackle the stigma head on. Thus, I would like to thank the Pontifical Council for making this symposium possible.

I hope the important messages to emerge will reach every corner of the earth and that our discussions here bring us a step closer to our shared goal of a world without leprosy and the discrimination it causes. ■

3. Stigma and Toxic Imagery

MR. JOSÉ RAMIREZ, JR
International Association for Integration, Dignity and Economic Advancement - IDEA, USA

Early in 2016, I made two presentations on the topic of leprosy. The first was to members of an organization known for their contributions to persons in need of medical care. The average age of the members was probably early 60's. The second group was comprised of university students at the undergraduate level. Most were likely in their early 20's.

I introduced an activity prior to starting my presentation. I asked each group to close their eyes. Then, I asked them to describe the image in their mind of the "L" word or "leper." Normally, I do not use this word, as even when written in reverse, it spells "repel." I mentioned this to both groups during my presentation and the pejorative image it portrays on the screen of one's mind.

The older group mentioned words straight out of most dictionaries. Words like sinner, outcast, pariah and untouchable. The younger group was much less dictionary savvy, but still descriptive. They said words like monster, cripple, contagious, claw hands, people without a nose and Freddy Krueger. Freddy is a character in a popular horror franchise with a lust for frightening and killing young men and women. His skin is badly damaged from severe burns and his signature weapon is a glove with knives attached to his fingers.

At the end of my presentation most of the attendees acknowledged that they had used the "L" word in an offensive manner.

I can add that when my son was in elementary school and at age 11 he completed a very simple science project. He asked his classmates to rank the things they feared the most such as the dark, snakes, monsters, fear of failure, teachers, clowns, bullies, spiders, girls/boys (the opposite sex) and leprosy (listed last). All of his peers identified leprosy as the thing they feared the most.

So here you have three generations forming an image of "leper" and a fear of leprosy, basically laying stones of negative perceptions and attitudes that create stigma.

How could this outcome have occurred among three distinct groups so far removed from one another in age and backgrounds? In my opinion, the common thread has been religion, and the use of terminology among all cultures to create differences, and fear of the unknown.

Knowledge about leprosy is powerful. However, ignorance about leprosy is more powerful.

This cycle though does not need to continue as all of us here have the opportunity to initiate change. This change will not come easy, but it is a battle worth fighting.

Being in the Vatican City during the Jubilee Year of Mercy means, to me, that I have come full circle on my journey with Hansen's disease. Forty-eight years ago I was diagnosed with leprosy at Mercy Hospital in Laredo, Texas. Even though my family, friends and girlfriend thought that my diagnosis meant upcoming death, the Sisters of Mercy nervously tried to reassure all that this was not so.

Nervously, because my mother immediately recognized the usual connection to leprosy-sin. She believed, and shared with me in inconsolable tears, that God was punishing her, through me, for *her* sins. I simply could not envision my saintly mother possibly being a sinner. I became petrified with anger because I could not understand why God was being so cruel to my mother. This cruelty included her witnessing a priest administer the last rites to me prior to being placed in a hearse en route to the national leprosarium in Carville, Louisiana- My mother felt great sadness for decades asking the question "why?" similar to a female Barabbas.

The initial diagnosis of leprosy can immobilize physically, emotionally, and spiritually. This paralysis affects the person diagnosed and impacts the extended family. Symbolically, most of us affected by leprosy have been transported in a hearse on a journey to ostracism. This journey becomes void of the laughter, celebrations, and milestones of loved ones. For every person affected by leprosy, as many as ten others are impacted. For me it was my six sisters, six brothers, parents, 29 aunts and uncles, girlfriend and many friends. I was institutionalized for seven years after I was driven 750 miles in a vehicle used to transport the dead to their grave. At least now I know what my final ride will feel like.

This painful experience with my mother, Rosa, was my introduction to stigma. I define stigma as "an act of labeling, rejection, or unexplained fear of a person." My mother definitely viewed the label of sinner.

Ironically, on my first well-guarded and pseudo secret visit home, my mother showed me her unconditional love. Using colored tape, I attempted to label a spoon and plate for my use only, as a form of protecting the family. The Carville staff had not explained to me and I did not understand that my level of contagion was non-existent after commencing treatment with Dapsone and experimental medications of Thalidomide and B-663, now called Chlofasimine. She grabbed the plate from my hands, forcefully throwing it to the floor, smashing it to pieces. In tears she screamed "You are MY son, I love you! Please don't ever think that we will abandon you." Since then, I always think of my mother when I see a plate in front of me. Having a plate with food in front of me obviously is not always a good thing!

It was 38 years after my diagnosis when Pope John Paul II described persons affected by leprosy. He said "they are my brothers and sisters" during mass at St. Peter's Square. Things changed for my mother when I shared with her his words. She was in advanced stages of Alzheimer's, but she was able to briefly regain her senses. She said, *Ya me puedo morir con una alma limpia*-Now I can die with a clean soul.

I was not the first to be attacked by stigma. Stigma can be traced back 4,000 years as evidenced by anthropologic findings. They discovered that persons affected by leprosy were often buried in segregated graves. These 40 centuries also represent over 100 generations of my brothers and sisters living a life of rejection and fear. They were labeled "the living dead" while alive, and then disrobed of their dignity after death.

Throughout the ages, this loss of dignity has taken on a unique portrait of emotional and physical trauma. Persons outside of this room have limited knowledge about the paths traveled by persons affected by leprosy. However, historically and in contemporary times, many have believed that the diagnosis of leprosy is the ultimate curse placed upon a human being.

I have wondered if the curse of leprosy might have been in Michelangelo's mind as he painted the Sistine Chapel. The bottom figures look so much like persons with leprosy in advanced stages. I have also thought about what curse the priest at Carville's Sacred Heart Chapel might have imagined when he would use two chalices to administer communion – one for staff and another for patients. I have no regrets from having had kneeled on the staff side of the alter and forced him to use only one chalice, and forever breaking one of the branches of stigma. However, my action had a counter action. I received the silent treatment for months from my peers and staff. It is very challenging to break the status quo as the Tree of Stigma has strong branches.

Roads traveled by the curse of leprosy have been filled with much sorrow. The curse has led to the denial of basic human rights; death by fire, bullets or loneliness; a lifetime of separation from family synonymous with incarceration; denial of all rights including marriage; separation from children or a fetus aborted if pregnant; being chained to an ostracized community; confinement to very cold or hot rooms as a form of punishment; forbidden to live or travel with others not affected; stripped of an identity; and much much more.

So, the toxic combination of historically believing that leprosy is a curse, and inhumane actions which continue to perpetuate fear provide the fuel to explode stigma across borders, cultures, mountains, oceans and faiths. This makes it possible for stigma to navigate complex social systems that I call the "Eye of Exclusion."

This system, that has made such a harsh and negative impact on stigma includes economics, housing, health, politics, education and the electronic, print and social media. These affect the psyche of society, and the well-being of the person affected.

On a daily basis there are stories about persons affected by leprosy challenged and labeled by individuals, groups, and potential employers within the "Eye of Exclusion" because of leprosy related myths. The obvious myths are the ones most labeling, i.e., toxic bacilli in our bodies will "deform and cripple" us to forever be a "victim or sufferer," a "patient." Society does not acknowledge the fact that while we may lose feeling in our limbs, pain in our soul is never ending. We are not less competent than someone without the disease. Our minds do not stop functioning. We are a "patient" ONLY while under the care of a physician or therapist. I recall as recently as the last International Congress on Leprosy being called a "patient," and receiving a shocked response when saying, "I am not a patient!"

The implosion also impacts the persons' extended support system which include family, friends and work colleagues. Again, rejection and fear surface to the top, denying dignity and respect for my brothers and sisters, and me.

The primary reason that the "Eye of Exclusion" and stigma are so effective is because of what I have witnessed and call the "Law of Silence." This law refers to the unwillingness of society in general and many in leadership in particular, to speak out-yell out- against the injustices associated with labeling, rejection and fear which make up stigma tattooed in imagery.

Leadership means being in a position to help others become better in the world of leprosy, better at advocacy and diplomacy. In parts of the world where stigma flourishes almost as certain as the sun rises from the East, galvanizing forces to extinguish stigma should be a top priority for all of us. This priority can be conceived and birthed via the creation of a leadership stipend. I will elaborate on this later in my presentation.

The opposite of the "Eye of Exclusion" is "The Eye of Inclusion." Research on other illnesses and conditions repeatedly show how engaging persons in decision-making protocols can lead to a greater level of empowerment. Collaboration with persons who can share their personal journey are able to attack the systemic barriers which contribute to stigma. Personal journeys are equivalent to being in the trenches while stigma bombs have been falling all around them. They see efforts that work, and are able to contribute to the lessening of trauma and stigma for others newly diagnosed. In essence, applied empowerment or self-empowerment become a powerful tool to rebuild the lives dismantled by stigma. The Law of Silence is overpowered by The Law of Knowledge.

ILEP will soon embark on a project to update existing data on written laws that allow discriminatory practices against persons affected, laws that disregard the negative results –stigma. Governmental insensitivity and community attitudes, intentionally or unintentionally, join forces to cause much harm to persons locked up in a cycle of stigma. This cycle can traumatize one so severely that they cease seeking treatment and support. This is why the spread of the highly toxic attitude of stigma must be stopped.

So, how can this be possible? Some generic recommendations which I consider hallmarks of collaboration include:

1. Create a standard definition of stigma and cease the anointment of persons affected as having self-stigma and creating an image of "victim". With 4,000 years of toxic imagery, how can we be blamed for stigma?

2. Spawn creative reforms such as funding a Leadership Stipend for persons affected by leprosy. Leadership is not learned by osmosis but by mentoring.

3. Kick down the doors to the board rooms and paid positions to become a part of the empowerment process and truly foster an era of collaboration. Remember that our brains and hearts do not stop functioning because of leprosy.

4. Include women affected by leprosy in all aspects of diagnosis, treatment, advocacy and leadership. Even though leprosy affects twice as many men as women, they experience a much greater level of stigma.

5. Adopt a statement of collaboration and strength such as "See the whole person, not the toxic images" and share with *ALL* media, in particular social media.

6. Collaborate on establishing one unified World Leprosy Day. Collaborations with common themes such as STOP STIGMA or STIGMA HURTS can enhance the education of young minds. Stigma is a form of bullying, so when children live in environments where degrading terminology is used, they learn to fear and ostracize those they label. When children live in an accepting environment, they learn to understand the inappropriateness of pejorative terminology and labels.

7. Stand up and be heard when degrading terminology is used and correct the offender.

In closing, I would like to share my personal goal on the issue of stigma. I would like to evict from society the actions, practices and laws which contribute to stigma. If my mother were alive today, I would want her to know her tears now would be for joy as I have traveled the world to meet many more of my siblings. She would also be elated that one of our own is a saint... Saint Damien. I am not a patient. I am not the only sinner on earth. I am not a "leper".

I likely caught leprosy after eating the meat of a nine banded armadillo when I was young. I consider this unique looking mammal as part of my extended family and am proud to forever be linked to the word zoonosis. I am, José Ramirez, Jr., and my labels include son, brother, husband, father, uncle, advocate, social worker, presenter at the Vatican City and much more. ■

4. Access to Education, Work and Marriage

PROF. YOZO YOKOTA
President of the Center
for Human Rights Education
and Training,
Japan.

Introduction

First of all, I wish to express my heartfelt gratitude to the organizers of this historic conference on various aspects of leprosy or, more appropriately, "Hansen's disease". I am particularly thankful to the Pontifical Council for Health Care Workers and the Nippon Foundation. It is my great pleasure and honor to address its second session which focuses on Hansen's disease and human rights.

As regards the many categories of human rights, from civil and political rights to economic, social and cultural rights, that have been gravely violated in the case of many persons affected by Hansen's disease and their family members, I would like to shed particular light on three fundamental social rights, namely (a) the right of access to education; (b) the right to work; and (c) various rights relating to marriage, the family and social services. I will do so because these rights are basic to maintaining human dignity, physical integrity, the search for spiritual fulfillment and the enrichment of one's life, yet they have been broadly restricted, or even denied, in the case of most persons affected by Hansen's disease and their family members.

1. Two Important Documents on which this Presentation is Based

Before coming to the three categories of human rights that I will focus on, I should mention two important relevant documents of the United Nations on which my presentation is based. One is the Universal Declaration of Human Rights adopted on 10 December 1948 by the UN General Assembly. This document was initially understood as a recommendatory, or legally non-binding, instrument because the General Assembly was not a world legislature. However, over the years, through consistent reference and endorsement by various international human rights treaties and conventions adopted and ratified by large numbers of States, and even by some national Constitutions, many international human rights experts today argue that the Universal Declaration has gained the status of a legally binding human rights instrument. For this reason, the UN-published volume containing various human rights treaties and conventions lists the Universal Declaration at the top of all human rights instruments, naming it the "International Bill of Human Rights". In my presentation, I will refer to it as "the Universal Declaration" for short.

The second document that I will use in this presentation is the "Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members", or "the Principles and Guidelines" for short. This document was adopted by the UN Human Rights Council in September 2010 and then endorsed by the General Assembly in December of the same year. Strictly speaking, these Principles and Guidelines are not legally binding. However, many of their provisions are based on the Universal Declaration, applying it more specifically to the actual and concrete situation of persons affected by Hansen's disease and their family members. The relationship between these Principles and Guidelines and the Universal Declaration is well summarized in Principle 1 of the Principles and Guidelines. This reads: "[P]ersons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights". In other words, these Principles and Guidelines are the application of the provisions of the Universal Declaration to the concrete cases of persons affected by Hansen's disease and their family members. As such, they have a certain legal weight which emanates from the binding nature of the Universal Declaration.

2. The Right of Access to Education

The right of access to education is a human right that is important in itself but it is also fundamental because without adequate education people cannot fully enjoy many other categories of human rights, such as the right to work, the right to property, the right to political participation, the right to health, the right to defend one's interests, the right to lead a satisfactory spiritual life, and the right to engage in cultural activities.

This is why the Universal Declaration has a detailed provision in Article 26. Paragraph 1 of Article 26 begins by clearly stating that: "[E]veryone has the right to education". Because education is very important and fundamental, the same paragraph goes on to say that: "[E]ducation shall be free, at least at the elementary and fundamental stages". It also lays down that "[E]lementary education shall be compulsory".

In spite of the importance and fundamental nature of the right of access to education, many persons affected by Hansen's disease and their family members, particularly children, have been deprived of the enjoyment of this basic human right.

For instance, children found to be infected with Hansen's disease have in most countries been forcefully hospitalized and made to stay there for life. They have been separated from their families and friends and have lost the opportunity to attend schools and engage in studies. Even if they may not have been infected with Hansen's disease themselves, children whose family members were found to be infected have commonly faced serious discriminatory treatment at school that hinders them from benefiting from normal learning opportunities. For instance, the son of a former Ethiopian patient with Hansen's disease who was not infected related that in classroom at school he was given a separate table and chair away from the rest of his classmates, and at lunch time he was not allowed to eat at the same table with his friends. As a result of such treatment at school, most classmates avoided close contact with him and he was totally isolated. This created an adversarial atmosphere and harsh conditions for this boy in his studies at school. During a decade of visiting Hansen's disease hospitals, sanatoria and communities in various countries, I have heard very many testimonies that children of persons affected by Hansen's disease had experienced similar discriminatory treatment, sometimes even bullying, at school.

This is why Guideline 8 of the Principles and Guidelines states unequivocally that: "[S]tates should promote equal access to education for persons affected by leprosy and their family members". All States must act immediately to carry out the task demanded of them in this Guideline.

3. The Right to Work

The right to work is another category of social rights that many persons affected by Hansen's disease and their family members have generally been deprived of. In many countries, a person who is found to be infected quite commonly loses their job because of a fear of possible infection by other workers, although such fear has been demonstrated to be scientifically and medically unfounded. It is usually the case that even uninfected persons lose their jobs when one of their family members is found to be infected.

This is the reason why Guideline 7 of the Principles and Guidelines affirms that: "[S]tates should encourage and support opportunities for self-employment, the formation of cooperatives and vocational training for persons affected by leprosy and their family members, as well as their employment in regular labor markets".

The right to work is fundamental for everyone when it comes to leading a normal and meaningful life with dignity, as well as sustaining a happy and harmonious family. Article 23 of the Universal Declaration, therefore, states that: "[E]veryone has the right to work, to free choice of employment, to just and favorable conditions of work and to protection against unemployment". Nevertheless, persons affected by Hansen's disease and their family members have been deprived of the opportunity to enjoy this fundamental human right.

Persons affected by Hansen's disease and their family members should enjoy equal opportunities to engage in "decent work" and should never be discriminated against at the level of employment, wages, working conditions or promotion because of Hansen's disease.

4. Rights Relating to Marriage, the Family and Social Services

The most often cited discrimination connected with Hansen's disease involves rights relating to marriage, the family and social services. An Indian lady, for example, complained that her engagement was cancelled when it was found out that her brother had been hospitalized for leprosy treatment. Another Indian lady told me that after having led a happy married life with her husband and after having had three children she was subject to divorce because one of her family members had been found to be infected with Hansen's disease. A Japanese man who had been diagnosed with Hansen's disease was forcefully hospitalized and left his family behind him. In his case, he had to change his name and identity so that his family would not risk discrimination and ostracism in the community in which they lived.

A Japanese lady who had been forcefully hospitalized in a sanatorium at the age of twelve cried every day, asking herself why she could not go home and live with her family. She showed me a letter she had written to her mother at that time. It read: "Dear Mom, please come to see me and bring me home. I will be a good girl. I would do everything you tell me. I only want to be with you at home". She was released from the sanatorium only years later when the Leprosy Prevention Law requiring forceful hospitalization of Hansen's disease patients was repealed. While in the sanatorium she was sterilized and therefore could not have children.

Here is another story about a Chinese man who had been hospitalized in a Hansen's disease sanatorium for over thirty years. He was very happy when finally released after the change in legislation. When he reached his dear "home-sweet-home", which he had long dreamed of doing, he rang the doorbell, noticing his father's face, which had grown old, through a door window. The next thing he expected was for the door to be opened and a big smile of his father happily welcoming back his beloved son. However, what happened in reality was that the door window was closed again and the door was not opened. He rang the bell again and again, but there was no answer. He had to recognize that he was not welcome at home; even his father did not welcome him. When he told me this story, he, a man of over sixty, cried and cried, and he had to stop talking several times because he was unable to control his overwhelming emotion.

In Brazil, children of persons infected with Hansen's disease had to be separated from their parents and placed in the care of stepparents, usually far away from their hometowns, without knowing who their biological parents were. Finding out the natural parents of children who were forcefully separated because of Hansen’s disease is now a political issue in Brazil.

Such cases of infringement of rights relating to marriage and the family should be immediately stopped and any legislation allowing such serious violations of human rights must be repealed so that people will no longer suffer sorrow as a result of forceful separation from their families.

This is why Principle 2 of the Principles and Guidelines states: “[P]ersons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood”.

In addition, Guideline 4 of the Principles and Guidelines further stipulates that: “[S]tates should, where possible, support the reunification of families separated in the past as a result of policies and practices relating to persons diagnosed with leprosy”. In other words, the UN Principles and Guidelines not only prohibits family separation because of Hansen’s disease but also require States to assist in their reunification.

As regards the rights relating to marriage and the family, I wish to draw the audience’s special attention to the provision of Article 25, paragraph 1, of the Universal Declaration. This reads: “[E] veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control”. Many persons affected by Hansen’s disease and their family members did not enjoy all these rights of access to various forms of social protection and services. In almost all countries, persons affected by Hansen’s disease and their family members have been marginalized and forced to live well below acceptable living conditions and without the adequate social protection provided for in this Article.

There have been other types of denial of the right of access to social services such as the use of public transportation systems or entering a religious site. The Chinese man whom I referred to earlier was not allowed to get on a bus to go home because the driver knew that he had just come out of the Hansen’s disease sanatorium. An Indian lady told me that she was denied access to a Hindu temple because of her history of Hansen’s disease.

Conclusion

Persons affected by Hansen’s disease and their family members have long suffered from discriminatory legislation, policies and practices based on a misunderstanding of this disease and the stigma associated with it. They have been deprived of all the human rights and fundamental freedoms proclaimed in the Universal Declaration; in particular, the right of access to education, the right to work, and the rights relating to marriage, the family and social services, which are extremely important in themselves but also very fundamental to the enjoyment of other human rights and fundamental freedoms. This situation should be corrected immediately and the necessary remedies should be provided to the victims as soon as possible. ■

FRIDAY 10 JUNE

ROUND TABLE

The Contribution of the Church and Other Faith Communities

1. The Catholic Church: the Results of the Survey of 'The Good Samaritan' Foundation on the Activities and the Projects of the Catholic Church for Care of People with Hansen's disease

DR. CLAUDIA DI LORENZI
'The Good Samaritan' Foundation,
the Holy See

We would now like to describe the results of the survey carried out by 'The Good Samaritan' Foundation' on the projects, centres and initiatives connected with the Catholic Church in the world that are involved in the fight against Hansen's disease.

Some months ago we drew up an *ad hoc* survey tool, a questionnaire which many of you have received and which we brought to the attention of all the Bishops' Conferences in the world and all apostolic nunciatures.

We received replies from over *760 dioceses* of all the continents of the world and the results are, in summarising form, as follows.

Cases of leprosy were encountered *in 187 dioceses (24.6%)*, prevalently in Asia and Africa, with a few cases in South America and Australia. In contrary fashion, in *573 dioceses (75.4%)*, in the United States of America, Europe, Chile and Ghana, cases of leprosy were not reported.

Looking at recent cases, over the last five years the number of new cases has undergone strong oscillations in various countries, moving from *no new case* (as happened in the diocese of Yokohama in Japan, or in the diocese of Taipei in Taiwan) to about *2,000 new cases* in Argentina. In general, a high number of cases were recorded in the diocese of Guayaquil in Ecuador *(426)*, in Tanzania with *799 cases* in its 34 dioceses, and in Bangladesh where in the two dioceses alone of Dinajpur and Khulna there were *1,289 cases*. In Tanzania there was a higher number of patients with the disease under the age of fifteen amongst the new cases, *135*, with *50* such cases in Bangladesh.

In addition to numerical data, we were also interested in understanding the *conditions of life of people with this pathology*, where they live, and the health-care services to which they have access. In general, according to the data that was received from the dioceses, people with Hansen's disease live in conditions of separation from the rest of society because of prejudice about the possibility of contagion and the difficulties of a cure that persist even though the scientific evidence – as the papers given yesterday indicated – go in the opposite direction. In many cases, people with leprosy live in their homes with their families but often they are distanced and stigmatised by their own family relatives. The most fortunate are received into leper colonies or hospitals and treatment centres. But there is a significant number who live in conditions of extreme poverty and total marginalisation, without shelter or drinking water or health care, whether specialised or even basic in character, and they are forced to live where they can, for example in railway stations, parks or the street.

In some hospitals they are denied treatment and resort is made to treatment at home. If the person with leprosy is an immigrant in a reception centre, in some countries such as Australia he or she does not have access to the care and treatment of the national health service.

People with leprosy – but whose state of health is not grave – who look for a job are often discriminated against: in Ecuador, in the diocese of Babahoyo, they are badly paid and have difficulty in finding a full-time job.

On the other hand, there are also situations where the patients live freely, are independent and receive adequate medical care and treatment, as happens in Japan, in the diocese of Yokohama, or in the diocese of Harare in Zimbabwe, where people with leprosy are helped by a group of Franciscan friars.

As regards the *primary needs of people with leprosy*, the answers were rather homogenous. Here one is dealing with high-quality medical support, drugs and medicines, laboratory examinations, food, clothes and shoes for the poorest of them, and then accommodation, a healthy diet, general hygiene, and the sacraments from baptism to communion and from confirmation to the anointing of the sick. And then there is also psychological and spiritual assistance.

In the same way, people affected by leprosy need to overcome the *stigma* that has afflicted them and to enter into contact, see and communicate ‘normally’ with other people in society without any form of discrimination. And also to find satisfaction in a job that takes them out of their ‘ring fence’ and enables them to become ‘generators of income’. If it is children who have this disease, then a service of distance education is required, that is to say schooling at home.

As regards the subject of *access to care and treatment*, in almost all the countries drugs and medicines against leprosy were available (except in Ecuador and some regions of India), even though in terms of quantity they are insufficient, and the same applies to the dioceses. On the whole, these are free drugs and medicines or ones that are readily affordable. Only countries such as Zimbabwe and Bangladesh reported prohibitive costs for such medical products.

In all cases national and local *public health-care institutions* treated people with leprosy free of charge, and judgements about the quality of the services and the help provided were on average satisfactory. One is dealing here with services involving traumatology, cardiology, physiotherapy, general medicine, laboratory analyses, the treatment of wounds and ulcers in particular, and – because in many cases the age of the patients is high – forms of treatment for illnesses typical of old people as well. And then there is activity involving prevention and early diagnosis, the distribution of medical products, food, clothes, shoes, and also the availability of housing and shelters.

However at times access to care and treatment is undermined by other factors and there were concrete *obstacles* to this in half of the countries contacted by the survey. Amongst the elements that compromise continuous and effective care for people with leprosy there are: a low level of prevention and monitoring; a lack of continuity in treatment and of formation and education about the disease; and prejudice, discrimination, indifference on the part of the community to which people with leprosy belong and their families, with these people suffering the affliction of stigma and marginalisation.

A special case is Japan where an old law for the prevention of leprosy fostered the rooting of a social prejudice and discrimination. From the diocese of Douala in Cameroon we learnt about the absence of health-care personnel who were trained in, and capable of carrying out, an early and correct diagnosis, of drugs and medicines that were not accessible, and in substantial terms a lack of interest in the fight against leprosy which has been declared to be eliminated. In Tanzania it is the excessive distance between people’s homes and the centres of treatment which obstructs diagnosis and treatment.

As regards *the attitudes of local communities* towards people with leprosy, activities involving information and sensitisation have in some cases fostered greater acceptance of people with Hansen’s disease, but in general a great deal remains to be done because in the majority of cases the prevalent attitude is that of indifference or rejection.

To come in specific terms to the *contribution offered by the Catholic Church*, almost all the countries surveyed reported activities, projects, and services made available by the local Churches. Where initiatives were not indicated this was because of a lack of economic resources or – as is the case in Australia – because the incidence of this disease is so low that action by the Catholic Church is not required.

In concrete terms, the Church is present as regards this challenge through the offer of *variegated* services which range from the treatment of patients in centres and hospitals of dioceses to the supply of food, clothes and shoes, and then activities involving counselling, health-care education, and initiatives for the social reintegration of patients who have been cured of the disease.

Local Churches do not fail to provide *spiritual assistance* to their patients, as well as the administration of the sacraments (baptism, communion, confirmation, the anointing of the sick) and Holy Masses, and usually there is a total taking of responsibility of them. In Zimbabwe a community of Franciscan friars and priests takes care of people with leprosy and lives with them.

There are *hospitals and health-care centres connected with dioceses*. In Haiti there is the Dermatological and Infectious Diseases Institute (the Fame Pereo Institute for Lepers), which was founded by Cardinal Leger, as well as a hospital named after him and managed by the Missionary Sisters of Christ the King which is responsible for a programme for the fight against leprosy and care for people with leprosy. In Cameroon, the diocese of Douala manages the leper colony of Dibamba. In Korea, the Archdiocese of Daegu runs the Skin Care Hospital whose origins go back to a hospital that was specialised in combatting leprosy. In Tanzania there are four centres connected with the dioceses: the Nazareth Leprosy Centre (in the diocese of Ifkara); the Busanda Camp and the Kolandoto Camp (in the diocese of Shinyanga); the Kabanga Referral Hospital (in the diocese of Kigoma); and the Prevention of Disabilities and Reconstructive Surgery Centre (at the Turian Hospital). These are centres which offer diagnoses, treatment, nursing, reconstructive surgery, medication, food, shoes, clothes, and admission. The diocese of Harare in Zimbabwe is responsible for the Mutemwa Leprosy Catholic Care Centre. In Bangladesh, the diocese of Dinajpur has created the Centre for Leprosy Control. In Taiwan, the diocese of Taipei created the St. William Catholic Church which is managed by the Combonian missionaries together with the Jesuits.

Some dioceses are involved in activities that are directed towards diminishing prejudice and fund gathering to provide economic support to the poorest leprosy sufferers. There is no absence of study meetings, activities involving teaching, and the offer of occupational activities directed towards the reintegration of people who have been cured of leprosy.

For the most part these are *projects* involving individual dioceses which are long-term (over five years in length) and directed towards the general population irrespective of age band, and whose *objectives* are activities involving prevention, medical treatment, surgical operations, assistance for patients and their families, the raining of health-care workers, and information and education for the local population.

Almost everywhere there is a *lack* of economic resources and a low level of information amongst the local population, and often there is a lack of medical and nursing staff, institutions and equipment, and also difficulties at the level of logistics.

Even though in the majority of cases these projects form a part of diocesan programmes for pastoral care in health, the level of *involvement of the activities of the Church community* is at an average level and is certainly capable of improvement. ■

2. The Contribution of Hinduism

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Hinduism is the religion of the Hindus which has been supreme in India. It is the oldest of all religions. It was not founded by a prophet. No date can be fixed for the establishment of Hinduism. Hinduism was not born from the teachings of particular prophets. Hinduism is also known by the name '*Sanatana-Dharma*' which means eternal religion.

Hindu scriptures are the oldest in the world. The Vedas are the foundational scriptures of Hinduism. They hold that the Vedas are without beginning and without end.

I am proud to belong to a religion which has taught the world both tolerance and universal acceptance. We believe not only in universal toleration: we also accept that all religions are true. With approximately one billion followers, Hinduism is the world's third largest religion in population terms, and the majority religion in India, Nepal, Mauritius and Bali (Indonesia).

Hinduism prescribes eternal duties such as honesty, refraining from injuring living beings (*ahimsa*), patience, forbearance, self-restraint and compassion.

The term *Hinduism* was introduced into the English language in the eighteenth century to denote the religious, philosophical, and cultural traditions native to India.

Swami Vivekananda was a key figure in introducing Hinduism to Europe and the USA, raising inter-faith awareness and making Hinduism a world religion.

Hindus believe that all living creatures have a soul. The soul is believed to be eternal. They worship the Supreme Being variously as Vishnu, Brahma, Shiva or Shakti, depending on the sect to which they belong.

A Hindu temple is a house of god(s). It is a space and structure designed to bring human beings and gods together and it is infused with symbolism to express the ideas and beliefs of Hinduism.

Two factors which have been common to all traditions and have survived many crises are the family and religion. These were the decisive factors that played a role in shaping attitudes to leprosy and practices connected with it in society. The family as a basic social unit played a crucial role in uniting and supporting its members and giving them a social identity. Like the family, religion also pervaded all spheres of life as a major force behind all social decisions and activities. This scenario has not changed much in spite of all global modern developments.

Punishment by God the Divine Force

People are the same all over the world in their treatment of people affected by leprosy. For several centuries these people were discriminated against, segregated and isolated from society. In India these segregated people live in nearly 800 leprosy colonies all over India. The Christian missionaries were pioneers in starting leprosy hospitals to provide various services to leprosy patients and promote their wellbeing. We all know the service of Father Damien who went to the Molokai Islands to mitigate the sufferings of people with leprosy on that island. He lived with them.

There is a belief in divine punishment in all religions and people tend to accept the condition of leprosy-affliction as something they deserve.

India preserves many old scriptures. There are references to the disease of leprosy in the Sanskrit hymns of the Atharva Veda which was composed before the first millennium BC. Those who indulge with prostitutes, commit adultery and lead an impure life contract leprosy. Kautilya's *Arthashastra* mentioned leprosy in 1500 BC. It disqualified a leprosy-affected person (among other categories of handicapped people) from inheritance but entitled him or her to maintenance by his or her family. Another scripture, *Dharmashastra* (the Hindu doctrines of righteous living), says that suicide by leprosy patients was permitted by many Hindu religious books. The scripture *Matsya Puran* said that Samba, the Son of Lord Shri Krishna, was cursed by his father with leprosy because he was vain. Samba was cured by worshipping Lord Surya, the Sun, who is the source of all energy and the healer of skin diseases. We can see this in Hindu Sun temples. In *Mahabaratham* Krishna cursed Ashwathama with a terrible leprosy that would haunt him for 3,000 years. The scripture *Garuda Purana* says that a murderer of a virgin will become a leprosy sufferer. *Sushrut samhita* in 600 BC gives s reasonably good account of the clinical symptoms and treatment of leprosy.

Hindu scriptures have provided elaborate commentaries on 'why people suffer'. The theory of Karma is propounded to explain all kinds of suffering. Karma implies that if one has committed misdeeds in previous births, one must inevitably bear the consequences. Leprosy suffering was considered a punishment for the sins of previous births and one is called upon to accept it as a divine retribution.

I am happy that in this Jubilee of Mercy the subject of this symposium is: 'Towards Holistic Care for People with Hansen's Disease that Respects their Dignity'. The dignity of people affected by leprosy and their empowerment depends upon the attitude of society. If you want to give dignity to them you should address them with dignified terminology as people who are affected by leprosy. My request is never to call them a 'leper'. In no other disease is a person called by the name of the disease. Mahatma Gandhi was the first person to advise the world 'not to use the word leper'. Help these people to develop in the social and economic conditions that exist. The Hindu organization Ramakrishna Mission provides social and economic rehabilitation services to leprosy- affected people in India.

The success of a leprosy control service programme in India will largely depend on how much it can draw on the traditional resources of society. In a country like India, where religion pervades all domains of life, there is nothing wrong if leprosy services can access the immense resources of religious institutions. Many NGOs are now trying to involve the spiritual leaders of different faiths in social and developmental programmes.

Mr. Yohei Sasakawa has spent almost forty years in an effort to eliminate leprosy as a public health problem. This has been his life's work. He has worked tirelessly with the World Health Organization, governments of endemic countries, and international and local NGOs. As the WHO Goodwill Ambassador for Leprosy Elimination, Mr. Sasakawa not only visits leprosy-affected people at leprosy sanatoriums and colonies around the world. He also solicits the support and cooperation of Heads of State and the media wherever he goes in order to spread correct knowledge about leprosy and to deliver the message that leprosy is curable, that treatment is free and that social discrimination must find no room.

In the year 2003 Mr. Sasakawa took the initiative of approaching the Office of the UN High Commissioner for Human Rights to report leprosy-based discriminations. In 2005 and 2006 he worked vigorously with the UN Human Rights Council on this issue. The UN Human Rights Council in September 2010 unanimously passed a resolution in favour of the elimination of discrimination against people affected by leprosy and their family members. Later the UN General Assembly formally adopted this resolution. This was truly a historic event and it was made possible by the persistent efforts of Mr. Yohei Sasakawa.

'Sectarianism, bigotry, and its horrible descendant, fanaticism, have long possessed this beautiful earth. They have filled the earth with violence, drenched it often and often with human blood, destroyed civilisation and sent whole nations to despair. Had it not been for these horrible demons, human society would be far more advanced than it is now' (Swami Vivekananda).

If there is no stigma and discrimination, leprosy-affected people can live with dignity. I strongly believe that all uncharitable feelings of discrimination against leprosy-affected people will come to an end if we all work together to eradicate leprosy. ■

Note

Material was collected from the Acworth Leprosy Museum in Wadala, Mumbai. Web address: www.theacworthleprosymuseum.org

3. Hansen's Disease: the Contribution of Buddhist Communities

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Introduction

In general, both illness and death are understood as natural events for all living things. They are not to be feared. It is most important that suffering is relieved. Clarity of consciousness is also important. Illness and death are to be faced as clearly and as wholeheartedly as possible while pain is relieved. They are not unnatural enemies but simply conditions to be taken care of.

The Buddha always informed his disciples that this life is very fragile and short. He told them that it was helpful to contemplate regularly on this fact. In his words: "For what good reason should man or woman, lay folk or monk, often contemplate on the fact that they are 'sure to become sick and cannot avoid it'? Beings while healthy take pride in their good health; and infatuated by that pride of health they lead an evil life in deeds, words, and thoughts. But in him who often contemplates on the fact (of the certainty of illness), the pride in being healthy will either vanish entirely or will be weakened. For that good reason, the fact (of sickness) should be often contemplated".[1]

Illness is not a suitable condition for *Dhamma* practices. Lord Buddha said that birth, aging, sickness and death are the four unavoidable dangers of humanity. He tried to support ill monks in order to encourage their rapid recovery. There are many topics in Buddhist disciplines that support an ill monk in living an easier life, in the same way as the Buddha allowed monks who were ill to behave differently: "Monks, you should not enter a village with your sandals on. Whoever should (so) enter it, there is an offence of wrongdoing … I allow, monks, a monk if he is ill to enter a village with his sandals on".[2]

The Buddhist approach to health and healing is an emphasis on spiritual practice. Buddhism asserts that spiritual practice makes it possible for an individual not only to see opportunity for practice in the face of adversity, including sickness and injury, but to use this opportunity for personal transformation and transcendence.

Buddhist practice allows a deep awareness of cause and consequence and insight into the nature of conditioned interdependence. Choice and practice are the two factors that the Buddhist patient has most control over. As a result of precept practice, meditation practice and skillful choice, the Buddhist patient suffers less and has a greater feeling of confidence and well-being.

Buddhism does not tell the patient the meaning of sickness; rather, it tells him what he needs to do. Buddhism is a present moment path of action in life, sickness and death. A Buddhist cannot change the past, but he does have some control over the future if he can act with skill and clarity in the present.

However, this paper is an attempt to present how the Buddhist community can contribute, by applying the Buddhist concept of health care, to the problem of Hansen's disease, and especially to reducing stigma and discrimination.

The Situation of Hansen's Disease in Thailand

The prevalence rate of leprosy in Thailand was approximately 5 per 1,000 in 1953. A specialized leprosy control program was first launched in 1956 in Khon-Kaen Province and it gradually expanded to cover the whole country in 1972. After a successful control, it was partly integrated into Provincial health services in 1971 and was fully integrated into the primary healthcare system in 1976. Effective case-finding in combination with chemotherapy using the WHO multidrug therapy regimen and health education brought about a decline in the prevalence of the disease to only 0.537 per 1,000 in 1987.[3] Thailand was able to eliminate leprosy by 1994, eleven years before the goal set by the World Health Organization – 2005 – when the country eliminated leprosy as a public health problem. Then, in 2013, seven years before the 2020 target date of the World Health Organization, Thailand was recognized as having met the criteria for a sustainable elimination of leprosy. These achievements would not have been possible without the vision and initiative of H.M. King Bhumibol Adulyadej who initiated the project to control leprosy in Thailand under the Ministry of Public Health in 1956.[4]

As regards the leprosy situation in Thailand[6] (as of December 15, 2015), there are currently 527 Thai leprosy patients. Out of these patients, there are 115 who were newly diagnosed as having the disease in 2015. There are 20 cases or 13 % of disability (level-2 disability) among those who are newly affected. The incidence has been decreasing since the year 2011 and the new cases are 405 with 60 cases of level-2 disability. It is evident from the past 5 years (2010-2014) that new patients with level-2 disability are at 10-17 percent.

The World Health Organization has set a target of reducing the number of new leprosy patients worldwide to no more than 100 per million people by the year 2020. The Ministry of Public Health has set a target of reducing the number of new leprosy patients in Thailand to no more than

100 and reducing the incidence of level-2 disability in newly diagnosed leprosy patients to 0.3 of 1 million (20 cases) by 2020.

The Department of Disease Control of the Ministry of Public Health has accelerated its activity in two major areas:[7] 1) the search for leprosy patients in areas with epidemiological indications, and through home contacts with patients, in order to immediately find new cases in a community and to obtain standard treatment so as to reduce the spread of leprosy in the community and reduce the incidence of level-2 disability in new leprosy patients; and 2) the development of a network for the rehabilitation of leprosy patients through a survey of disability and the socio-economic problems and needs of leprosy patients in order to obtain appropriate rehabilitation or self-reliance.

Apart from the successful control of leprosy, Thailand has also succeeded against HIV and AIDS. In the year 2016,[8] Thailand received validation from the WHO for having eliminated the mother-to-child transmission of HIV and syphilis, becoming the first country in Asia and the Pacific region and also the first with a large HIV epidemic to ensure an AIDS-free generation. The Minister of Health of Thailand was presented with the certificate of validation during a ceremony that took place in New York on the eve of the United Nations General Assembly High-Level Meeting on Ending AIDS. "This is a remarkable achievement for a country where thousands of people live with HIV. Thailand's unwavering commitment to core public health principles has made elimination of mother-to-child transmission of HIV and syphilis a reality, a critical step for rolling back the HIV epidemic. Thailand has demonstrated to the world that HIV can be defeated", Dr. Poonam Khetrapal Singh, Regional Director, WHO South-East Asia Region, said when presenting the certificate of validation to Thailand in New York.

However stigma and discrimination are still among the foremost barriers to HIV prevention, treatment, care and support. Specifically, research has shown that stigma and discrimination undermine HIV prevention efforts by making people afraid of seeking information about HIV, as well as services and ways of reducing their risk of infection and adopting safer behavior to avoid these actions provoking suspicion about their HIV status. Research has also shown that fear of stigma and discrimination, which can also be linked to fear of violence, discourages people living with HIV from disclosing their status even to their family members and sexual partners and undermines their ability and willingness to obtain access, and adhere, treatment. Thus, stigma and discrimination weaken the ability of individuals and communities to protect themselves against HIV and to stay healthy if they are living with HIV.[9]

Stigma and Discrimination towards People with Hansen's Disease in Thailand

Leprosy-related stigma appears to be common in Thailand and other leprosy-endemic countries. Its manifestations have a negative impact on the affected persons and their families. Stigma has an effect on the lives of persons affected by leprosy in both socio-economic and physical terms. People affected may face social rejection, lose social status and gradually become isolated from society, family and friends. The main manifestations of stigma in many studies have been that people affected by leprosy try to conceal their disease and practice self-isolation. Communities express their negative attitudes towards people affected by leprosy by avoiding them, by forcing them to go to a leprosy colony, and by refusing to share public transport with them. It has been found that community members perceive that people affected by leprosy or tuberculosis are stigmatized by the community. However, community members perceive more stigma towards leprosy than towards tuberculosis, particularly in terms of shame, embarrassment, and problems in getting married. Community members perceive negative attitudes towards people affected by leprosy or tuberculosis. A majority of respondents consider that both people affected by leprosy and people with tuberculosis have been treated poorly by others in the community.

In Thailand,[10] leprosy-affected people are still also stigmatized by health providers and by their neighbors. Some leprosy patients have been shunned and refused treatment for their ulcers by nursing aid, resulting in delay in diagnosis and poor compliance with treatment in many of them. Before applying for certain types of work, an applicant needs confirmation from a doctor that he/she does not have leprosy. However, stigma manifestations and effects may differ depending on a person's external appearance, status, gender and social distance to those who stigmatize.

Intervention to Reduce Stigma and Discrimination against People with Hansen's Disease in Thailand

To prevent stigma and to reduce the manifestations that cause so much suffering to individuals and their families, effective intervention is needed. This systematic review aims to identify forms of intervention that have been used to reduce such stigma and to assess their efficacy. Forms of intervention implemented to reduce leprosy stigma in various studies are presented in five categories: the integration of leprosy services into general health care; information, education and communication (IEC) programs; socio-economic rehabilitation (SER); changing the name of the disease; and counselling.

Integrated services. Following trends in the international community, leprosy services in Thailand have gradually been integrated into the general health care system starting in 1973. This process was completed in 1998. However, the monitoring and evaluation report of the National Leprosy Elimination Plan (1994-1996) did not mention whether leprosy-related stigma had decreased, despite the fact that enabling people affected by leprosy to live with dignity in the 'normal community' was the major objective of the Plan.[11]

Information, education and communication (IEC). The Thai Leprosy Control Program (TLCP) carried out four IEC campaigns between 1996 and 2007 as a major part of the Leprosy Elimination Campaigns conducted to observe various special occasions of the present King, His Majesty King Bhumibol Adulyadej, who has kindly supported the TLCP since the beginning. Dissemination of knowledge was conducted at national, regional and provincial levels through leaflets, television, posters, radio, local performances and village radio announcements. After the first three campaigns, the number of newly detected cases had increased by 20% while the number of newly detected cases in subsequent campaigns decreased. There is no record of whether the stigma attached to leprosy changed as a result of the campaign.[12]

Socio-economic rehabilitation (SER). In Thailand, during the period July 1998 to June 2000, a study was launched to develop an appropriate model for community-based rehabilitation (CBR) and to improve the quality of life of people affected by leprosy. The research was undertaken in two phases. In the first phase, a research team spent three months in a community using anthropological tools to collect relevant information. People affected by leprosy were found to encounter different levels of stigmatization according to their relationships with relatives and friends, disability status, and social-economic status. In the second phase, the team encouraged local people to establish CBR through participatory identification and an analysis of the problems of people affected by leprosy and of other people with other disabilities. They participated in planning and in implementing rehabilitation activities. These activities included a disability survey; taking people with disabilities to hospital; registering people with disability in order to be eligible for government assistance; raising funds; organizing stores where people with disability worked as shopkeepers; and establishing disability development centers. However, the effect of the intervention on stigma reduction was not assessed.[13]

Changing the name of the disease. Thai people still use the terms *khi ruan* and *khi thut*, which translate as "leprosy" and "leprosy with disability", to degrade another person. An attempt to change the name "leprosy" to be "numbness skin disease" was initiated at a meeting of leprosy workers at national and regional levels in 2003. The new name was used by some regional leprosy programs in the IEC campaigns. The "Leprosy Clinic" of the National Leprosy Organization changed its name to "Numbness Skin Disease Clinic". There is no evidence to show to what extent the new name has changed attitudes towards leprosy.[14]

Counselling. Counselling for leprosy patients in Thailand has been done only in some health units, such as the outpatients department of the National Leprosy Organization, and in some regional and provincial health units. There is no evidence to show to what extent it has helped to reduce stigmatization.[15]

These forms of intervention have been carried out at different levels such as the intrapersonal level (counseling, encouraging self-care practice and socio-economic rehabilitation); the interpersonal level (home care teams: these consist of a doctor, a nurse, a pharmacist, a physiotherapist, a social worker, an occupational therapist, and health volunteers); the community level (education and contact); and the organizational level (education and contact).

An intervention study[16] was conducted to develop de-stigmatizing interventions aimed at reducing the stigma related to leprosy and to improve the quality of life of the people affected by it. This intervention study, analyzing three different approaches to de-stigmatization, showed that the most effective de-stigmatizing interventions were those that involved local stakeholders, including the beneficiaries themselves. Their involvement helps to facilitate the improvement of self-esteem and the social participation of people affected by leprosy and contact between people who are affected and other stakeholders. This results in a reduction of a community's negative attitudes.

The Buddhist Mission in Social Work

The Buddha was very compassionate towards all human beings. He realized how much human beings suffer mentally and physically. Therefore, he urged his first sixty well-disciplined disciples to go in different directions individually to propagate the *Dhamma* and to teach the attainment of inner peace. The *Mahavagga pali* contains the following words: "*Caratha bhikkhave carikam bahujana hitaya bahujana sukhaya lokanukampaya atthaya hitaya sukhaya sadevamanussanam. Desetha bhikkhave dhamman adikalyanam majjhekalyanam pariyosanakalyana sattham sabyanjanam kevelapparipunnam parisuddham brahmacariyam pakasetha* – O monks! Go on tour for the good of many people, for the happiness of many people out of compassion for the world, for the good and wellbeing and happiness of God and men. O Monks! Preach doctrines that are good at the beginning, good at the middle, good at the end, proclaim the pure noble life with meaning, in full, completely".[17]

With respect to the duty of a Buddhist monk to care for the sick, there is the story that the Buddha advised his disciples to take care of a sick monk. "Now at that time a certain *bhikkhu* was sick with dysentery. Then the Blessed One, on an inspection with Ven. Ananda as his attendant, saw the *bhikkhu* lying fouled in his own urine and excrement. The Blessed One sprinkled water on the *bhikkhu*, and Ven. Ananda washed him. Then the Blessed One had the *bhikkhus* assembled and asked them: 'Is there a sick *bhikkhu* in that dwelling over there?' 'Yes, O Blessed One, there is'. 'And what is his illness?' 'He has dysentery, O Blessed One'. 'But does he have an attendant?' 'No, O Blessed One'. 'Then why don't the *bhikkhus* attend to him?' 'He doesn't do anything for the *bhikkhus*, lord, which is why they don't attend to him'. '*bhikkhus*, you have no mother, you have no father, who might tend to you. If you don't tend to one another, who then will tend to you? Whoever would tend to me, should tend to the sick'".[18]

In Buddhism, persons belonging to any caste, both males and females, are eligible for membership of the Buddhist Sangha. There are many conditions in the process of ordination to be in the Order of Sangha. Those are as follows:[19]

1) The person who wishes for *Upasampada* must be a man.

2) He must have attained the prescribed age of 20 years calculated from conception (this is fixed by carefully counting the time spent in the mother's womb as six lunar months).

3) He must not be defective as a man, that is to say a eunuch (or defective in other ways lacking limbs, organs or deformed).

4) He must never have committed any serious crime, including a capital offence.

5) He must never have committed any serious offence according to *Buddhasasana*, such as committing a *Parajika* offence when previously ordained as a *bhikkhu*, and he must not have been a *bhikkhu* in the past who had wrong views and entered some other religion.

Regarding prohibition of those affected with some diseases, at that time ordained *bhikkhus* were seen who were afflicted with leprosy, boils, dry leprosy, consumption, and fits. This was told to the Buddha. The Buddha then observed:[20] "I prescribe, O *bhikkhus*, that he who confers the *upasampadâ* ordination, ask (the person to be ordained) about the Disqualifications (for receiving the ordination). And let him ask, O *bhikkhus*, in this way: Are you afflicted with the following diseases; leprosy (*Kuttham*), boils (*Gando*), dry leprosy (*Kilaso*), consumption (*Soso*) and fits (Apamaro)? …". The Buddha also addressed the *bhikkhus* (monks): "Let no one, O *bhikkhus* (monks), who is affected with the five diseases, receive the *pabbajja* ordination. He who confers the *pabbajja* ordination (on such a person) is guilty of a *dukkata* offence".

Leprosy (*Kuttham*) is the first of the five diseases to prohibit higher ordination. However, Navon's study in Thailand reported that Buddhism did not assign a unique status to leprosy. Although Buddhism officially forbade males affected by leprosy from fulfilling their traditional duty of joining the monastic order (for a period 3 months), it was revealed that this prohibition was not strictly enforced and had no adverse effects on the image of the disease.[21]

The Reduction of Stigma and Discrimination in Relation to HIV/AIDS in Thailand: Lessons Learnt for Hansen's Disease

The Interfaith Network on HIV/AIDS in Thailand – INHAT – works with the support of the GFATM and the NCA on the program of care and support. Apart from care for PLWHA and affected people through the setting up community rehabilitation centers, the INHAT also organizes TOT programs for them to play a role in organizing the process to convey the concept of community-based AIDS management by the community to volunteers for home visits. Using various tools to convey ideas such as S-A-L-T and After Action Review (AAR), they also promote using the tools at work and links to understanding and accepting PLWHA in order to reduce disgust and stigma in the community. These ideas will help to change the attitudes and work of volunteers, especially on home visits, where home visit teams often go as "givers" and view the person who is visited as a "recipient" and overlook the potential or strength of the person who is visited in managing his or her own problems.

The process of promoting learning for the volunteers of the rehabilitation centers aims to provide volunteers with an understanding of the processes and tools, especially S-A-L-T and AAR, and to practice the tools used to implement the core activities of volunteer roles, including home visits and counseling in order to contribute to the sustainability of AIDS management.

Self-Esteem Development for PLWHA and the SALT Group.[22] S-A-L-T is a way of working in harmony with the way human thinking is developed to respond to, and deal with, problems. Working with the S-A-L-T community empowers communities to use their potential and its strengths fully. And the community can handle its problems sustainably. Volunteers can apply S-A-L-T to home visits to discovering potential. The strength of HIV-infected people and the family is great. S-A-L-T stands for: - S – Share/Support/Stimulate; - A – Appreciate/Analyze; - L – Learn/Listen/Link;- T – Transfer/Team

Appreciation: Appreciation is the first important way of getting into the S-A-L-T community and involves appreciating what people, families and communities are doing or succeeding in (this may be a simple way of handling problems but works for the community and the individual).

Listening: Listening to learn is a way of making the community listen, learn, understand and appreciate the strength and the ability of people in the community so that they can manage their own affairs.

Support: Another important element is supporting people/the community. It is not necessary to support by giving material things: what is needed is encouragement and support after understanding, learning and appreciating potential/strength, including how to handle community problems. This is because people/the community (including ourselves) are often not aware of their own strengths.

Stimulation: Careful listening is also an important part and involves understanding and analyzing what we have heard from the community. This allows us to ask questions to stimulate the community so that they can analyze themselves and what they are doing. Questioning is very important for the volunteer teams in helping to share roles and support each other in generating questions that encourage the community to analyze the answers on its own. It is not the duty of the volunteer teams to give responses or suggestions as experts.

Analysis: In the use of S-A-L-T, volunteer teams need to analyze what they listen to and learn and to help in encouraging the community to analyze by having discussions and exchanges to understand the root causes of AIDS and other related issues.

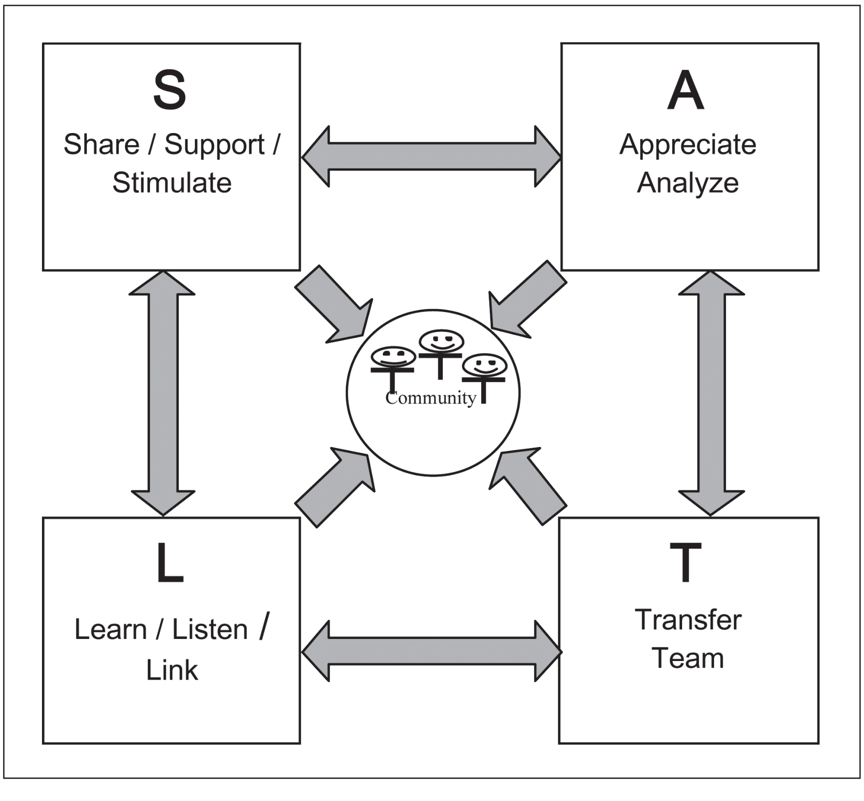
Linking: When they begin to talk with the community, volunteer teams may focus on meeting with someone or some groups only. It is essential to have links with other people in the community and to persuade all groups to participate and exchange ideas that will allow linking work in relation to other issues as well.

Transferring/Transmission: Transferring can take many forms. As regards the volunteer teams, they can bring what they have learned from one community and transfer it to other communities. And a community can directly transfer, exchange and learn with other communities, which may bring about changes in other communities as well. In addition, the volunteer teams can also stimulate the community to engage in exchanging, learning and transferring as regards lessons learnt from each other.

Practice and Review: A community visit with S-A-L-T is work involving a "learning-by-doing" approach. Then there must be a review to improve the process. Therefore, practice, review and development must be done alternately at all times.

Conclusion

The programs that aim to enable volunteers to understand the processes and tools are in particular "S-A-L-T" and "AAR". They help volunteers to improve their skills in using tools to implement core activities, including home visits and counseling, in order to reduce stigma and discrimination towards PLWHA and contribute to the sustainability of AIDS management in Thailand. This lesson about the reduction of stigma and discrimination, together with the Buddhist idea of health care, can be applied in response to the problem of Hansen's Disease, especially in the work of reduction of leprosy-related stigma and discrimination in leprosy affected areas around the world.



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Notes

[1] A.V 57 in Nyanaponika Thera, 1975: 12.

[2] Vin.IV in Horner, 1982: 260.

[3] https://www.ncbi.nlm.nih.gov/pubmed/3217829

[4] Ramasoota, Teera, The History of Leprosy in Thailand, Masterkey Co., Ltd., Bangkok, 2016. p 5.

[5] Chiangmai Leprosy Colony, founded by James McKean in 1908 (source: McKean Rehabilitation Center).

[6] ThaiHealth Fund: http://www.thaihealth.or.th/Content/30249-สถานการณ์โรคเรื้อนในประเทศไทย.html.

[7] *Ibidem*.

[8] http://www.searo.who.int/mediacentre/releases/2016/1627/en/

[9] http://www.unaids.org/en/resources/documents/2014/ReductionofHIV-relatedstigmaanddiscrimination

[10] Silatham Sermrittirong, Stigma in leprosy: concepts, causes and determinants, http://www.lepra.org.uk/platforms/lepra/files/lr/Mar14/1835.pdf, p. 37.

[11] Silatham Sermrittirong, *Stigma and stigma interventions related to leprosy and tuberculosis in Thailand*, Ridderprint, Ridderkerk, The Netherlands, 2014. p. 74.

[12] *Ibid*., p. 75.

[13] *Ibid*., p. 76.

[14] *Ibid*., pp. 76 – 77

[15] *Ibid*., p. 77.

[16] *Ibid*., p. 139.

[17] Mv 1.11.1 p. 21.

[18] Mv 8.26.1-8.

[19] Sompong Suvannaphuma, 'LIVING IN PEACE: THE HARMONIOUS SOCIETY', *Journal of MCU Social Development*, vol.1 n.2, May-August 2016, pp.42-56.

[20] http://www.sacred-texts.com/bud/sbe13/sbe1312.htm, p. 76.

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[22] INHAT Team,คู่มือวิทยากรแกนนำอาสาสมัครศูนย์ฟื้นฟูคุณภาพชีวิตในชุมชน (ครู ก.): กระบวนการเสริมสร้างความสามารถในการจัดการปัญหาเอดส์, , p.16.

THIRD SESSION

GOOD PRACTICES AND TESTIMONIES

1. The Current Status of Leprosy in India and the Role of the Indian Catholic Church in Reaching out to Socially Excluded People Affected by Leprosy

FATHER ARPUTHAM ARULSAMY
Associate Director of the Catholic Health Association of India

'Leprosy work is not merely medical relief but it is transforming the frustration of life into joy of dedication and personal ambition into selfless services' – Mahatma Gandhi.

"This is my new life and I am indebted to my Ma [mother]," says Gundeli Bai, who has lost fingers on both hands due to leprosy. "I would have died, and my body could have been eaten by dogs long ago," says Bai, who has been living for more than two decades in the Harsha Nagar (joyful city) enclave, started by her "Ma," [an Augustinian nun]. The enclave is at Sendhwa, a village in Barwani district in the central Indian state of Madhya Pradesh for leprosy patients.

The septuagenarian Bai says her parents had died early, and after she was detected with leprosy, her only sister left her on the road. At the enclave, she earned the nickname "Sundari Bai" (beautiful woman) because of her cheerful disposition. Sundari Bai is among 258 Leprosy patients from 85 families living in Harsha Nagar enclave.

The Sub Divisional Magistrate Mahesh Badole, who is also the President of the Harsha Nagar Trust, says, "[The sister] provided proper accommodation for every family in the [enclave] with the resources she had mobilized …." What impresses him is that the nun cleans the wounds of the Leprosy patients and dresses them "one after another, every day, without any hesitation, as if caring for a small kid."[1]

This story vividly depicts the self-sacrificing life of hundreds of invisible nuns of various religious Congregations and their lay coworkers in India who have found joy in serving people infected/affected by leprosy (Hansen's disease), irrespective of caste, color, creed, religion or ethnicity. They are the visible faces of Christ's compassionate care and healing touch: Christ-inspired positive influence![2] The Salt of the earth! (Mt. 5:33).

Despite all the government's claims of having eradicated leprosy and spreading awareness that it is not an infectious disease, separate colonies of leprosy patients continue to exist in various States, while thousands are forced to live along roadsides. Srinivas, a leprosy patient living on the road near Raipur's railway station, says: "Millions and billions of rupees have been spent in our name, but we are still on the roads". [3]

In this short discussion, we will glance through the current state of leprosy which has been deemed to have been eliminated in the country. A review of the current challenges brings out the need for continuing measures to prevent and control the disease, along with the provision of care and support to patients and their families. We will also dwell on the Catholic Church's role in these efforts, especially the Catholic Health Association of India (CHAI), one of the main healthcare organs of the Bishops' Conference of the country, and CHAI's member Institutions. We will conclude by describing a *Way Forward* for the Catholic Church in this whole endeavour.

The Current State of Leprosy in India

India tops the list of countries fighting the stigma of leprosy, albeit fifteen years after the disease was deemed to have been eliminated globally. India, Brazil and Indonesia contributed 83% of the new cases detected in 2011, with India contributing 58%, Brazil 16%, and Indonesia 9%.[4] This is despite all countries in the world having achieved the WHO-prescribed rate that qualifies for elimination (below 1 per 10,000 inhabitants).

The National Leprosy Eradication Programme (NLEP) was launched in 1983. India declared that it had achieved the goal of the elimination of leprosy as a public health problem at the national level at the end of December 2005, as the prevalence rate recorded then was 0.95/10,000 inhabitants.[5] This was thanks to the hard work of a large number of health personnel of the government sectors and donor partners but also of voluntary organisations (NGOs/CBOs), including the care and support centres of the Church's institutions.

Nevertheless, leprosy continues to afflict the vulnerable, causing life-long disabilities in many patients, subjecting them to discrimination, stigma and a life marred by social and economic hardships. The latest figures point out that in some pockets of the country the disease has tended to make a comeback. According to the NLEP Annual Report 2013-14:[6]

– A total of 126,913 new cases were detected during the year 2013-14, which gives an annual new case detection rate (ANCDR) of 9.98 per 100,000 inhabitants. This shows a decrease in ANCDR of 7.4% from 2012-13 (10.78).

– A total of 86,147 cases were on record as of 1 April 2014, giving a prevalence rate (PR) of 0.68 per 10,000 inhabitants. This shows a decrease in the PR of 12.8% from 2012-13 (0.78).

– Detailed information on new leprosy cases detected during 2013-14 indicates the proportion of multi-bacillary *leprosy* (MB): 51.48% & female: 36.91% & children: 9.49% & grade II deformity: 4.14% & ST cases: 17.88% & SC cases: 18.03%.

– In absolute numbers, Bihar has the highest number of leprosy patients with 18,188, followed by Maharashtra with 16,400, Odisha with 10,645, Gujarat with 9,721, and Chhattisgarh with 8,519.

– However, in terms of the prevalence rate, Dadra and Nagar Haveli tops the list with 4.04 out of 10,000 inhabitants, followed by Chhattisgarh (2.10), Lakshadweep (1.98), and Chandigarh (1.22).

– According to the Central Leprosy Division of the Government of India, 10% of all new cases of leprosy in India occur among children under the age of 14. The proportion of child cases was more than 10% of new cases detected in 13 States/UTs, including the rather affluent southern States of Andhra Pradesh, Pondicherry and Kerala, along with other States across the country Maharashtra, Bihar, Goa, J&K, the Punjab, Nagaland and Sikkim.

It is true that India could bring down leprosy to a remarkable level, reducing the case load to a point where we could achieve elimination at the national level, thanks to the introduction of MDT as a cure for leprosy and simpler case definitions for the diagnosis of new cases, along with concerted and coordinated efforts of national, international and donor agencies. Post-elimination leprosy control services have been integrated into the general health system with the aim of achieving an equitable distribution, as well as a rational allocation, of resources.[7] However, as the aforementioned figures suggest, of late it seems that the disease has tended to make a comeback in certain pockets due to a lack of vigilance and a drastic reduction of resources. The trends over the years post-integration suggest an ongoing active transmission within the community, delayed diagnosis, and poor monitoring and epidemiological control.[8]

The Current Challenges

The escape of the duty bearer from responsibility

It is true that until two decades ago 'the false religio-social correlation with sins… further made the plight of leprosy sufferers difficult. To overcome this injustice meted out to these unfortunate ones some missionaries took courageous steps to look after them and established 'leprosoria' for their care, but the same step became counterproductive and a cause for dehabilitation of the leprosy patients and for perpetuating and strengthening the social stigma against the disease'.[9] Though this may be true to a great extent, when government and agencies either fully or partially stopped support for these leprosoriums, and wanted to integrate the care and support systems for the leprosy patients into the general health system, there was no proper transition planning. In fact, due to a shortage of funds many of the centres (many of which were maintained by Church institutions) were forced to stop functioning and most of the leprosy patients and their dependents were again thrown out on the roads, earning their livelihood by begging and suffering the scorn of the public.

This is also what happened when the government stopped funding in April 2013 for the Community Care Centre for PLHIV in the name of integrating HIV into the general health system. Of the 256 CCCs, 123 of them were maintained by the Catholic Church. Even today some of these centres continue to operate, though with great difficulty, mobilising their own and local resources.

In reality, the State abdicated, or escaped from, its responsibility, without establishing suitable systems: not allocating sufficient human and financial resources and facilities; not making medicine available; and not taking the social stigma meted out to patients in the general health context into account. People suffering from leprosy and HIV/AIDS were left to their own devices.

Legal discrimination

India's first leprosy case was detected way back in 600 BC; the disease was mentioned in the *Sushruta Samhita* and other literary works of the Vedic period. Leprosy was then seen as an infectious disease and leprosy patients faced a social boycott. Centuries later, even though we know today that people can be completely cured, social stigma and discrimination are so strong that the laws to protect the marginalised and vulnerable have discriminatory clauses against leprosy victims.[10]

Several State laws (some of them enacted before the introduction of multi-drug therapy (MDT) in 1982 by WHO but not updated) in the States of Chhattisgarh, Rajasthan, Madhya Pradesh, Andhra Pradesh and Orissa have provisions that prohibit leprosy patients from contesting elections, obtaining driving licenses or travelling in trains, and they even see the disease as valid grounds for divorce. Furthermore, Orissa's

Panchayati Raj Act has the clause that if a member of a local office contracts tuberculosis or leprosy during their tenure they can be declared ineligible for the job. In Andhra Pradesh and Karnataka the hearing impaired and the mute cannot stand for *panchayat* elections. When India passed the Leprosy Act in 1898 it was to ensure that leprosy patients did not face discrimination. A hundred years on, Indian laws and regulations do exactly that.[11]

The government, non-governmental organisations (NGOs) and private organisations need to work together to maintain constant vigilance, provide care and support, and remove legal and other social taboos relating to people infected and affected by leprosy. The ongoing training and motivation of medical officers, nurses, physiotherapists and paramedical workers in relation to quality diagnosis and the treatment of leprosy is necessary.[12]

Social stigma and discrimination against the infected and the affected

As the WHO has stated, the main and continuing challenges to leprosy control have been delay in the detection of new patients and persisting discrimination against people affected by leprosy which has ensured the continued transmission of the disease.[13]

Although the government of India declared that it had achieved a prevalence rate below 1/10,000 inhabitants in 2005, the stigma of leprosy endures in India. Persistent stigma, prejudice and misunderstanding in relation to leprosy continue to be stubborn barriers for leprosy patients and their family members. Once diagnosed with leprosy, patients face the long and uphill task of recovering and then reintegrating into their community. Employers regularly turn away people who have had the disease, even if they have been treated and cured. Often people diagnosed with leprosy hide their condition from their families and loved ones out of the fear that they will be ostracised by the community. Obtaining legal documents such as a driver's licence, ration card, etc. is very difficult. Often the disease-free children of leprosy patients are also shunned by the communities they live in.[14]

Psychiatric disorders

Efforts have been made by the government and other organisations, including the Church's institutions, to solve the medical problems of people infected and affected by leprosy. However, not much is done about the prevalence of psychiatric disorders amongst them, including comorbid psychiatric disorders (social stigma and discrimination being the main causes of this). Even today people infected with leprosy have to leave their village and are socially isolated. Depression is the most common psychiatric disorder found in these patients. Early detection and the provision of comprehensive psychiatric care for psychiatric disorders is a very much needed psychotherapeutic measure.[15]

Maintaining knowledge, skills and motivation in health-care professionals and community social workers and the shortage of resources

Increasing community awareness and involvement as well as the continued commitment of health-care personnel are required to improve early case detection, compliance with treatment, and community-based rehabilitation. Otherwise, we may lose the remarkable gains that have been achieved.[16]

The latest figures indicate that the disease has tended to make a comeback in certain pockets of the country. This highlights the significance of the continued role of health-care professionals, especially dermatologists, in the management of control programmes, diagnosis, and the treatment of the disease, as well as in the ongoing education of other health-care professionals. Give that vigilance in relation to leprosy and consequent resource allocation has been drastically reduced by the government, with an accompanying reduction of non-governmental/private initiatives, the problem at present is how to maintain the knowledge, the skills and the interest that are needed to deal with leprosy in the context of its declining endemicity. There is a need to have a permanent education system for primary health-care professionals for leprosy in addition to motivating and training professionals to work in specialised reference centres and in care and support centres to provide long-term care to people who are permanently disabled because of leprosy.[17]

The lack of efforts as regards vigilance and the creation of public awareness has also produced a reduction of motivation in social workers and non-governmental and private organisations.

There is a lack of adequate human resources and volunteers as well as diagnostic services to identify cases at an early stage. As has been noted, there is a shortage of funds provided by the government.

As a result of the inadequate support for committed organisations and social workers/volunteers, patients and their families are not facilitated in gaining access to the support that is available from the government in various schemes.

Apart from social stigma and discrimination, in the name of a lower degree of disability (75% of disabled people are entitled to government schemes), the patients are often denied these benefits on technical grounds too.

The New Global Leprosy Strategy of the WHO

In April 2016 the WHO launched a new global strategy for leprosy guided by the principles of initiating action, ensuring accountability and promoting inclusivity. It called for stronger commitments and accelerated efforts to end leprosy disease transmission and associated social stigma and discrimination. This new strategy aims to achieve a zero number of visible deformities among children diagnosed with leprosy by 2020; to reduce the rate of newly-diagnosed leprosy patients with visible deformities to less than one per million; and to ensure that all legislation that allows discrimination on the basis of leprosy is repealed. The strategy focuses on equity and universal health coverage which will contribute to attaining the Sustainable Development Goal as regards health.[18]

The Biblical Perspective and the Church's Mission

The narratives of the gospels about Jesus' healing of people suffering from leprosy and his interactions with them provides an unambiguous message and mandate as regards the Church's mission and how she has to respond to society's condemning attitudes towards those suffering from leprosy and similar diseases in today's situation: HIV, TB, etc.

For instance, Mark's narrative may be seen as a primary example of Jesus' non-judgemental response to these condemning attitudes of devaluation, distancing, hatred, rejection by the family, exclusion, and labelling. Fear was often at the root of these negative attitudes, e.g. fear of exposure to the disease, fear of being infected, fear of association with a person affected by leprosy.[19]

'A leper came to him begging him, and kneeling he said to him, "If you choose, you can make me clean." Moved with pity, Jesus stretched out his hand and touched him, and said to him, "I do choose. Be made clean". Immediately the leprosy left him, and he was made clean' (Mk 1:40-42).

"First of all, as Mark says, Jesus has profound compassion for this person, which means that you feel with. You enter into the suffering, the pain, so that you share the very same things this person is experiencing. Sometimes in this Gospel you read that Jesus had pity, but pity is not really what it was. It was compassion. So Jesus reaches out and touches the man, breaking down that barrier of isolation, drawing the person in out of love. Jesus felt his isolation, his pain, and He touches him. Jesus shares that, but then, by sharing it, Jesus heals the man or cleanses him, so that now he is able to rejoin the community. That kind of love that Jesus shows for this person is the kind of love that all of us are called to share, to reach out in a spirit of healing, a spirit of compassion, the share the suffering of others, to be joined with them. If we join together, people are healed. They are lifted up. Their suffering becomes more bearable."[20]

Jesus calls us his disciples and his Church to be "the visible face of the invisible Father." 'Then Jesus summoned His twelve disciples and gave them authority over unclean spirits, to cast them out, and to heal every disease and every sickness. …. "Heal the sick, raise the dead, cleanse the lepers, cast out demons. Freely you received, freely give"' (Mt 10: 1, 7-8).

Be the healers and carers of the sick and the crippled, the ones that God himself never fails to care for (Ezek 34:4).

The Church by being 'the visible face of the invisible Father' has to continue to be a *Christ-inspired positive influence* in local contexts, countering and acting upon condemning attitudes towards the socially excluded and marginalised, especially when this is the result of illness.

Christ's mandate to his Church has been categorically repeated in our times by Pope Francis, and without mincing his words: 'I prefer a Church which is bruised, hurting and dirty because it has been out on the streets, rather than a Church which is unhealthy from being confined and from clinging to its own security. I do not want a Church concerned with being at the centre and which then ends by being caught up in a web of obsessions and procedures. If something should rightly disturb us and trouble our consciences, it is the fact that so many of our brothers and sisters are living without the strength, light and consolation born of friendship with Jesus Christ, without a community of faith to support them, without meaning and a goal in life'.[21]

The ultimate question here, then, will be whether the Church and its health-care institutions and initiatives, pastoral work, and social development projects will remain the 'Salt' of the earth or whether, under the cover of a lack of human resources, a lack of funds from the government and other agencies etc., it will abdicate its responsibility towards the socially and economically marginalised and vulnerable while keeping safe within the four walls of our institutions. 'You are the salt of the earth, but if salt has lost its taste, how can its saltiness be restored? It is no longer good for anything but is thrown out and trampled underfoot' (Mt. 5:13).

Care and Support for People Infected and Affected by Leprosy: the Role of the Catholic Church

Heeding the mandate of Christ, the Catholic Church in India has been actively involved in the treatment and eradication of leprosy and other infectious diseases for many years. St. Joseph's Leprosy Hospital, founded in the year 1890 by Father Augustus Muller, is one of the first leprosy hospitals in southern India. Modern scientific treatment and the concept of leprosy control did not exist then and leprosy was the disease that was most dreaded. It had no specific treatment, was associated with social stigma and patients were ostracised by society.[22]

The Catholic Health Association of India (CHAI)

The Catholic Health Association of India (CHAI), one of the main arms of the Health Commission of the Bishops' Conference, is the largest not-for-profit faith-based health-care network in India, with over 3,517 member institutions. 80% of them are located in remote, medically underserved rural areas, and operate under eleven Regional Units across the country. Over 90% of these institutions are run by sisters of various religious Congregations.

Founded in 1943 by Sr. Dr. Mary Glowrey, an Australian medic and Catholic nun, CHAI comprises most Catholic health-care facilities: 746 small, medium, and major hospitals, 2,574 health centres, 107 centres for mental health, 61 centres for alternative systems of medicine, 162 non-formal health facilities and 5 medical colleges, 615 residential health-care centres for the aged, 678 training centres and 443 rehabilitation centres involved in the preventive and curative care of people, 123 community care centres for people living with HIV/AIDS including 40 centres for infected/affected children, 60 counselling centres, 82 centres for tuberculosis and the terminally-ill (palliative care centres), 120 nursing schools/colleges) and 600 project-based institutions focused on certain diseases in cooperation with the government as well as other social concerns.[23]

These health facilities provide critical health-care services to the poor and marginalised with a network of over 1,000 nun-doctors, 25,000 nun-nurses, 10,000 plus nun-paraprofessionals, and 5,000 nun social workers, along with their lay co-workers.[17] One can safely assume that nearly 130,000 people (religious, lay workers and volunteers) render services in these institutions collectively. CHAI's member institutions treat more than 21 million patients every year. This includes 5,000 HIV patients, approximately 2,000 children affected or infected with HIV in institutional care, 15,000 cared for in community-based care, and 10,000 children with special needs who are provided with annual educational, health and rehabilitation support. CHAI member institutions and their sister concerns facilitate more than two million self-help group members. Over 5,000 students graduate every year from CHAI-member nursing schools.[24]

The Role of CHAI and its Member Institutions in Reaching out to Socially Excluded Leprosy Patients and their Families

The Catholic Church once maintained 165 homes dedicated to those afflicted by leprosy for over 30 years and these were mostly maintained by CHAI member institutions.[25] Today, due to inadequate resources, the number of these care and rehabilitation centres has been reduced to 60. Many of these centres now focus their attention on other communicable diseases, especially HIV/AIDS etc., as the prevalence of leprosy is decreasing in many of the operational areas.

The average number of in-patients treated in 60 leprosy care centres is 66,000 per annum. These include ulcer wounds treatment for over 30,000 patients and bed-ridden care for over 5,000 patients. These centres do follow-up care for around 50,000 patients. They do referral services and on average 4,000 patients every year are referred to higher centres and NLEP. They facilitate social security for the patients and their families through tie-up with government disability pension schemes, promote the distribution of aid and assistance, and encourage treatment adherence.

They also organise awareness programmes, self-care, mobile clinics, counselling and physiotherapy. They address stigma and facilitate marriages, and help these people cope with the side effects of treatment.

These centres provide community-based rehabilitation services such as employment opportunities for patients and their family members in small industries; the construction of houses; inclusive education of children and the free distribution of text books, uniforms and other stationery; the distribution of provisions to meet basic needs, providing free of cost dhal, rice, oil and vegetables etc.; financial support to children and self-employment opportunities such as jute centres, making bags, coir mats and also cultivation, weaving and sewing units, and making MCR chapels for foot care.

Five of these centres across three States are exclusively dedicated to providing medical care, physical and vocational rehabilitation, reconstructive surgery, social support and counselling to people affected by leprosy. These five centres cater to an annual inflow of more than 3,600 leprosy-affected individuals and provide for a range of inpatient and outpatient facilities through a bed capacity of over 200 with reconstructive surgeries.

The untiring efforts of sister nurses in providing regular cleaning and bandaging for ulcers, as well as moral and spiritual support, is exemplary and provides a beacon of hope to the leprosy affected who are often cast out by society and their families. These institutions also provide outreach activity and mobile services so that patients can become a part of the communities. They also reach out to people in their villages and facilitate their integration into society and enable them to live to the fullest extent, performing activities of daily life without hindrance or stigma. They also provide them with end of life and palliative care, supporting patients until their last breath, even when abandoned by their families.

These centres receive little or no local support, monetary or otherwise; they have to face a lack of funds, a lack of support through governmental schemes; they have to advocate for quality and the timely supply of drugs and they have to rely on self- generated funds or foreign hand-outs for sustenance.

At this point, we have to observe that in some States some of these centres are being forced to close down by a fanatically motivated political will under the cover of false allegations of religious conversion. Some of these centres, which are singlehandedly managed by sister nurses, are being closed down under the cover of the Clinical Establishment Act which makes imperative the presence of doctors to maintain health centres. Some of them, working in participation with the government, face being closed down under the cover that leprosy in India has reached the stage of elimination, that it is a 'dying disease'.[26]

The Way Forward

The Indian Catholic Church has to refocus on the process of care and support for people infected and affected by leprosy. For the last few years, as the government and other agencies have stopped or substantially reduced funding, many of our care centres for people infected and affected by leprosy and others dedicated to leprosy initiatives have altogether stopped functioning or have focused attention on other communicable diseases such as HIV and TB. Unlike other NGOs, it is time for the Indian Church to stop being donor-driven, and instead, carry forward these initiatives, including those relating to leprosy, with a necessary process mode rather than a donor-driven project mode.

The Church must be the ongoing visible face of Christ's compassionate care and healing touch rather than ceasing initiatives under the cover of the non-availability of funds from the government and other regular sources. She can, and she must, mobilise resources internally and externally from other local sources. To this end she has to facilitate, coordinate and advocate the efforts of various internal stakeholders (parishes, dioceses, religious Congregations and patients themselves) and external stakeholders (the government, Corporate Social Responsibility (CSR), individual donors, etc.) at local, State and national levels.

There is a need for government, non-governmental organisations (NGOs) and private organisations to work together to maintain constant vigilance, provide care and support, and remove legal and other social taboos against people infected and affected by leprosy. The continued training and motivation of medical officers, nurses, physiotherapists and paramedical workers in relation to quality diagnosis and the treatment of leprosy is necessary.[27]

The Church has to campaign for the rights and entitlements of patients and their families. If necessary, direct advocacy is needed against apathetic and corrupt political forces which are unwilling to allocate resources for socially-economically marginalised and excluded leprosy patients and in order to make their concerns known about by the general public.

To perform this advocacy with public integrity and to be a genuine 'Community Enabler', the Indian Catholic Church has to refrain from being the 'opportunistic' faces of Christ's mercy who act only when and where there is a possibility of benefit for themselves! It must stand instead, in line with Christ's mandate, for the universal acceptance of the sick and suffering, irrespective of caste, creed, colour, language, region, ethnicity, and, above all, benefits for herself.

This apart, it is also good to reflect, while we fight against the social stigma and discrimination against people infected by leprosy and HIV, on how many of us are ready to support these people by giving them employment and livelihood opportunities in our institutions and initiatives. Are we ready to practise what we preach? Walk the talk?

Even while government, as the first duty bearer, is tending to abdicate its responsibilities towards people infected and affected by leprosy, the Church's faith-based health-care centres, as the visible faces of Christ's compassionate care and healing touch, have to bear witness and inculcate Christ-inspired positive influence! The Salt of the earth! (Mt. 5:33)

'The biggest disease today is not leprosy or tuberculosis, but rather the feeling of being unwanted, uncared for, and deserted by everybody' (Mother Teresa).

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2. The Pastoral Project for People with Leprosy in the Diocese of Bunia in the Democratic Republic of the Congo

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Coordinator of the Diocesan Offices for Medical Works,
BDOM, Bunia Catholic Diocese

The Vision of the BDOM/Bunia

The quality of care of BDOM centres around integral care for man at the level of his body, his soul and his spirit – the basis of the wellbeing and overall health of every human being.

Today more than yesterday, and yesterday more than today, the BDOM will continue to give hope to the population of the Province of Ituri, providing health care of high-quality that is impregnated with human attention and charity, with greater attention being addressed to the most vulnerable, including lepers and people with tuberculosis, in order to combat all the scourges that afflict and undermine families.

We are dealing here with maintaining and strengthening the chain of continuity of care for the most vulnerable in a spirit of true solidarity and the sharing of risks.

The Mission of BDON/Bunia

BDOM/Bunia is one of the four commissions of the diocesan Caritas-Développement. This is a non-profit making association of the diocese.

It has adopted the national policy of primary health care with a view to obtaining 'Health for Everybody', a policy in harmony with the social pastoral care of the Church.

The BDOM has to meet the health-care needs of the community of the city of Bunia and its hinterland through the various services that it has developed in order to foster: treating the sick: general and specialist health care; the prevention of illnesses: vaccinations, health-care education, etc.; and the promotion of health through communication in order to achieve a change in behaviour, through activity involving nutritional rehabilitation and food security etc.

It has to assure continuity and growth in its medical agencies through healthy and rigorous management in an atmosphere of sincere partnership

In relation to other organisations that offer health-care services, it has to have the following competitive advantages: sound credibility with the state and donors; and the trust of that part of the population attracted by Christian moral values: love for neighbour, sharing, solidarity, justice, etc.

The Mandate of BDOM/Bunia

BDOM/Bunia is a service of the diocese of Bunia that is entrusted with coordinating all initiatives begun in the health-care sector by the diocese for the population of the Province of Ituri. In this capacity it is entrusted with: planning, coordinating, supervising and assessing the activities of the health-care agencies of Bunia; assuring the supply of essential medical products, laboratory products and current medical material; and supervising the administrative and financial management of medical agencies with a view to achieving self-financing.

1. The Diocese of Bunia: a Profile

1.2. Its geographical location

The diocese of Bunia is located in the north-east of the Democratic Republic of the Congo and it is in the Province of Ituri. It includes the territories of Djugu, Irumu and a small part of the territory of Mambasa, and it covers twenty-three health-care areas of the Province of Ituri.

The diocese of Bunia has twelve parishes and five autonomous sectors. To the north it has a boundary with the diocese of Mahagi-Nioka, to the west with the diocese of Isiro-Niangara, to the south-east with the diocese of Beni–Butembo, to the south-west with the diocese of Wamba, and to the east with Lake Albert, which separates it from Uganda.

It has a surface area of 22,470 km^2 and an estimated population of 2,512,760 inhabitants with a density of 112 inhabitants every square kilometre. It should be observed that there has been a strong population increase since the exodus from the rural areas that was caused by the armed conflicts.

Water: various areas of water are to be found in the diocese of Bunia, the most important of which are Lake Albert and the rivers Ituri, Shari, Nizi, Ngezi, Abombi and Tsé.

*Access***:** the diocese of Bunia can be reached by air, by road and by boat across Lake Albert.

1.2 Caritas-Développement: a profile

Caritas-Développement is a technical institution of the diocese of Bunia whose aim is to implement the pastoral mission of the Catholic Church in line with its statutes and the goals that they set out, amongst which are the promotion of integral human development. Caritas-Développement in the diocese of Bunia carries out its mission through four commissions, respecting the ethics of the Catholic Church and the labour laws in force in the Democratic Republic of the Congo.

These commissions are the following:

The Diocesan Office for Development (BDD) whose mandate is to contribute to the lasting economic and socio-cultural development of the population.

The Diocesan Office for Medical Works (BDOM) which is entrusted with organising and accompanying activity connected with health care for the population. This includes curative, preventive and predictive medicine.

The Diocesan Office for Solidarity and Sharing (BDSP), an office for the promotion of assistance for vulnerable groups and individuals.

The Diocesan Office for Justice and Peace (CDJP), an office for the promotion of human rights, peace and reconciliation.

Leprosy: a Profile

1. Introduction

Leprosy is a skin disease which has been known about since antiquity – six hundred years before Christ. For a long time this disease was seen as a disease to be stigmatised, a curse, and it could involve a person's exclusion from society.

Raoul Follereau denounced the fate of lepers closed up in leper colonies for the first time to the United Nations. This led to the establishment of the World Leprosy Day in 1954.

Action Damien was created in 1964 by various associations in Belgium. Subsequently, in 1966, as a result of the pressure exercised by Action Damien, international cooperation led to the creation of the International Association of Associations for the Fight against Leprosy.

Missionaries of the Catholic Church established three centres for lepers in Ituri: in Badiya (1965), in Bunia (1966), and in Aru (1970). These developments were supported by Aktion Canchanaburi, an independent German NGO whose aim is to reduce the suffering of people with leprosy through treatment and holistic care. These people had been abandoned without treatment and food after independence and were helped by the Help for Lepers Project of Ituri (ALI).

In 1970 the government of Zaire created the National Leprosy Office whose mandate was to coordinate the programme for leprosy at a national level. In 1980 the World Health Organisation recommended the integration into this programme of care for tuberculosis because it perceived the similarity of these two pathologies. The programme then became 'Help for Lepers and People with Tuberculosis in Ituri' (ALTI).

Leprosy is a neglected tropical disease (NTD) which requires intensive therapy. In some countries it remains a problem of public health. Thanks to polychemotherapy some countries are moving towards its elimination.

In the year 2014 about 200,000 new cases were registered in the world, of whom about 20,000 were children. 94% of cases are to be found in thirteen countries in Asia and Africa (India, Indonesia, Brazil, the Democratic Republic of the Congo, Ethiopia, Madagascar, Nigeria, Tanzania, etc.).

The Democratic Republic of the Congo reported 5,000 new cases in the year 2009. This was the country that had the highest number of people with leprosy in Africa (18% of cases).

The prevalence of leprosy is still high in the Provinces of Katanga, Bandundu, Equateur and the old Eastern Province (Ituri, Haut Uélé, Bas Uélé and Tchopo). In Ituri, the number of cases was estimated in 2013 at *208*, in 2014 at *157* and in 2015 at *267*.

2. Goals

– To demonstrate to the world the extensive presence of leprosy in the Democratic Republic of the Congo and in the Province of Ituri in particular.

– To describe the aetiological agent of leprosy.

– To describe the epidemiological state of leprosy.

– To describe the clinical signs of this disease.

– To list the elements that are

needed for a diagnosis of leprosy and its treatment.

– To describe the strategies of the fight against leprosy of the country and the Catholic Church.

3. Methodology

– Individual reading.
– Review of the literature.
– Research on internet.
– Papers during plenary assemblies.

4. Contents

4.1. Definition

Leprosy is a transmissible infectious disease caused by *Mycrobacterium leprae (M. leprae)* or Hansen's bacillus, which was discovered 1873. This disease afflicts the skin, mucous liquids, the peripheral nervous system, the eyes, and according to the cellular immunity of the individual who is infected it takes different clinical forms.

The World Health Organisation defines leprosy as when an individual has evident diagnostic signs of the disease, with or without bacteriological confirmation, and needs to follow a specific treatment.

4.2. The aetiological agent

Mycrobacterium leprae, or Hansen's bacillus (described by Hansen in Norway in 1873), is a resistant-acid-alcohol of 1 to 8 μ/0,3 μ that becomes coloured when the Ziehl-Nielsen method is used. It is intracellular (penetration, multiplication) and cannot be cultivated *in vitro*. It cannot be inoculated into mice or armadillos. Its transmission is direct: through the nose (secretions, saliva, aerosols). Indirect transmission is possible through contaminated objects. The pathways of penetration of this disease are essentially the respiratory pathways, both incoming and outgoing. Just one sneeze of a person with leprosy who has not been treated can contain more than 10 M. BAAR. The cutaneous pathway is secondary. This disease is principally rural in its incidence. Its incubation period is long (from two to seven years) if not indeed twenty-five years. It afflicts all ages and both sexes.

Leprosy is a disease that is not very contagious and man is the only creature to be afflicted by it. Only one person with leprosy in every ten is contagious; when treated, that person quickly becomes no longer contagious (48 hours). Only five individuals in every hundred individuals who are exposed to the disease actually contract it.

4.3. Epidemiology

The World Health Organisation established the elimination of leprosy as a problem of public health by the year 2005. The prevalence had to be <1/10,000 inhabitants of the world. The elimination of this disease has still not been achieved, even though the world prevalence rate has decreased, going from 8.4/10,000 in 1966 to less than1/10,000 since the end of 2000. The number of new registered cases has been falling: 407,791 (2004); 258,133 (2007); 219,075 (2011); 181,941 (2012).

This disease is strongly endemic in some regions of Brazil, India, Indonesia, Madagascar, Mozambique, Nepal, the Philippines, the Democratic Republic of the Congo, and the United Republic of Tanzania.

Table 1. Registered prevalence of leprosy and number of new cases in 105 countries and territories by WHO region in 2011 and at the end of the first quarter of 2012 (with the exception of the region of Europe)

WHO region	Number of registered new cases (prevalence for every 10,000 inhabitants*) first quarter 2012	Number of identified new cases (level of screening of new cases for every 100,000** inhabitants) in 2011
Africa	15,006 (0.37)	12,673 (3.14)
Americas	34,801 (0.40)	36,832 (4.18)
Eastern Mediterranean	7,368 (0.12)	4,346 (0.71)
South-east Asia	117,147 (0.64)	160,132 (8.75)
Western Pacific	7,619 (0.05)	5,092 (0.30)
Total	181,941 (0.34)	219,075 (4.06)

* In brackets: prevalence for every 10,000 inhabitants
** In brackets: prevalence for every 100,000 inhabitants

Table 2: The epidemiological situation of leprosy in the Democratic Republic of the Congo

Year	Prevalence	Identified	Children/NC	Infirmity 2/NC
2003	7,173	7,472	963	912
2004	10,567	11,797	1,499	1,252
2005	9,932	10,776	1,329	1,042
2006	8,275	8,257	902	784
2007	6,502	8,820	1,074	743
2008	4,851	6,115	804	614
2009	4,290	5,131	596	524
2010	4,129	5,097	562	557
2011	3,625	3,949	442	436
2012	3,492	3,651	383	526
2013	3,650	3,744	452	471
2014	3,231	3,272	410	482

Although in seven Provinces of the Democratic Republic of the Congo the elimination of leprosy has been registered, the situation remains worrying in four Provinces of the country. These, on their own, provide more than a half of notified cases: Bandundu, Equateur, Katanga and the ancient Eastern Province.

The impact of leprosy on the body principally involves handicaps: mutilations, deformations, and blindness because the disease attacks the peripheral nerves.

4.4. Clinical symptoms

The incubation of the disease is generally two to seven years, if not at times twenty-five years. The principal clinical expressions of the disease are: hypopigmented or hypoesthetic macules; asymmetrical hypertrophy of one or more of the peripheral nerves; and red-yellow or slightly erythematous papules or patches that can come together to produce leontiasis.

The marks due to leprosy can appear anywhere…they do not cause pain…they do not itch… and they are insensitive to warmth, touch or pain. Leprosy can be diagnosed simply, starting with its clinical symptoms.

The following are some of the determining causes of leprosy: poverty, a lack of hygiene and promiscuity ('leprosy withdraws in the face of progress'); a genetic susceptibility to *m. leprae* (family cases); living in areas where the disease is endemic; repeated and close contact with a multi-bacillary patient. Rapid diagnosis and treatment prevent invalidating forms.

The principal complications of leprosy: 1. at the level of limbs: drooping hands, monkey hand, deformed soles of the feet. The infection of this ulcer leads to cellulitis or adjacent osteomyelitis. Mutilation of the fingers and of the toes. 2. At the level of the nose: chronic nasal congestion and epistasis, destruction of the nasal septum and anosmia. 3. At the level of the eyes: lagophthalmia and insensitivity of the cornea because of paralysis of the cranial nerves that can lead to blindness. 4. At the level of the testicles there can be: orchitis, aspermia, hypospermia, impotence and sterility.

4.5. Clinical diagnosis

The clinical diagnosis of leprosy involves: hypopigmented marks on the skin, nodules or papules. 1. According to the number of marks, leprosy is classified as paucibacillary (from 1 to 5 cutaneous lesions); multi-bacillary (more than 5 cutaneous lesions). 2. These marks are insensitive to surface palpation, with hypertrophy of the cubital nerves and external popliteal sciatica. Signs of complications are: mutilations, anosmia, sterility and impotence. The bacteriological diagnosis involves a search for *m. leprae* in the nasal mucous liquid and the cutaneous lesions. Histopathology: biopsies.

4.6. Treatment

Treatment is based upon polychemotherapy (PCT). For leprosy PB: six capsules of PCT BB (rifampicin + dapsone). Duration: 6-9 months; six capsules. For leprosy MB: twelve capsules of PCT MB (rifampicin, dapsone and clofazimine). Duration: 12-18 months; twelve capsules. Treatment in the case of complications (deformed sole of the foot, damage to peripheral nerves, etc.). The treatment is effective when there is an early identification of the disease.

4.7. Strategies for defeating leprosy

The principles are well known but they have not followed up by the production and use of instruments to achieve a complete fight against leprosy. Prevention: this involves sensitisation by the RECO (*Relais communautaires*); the identification (screening) of the disease and its swift treatment, with the psycho-social reintegration of people who have had leprosy. Also important is training of the RECO, IT, ECZS. We need curative treatment of this malady: polychemotherapy. Epidemiological monitoring is also required: the gathering of data by the RECO starting with communities. Operational research also has an important role to play.

4.8. Problems and challenges

The problems and challenges are: low financial support from the government for the programme, low motivation of the personnel in the field, only a partial fight, and a lack of products at the level of institutions.

4.9. Future prospects

Future prospects relate to the mobilisation of funds to support the leprosy project; a strengthening of the capacity of the DPS teams and suppliers in order to achieve a better treatment of cases of leprosy and avoid complications; motivating the RECO to achieve a systematic orientation; and fostering operational research.

Conclusion

Notable progress has been achieved in the fight against leprosy thank to the national and local campaigns that have been promoted in most countries where the disease is endemic.

The integration of essential services in the fight against leprosy that form a part of general existing health-care services has facilitated the diagnosis and treatment of this disease.

Other countries have still not managed to eliminate leprosy, in particular the Democratic Republic of the Congo and the four eastern provinces of that country in particular. If this disease is not treated it can involve progressive and permanent lesions of the skin, the nerves, the limbs and the eyes, thus turning a good number of people who are useful for society and the Catholic Church into invalids.

All of us are invited to roll up our sleeves to save our brothers and sisters, who are in the image of Christ. ■

3. Testimony about Leprosy

FATHER GIORGIO ABRAM, OFM CONV
Priest, medical doctor and missionary, Italy

When I arrived in Ghana in 1977 the situation as regards leprosy in the country was tragic: mutilated and neglected patients who did not have an opportunity to obtain access to treatment; treatment, for that matter, at that time was more an attempt to control the disease than a secure way of curing it! Above all else, they were patients marginalised by society, concentrated in hospitals, emergency refuges, villages for lepers…about fifty thousand patients of whom only a half regularly received dapsone, the only medicine that was available at that time for this disease.

And this state of affairs, unfortunately, was a reflection of the general health-care situation which, like for that matter the whole of the socio-political substratum, was in a very bad condition because of the corruption that had followed in the wake of the euphoria of independence which had just been obtained.

When re-reading the Biblical episode of Nahum the Assyrian, I find a close similarity with the anti-leprosy programme of Ghana: patients who did not believe that they could be cured and patients who did not want to be cured! This attitude, which for us is incomprehensible, had its roots, and found its justification, in the belief that leprosy was caused by curses or by supernatural intervention. This, naturally enough, led those with the disease to turn more to witchdoctors than to medical doctors.

Given that I lived in a mission near to a leper colony, I believe that I was very fortunate: after the initial indifference of the local authorities, I was accepted as the coordinator of the national programme for the treatment of leprosy in Ghana. The strategy that was adopted to win the trust of the authorities and patients involved close cooperation with the authorities of the country and with the local medical personnel; providing basic health-care education; dismantling the leper colonies; and placing the anti-leprosy programme within the framework of basic medicine, as well as home treatment of the disease – this was unconfutable proof that it was possible to be cured of leprosy.

Said in a single sentence, these things may appear simple and easy to put into practice, but in reality I have dedicated to them more than a half of my life and they have required the same time and energy from those who have worked with me.

I believe that I can state that the beginning of the final defeat of leprosy, the winning card, was the shift of our attention from the disease to the patient, when, that is to say, we managed to place the person of the patient at the centre of our concern.

In my work I have been inspired by two great personalities: Fr. Damiano De Veuster, who has since been declared a saint, after in my seminary I saw the film ‘Molokai’; and St. Francis who in his testament for his friars said: ‘When I was still full of sins it seemed to me to be terrible to see lepers. But the Lord led me amongst them and I did deeds of mercy with them. And in drawing away from them what before had seemed to me to be horrible, was transformed into tenderness of soul and body. And I was shortly to abandon the secular state’. The vocation of Francis was born in his encounter with people with leprosy.

I am therefore convinced that to work with lepers is an authentically Franciscan vocation. Certainly, this work of mine for the poorest, engaged in as a service to the Ministry of Health of Ghana, has defined our presence as Franciscans in the country.

Very many stories, my own direct experiences or experiences of patients who confided in me, stories of pain, of marginalisation, but also stories of a humanity wounded but never defeated, emerged and above all during the precarious initial situation.

Like the story of Abu, a boy aged twelve afflicted by the disease and accompanied by his family relatives to a healer who, at the end of all her divinations, declared that in order to be cured the boy had to be taken to the white doctor. Abu is now forty; he has a family and a shop that sells various things, a sort of miniature village supermarket.

Or the story of Abdullah, an old former patient of the north of the country. After a violent storm he drew near to the fire to get dry and because of a lack of feeling in his feet he scorched them. Because he had to continue working at his mill to maintain his family, he dragged himself along on his knees every day until a nail pierced a knee. Together with a woman nurse, we found him suffering from a high fever in his hut. We treated him and once he had got better he went back with peace of mind to his job.

Or the story of Dadi, a boy worn out by what is commonly called children’s leprosy (Buruli ulcer). We met him for the first time when he was sitting down in front of his hut, wrapped in a ragged blanket, with a swollen face and only his right hand free to ward of the swarm of mosquitos attracted by the terrible smell that beset the whole scene. Once the faded rags he was wearing had been removed, I found an example of poor humanity in decomposition. Old wounds had already consumed the bones of his knees and various scars without pigment indicated the places where the wounds had closed. But there were also new wounds; they were open, rotting, evil-smelling, and spread all over his body. From his parents I obtained their consent to go with me with Dadi to the hospital – it was a very hard struggle but in the end we won together. Now Dadi has a school diploma and works in his village.

Or the sad story of an old mother with a family in Yendi. We had had to amputate her right leg above the knee which already had gangrene. After recovering completely she went back to her village. I went to visit her one day as I was passing through that area. She was well, she was well looked after by a young granddaughter of hers in a clean hut. “We will not see each other again”, she said as I was leaving. A few days later she died: she could bear to be seen going round without a leg.

Or the happy result of another amputation. A friend of mine who is a photographer immortalised a moment when Yaw and I, hand in hand, were talking to each other. Yaw was a patient with evident signs of untreated leprosy, convalescing after the amputation of his leg below the knee. He was speaking in a calm and peaceful way about his plans for the future. He would have liked to go on being a tailor but he needed a new sewing machine. Some Italian friends of mine gave him one: he went back to his village and continued with his profession, helped by his family and assisted by our district nurse.

And a story which touched my innermost being: that of a very elderly patient who displayed all the damage that had been caused to him by the disease in an evident way, including to his face: he had nodules and examples of tumefaction, what in jargon is called a ‘lion’s face’. He had a large and inexpressive face because the disease had damaged his facial nerves. He had come to the clinic accompanied by a granddaughter but when he saw me he became agitated. The matter worried me because I did not understand his language, Ewe, which is spoken in the far South-East of Ghana. His granddaughter went away and they explained to me that the patient wanted me to see his photograph which he kept in a frame at home, a photograph of ‘when he was a handsome man’. What moved me the most was the great joy that I saw in his black eyes when he held that portrait in his hands. The disease may have disfigured him, but it had not taken away his *joie di vivre*!

And a story which seems to me to me to be an anecdote, that of a young man who had had an operation on his foot to remove a grave ulcer on the sole. He had to stay in bed but he got up secretly and so as not to be surprised by someone he took off the bandages and walked naked on the ground to reach his poor chicken coup. He had four chickens that he had to look after. “What is more important: your foot or your four chickens?”, I asked him severely. And in reply he gave me a disarming smile: “I can live without a foot but not without my chickens!”

And to end, a little tale. I will read from a book published a few month ago by Edizioni Messaggero of Padua, *Quattro Gatti senza Storia* (‘Four Cats without a History’) which is a collection of some of my ‘semi-serious’ thoughts. Often the people who talk to me have a doubt: “but is leprosy contagious?” I prefer to define it as an infectious disease but this in practical terms is the same thing. And then curiosity comes forth: “have you ever caught it?” When I was much younger, during the first years of my work in Ghana, a dear secretary of the Italian anti-leprosy organisation always repeated to me: “if you get leprosy, we will write a book about you, and they will make you a saint”. I got leprosy, I had it treated, and I recovered, bearing as a memory of it a widespread loss of feeling in my left foot. Nobody has ever written a book about me, and they will certainly never make me a saint.

Conclusions and Recommendations

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The international symposium on the topic, "Towards Holistic Care for People with Hansen's Disease, Respectful of their Dignity," was jointly organized for June 9 to 10, 2016, at the Vatican City by the Pontifical Council for Health Care Workers, the Good Samaritan Foundation and the Nippon Foundation in cooperation with the Raoul Follereau Foundation, the Sovereign Order of Malta and the Sasakawa Memorial Health Foundation. These Conclusions and Recommendations were presented at the end of the two-day symposium and were approved in principle by the organizers and the participants who were present.

Note: While the terms "Hansen's disease" and "leprosy" are used interchangeably in this document, in some countries the preferred term is Hansen's disease.

Conclusions

1. Every new case of Hansen's disease is one case too many. It has been observed that new cases of Hansen's disease are on the decrease and we should be very happy about this. But this decrease, which is in itself positive, could have resulted from *a decline in case-finding activities and reduced community awareness*. The increase in the rate of disabilities in new cases detected seems to support this explanation. Therefore, it is essential *to aim at early detection*. This applies to all new cases, *but particularly to child cases*. The WHO's Global Leprosy Strategy 2016-2020 is moving in this direction. A second cause for concern comes from the substantial *risk of partly losing the expertise* that has been accumulated over recent decades by leprosy experts, medical doctors and health workers in relation to Hansen's disease. Grants for study and training may be needed for service providers and caretakers including persons affected by the disease. Here, the principle, "Nothing about us without us" should be respected, and this is an important way of fighting against the stigma that is associated with Hansen's disease. A number of valuable recommendations in the presentations concerned methods to improve early diagnosis and promote the social integration of persons affected by leprosy. Public and private institutions should work in close cooperation with health authorities in each country to provide medical and health personnel with basic education about leprosy in order to strengthen leprosy programs within the framework of general health services. Efforts should be made to reintegrate communities of persons affected by leprosy into society. The message that leprosy is curable and can be treated while the patient continues to live at home should be emphasized.

2. Every case of stigma and social exclusion is one case too many. Stigma is often associated with a religious vision of life and it would be advisable to revise this belief. In reality, stigma has been linked from the earliest times with fear of a disease that cannot be defeated. Biblical texts of the Old Testament themselves record a practice of exclusion that was present in Egyptian, Assyrian-Babylonian and Canaanite cultures during the second millennium before Christ. The same fear is to be found in non-Christian and non-religious contexts. The teaching of Christ in the New Testament, first of all, *breaks, with great clarity, the connection between illness and sin* (John 9:2-3). Secondly, *Jesus Christ touches people with leprosy, enters into contact with a sick person without any fear of contagion or impurity, and heals and reintegrates people into the community*. Even more, he himself accepts being treated as if he had leprosy. The example of Christ has often not been followed—this neglect enables us to understand that it is easier to eliminate the disease at a medical level than the social prejudice that surrounds it. In this sense, it is absolutely necessary that we place the human being at the centre of all medical activity, rather than, as is often the case, placing the disease at the centre of attention.

It is the teaching of Christ which has led Christians, especially over the last two centuries, to develop a high level of care and treatment for people with Hansen's disease. This took place even before pharmacological therapies were available, when care involved accepting and rescuing people and ending their state of abandonment. There is no need to recall here the giants of charity who were dedicated to this service. Today, as well, the Catholic Church remains strongly committed in almost all countries where the disease is found to providing medical and humanistic care. Here a pathway opens up of cooperation with religious communities of other faiths and with all men and women of good will.

It is the shared opinion of experts who work in the field of Hansen's disease that the elimination of the stigma attached to leprosy requires an important work of education that must involve all social groups and in particular religious communities because they promote respect for human dignity throughout the world.

3. Every law that discriminates against people affected by Hansen's disease is one law too many. Following intensive work, the General Assembly of the United Nations in December 2010 adopted a resolution on the Elimination of discrimination against persons affected by leprosy and their family members, accompanied by ‘Principles and Guidelines’. The resolution and ‘Principles and Guidelines’ constitute a *milestone in the upholding of the human rights of persons affected by Hansen’s disease*. One must take into account that for every person with the disease, his or her family members and even relatives may also be ostracized due to the stigma attached to leprosy, resulting in a serious violation of fundamental human rights. An enormous amount of work still has to be done by governments and social and religious institutions to ensure that these ‘Principles and Guidelines’ are fully implemented.

Unfortunately, various forms of discrimination continue to exist in many parts of the world which bear upon all spheres of life: schools, workplaces, social groups, public places, religious centres, restaurants, hotels, trains and other means of transport. Especially grave are the violations of the rights of persons affected by leprosy in the field of education, work, and marriage. *The necessity to repeal discriminatory laws that impede fundamental human rights is very urgent and can no longer be postponed.*

Implementation of the ‘Principles and Guidelines’ requires constant work involving the sensitisation of governments and societies. To this end, in 2012 the Nippon Foundation created a working group (the International Working Group, hereafter IWG), *which had the aim of assisting the process of implementation of the ‘Principles and Guidelines’*. The IWG prepared a 'Suggested Framework for National Plans of Action' for States to use in their own domestic contexts.

The IWG came to the conclusion that the ‘Principles and Guidelines’ were more likely to be effective if States were called upon *to undertake specific ways of implementing them*, which could then be brought to the attention of various governmental offices and communicated to relevant UN bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions. To this end, the IWG recommended *the institution of a follow-up mechanism* at an international level which would have the mandate to follow up the actions of States and other stakeholders, drawing upon the experience of Special Rapporteurs on various topics of human rights appointed by the United Nations Human Rights Council, or committees of experts which monitor the implementation of international human rights treaties and conventions. This follow-up work must not be neglected, otherwise there will be no perception of progress or steps back.

Accordingly, in the Resolution adopted by the UN Human Rights Council on 2 July 2015, the UN Human Rights Council Advisory Committee is requested to submit a report containing practical suggestions for the wider dissemination and more effective implementation of the ‘Principles and Guidelines’ at the 35th session of the United Nations Human Rights Council in June 2017.

The IWG has observed, in particular, the need for civil society and religious communities to use dignified terminology when speaking about Hansen’s disease. It has been observed that the old perceptions of leprosy continue to be reinforced by inappropriate language. The offensive term ‘leper’ as a description of someone with leprosy evokes a marginalised person, a sinner, or a person who is rejected by other people for moral or social reasons. This terminology contributes to discrimination against persons affected by leprosy and even discourages those who need treatment from seeking help. The IWG has thus invited religious leaders and their communities to reflect upon the best ways of expressing themselves in language that is able to transmit respect for persons affected by leprosy. Awareness-raising activities at the global level should make full use of new media to inform people about advances in treatment of leprosy and the fact that people who are under treatment or have completed treatment are not infectious. It is important that this information is available even in countries where leprosy is not an issue, in order to eliminate the myths surrounding this disease.

Final Recommendations

Two Introductory Points

1. Persons affected by Hansen’s disease must be seen as the main actors in the fight against this disease and the discrimination it causes. This involvement is a powerful instrument for the recognition of their equal dignity and rights for social inclusion, and for the breaking of the stigma attached to them. This point applies to all of the recommendations listed below.
2. The use of discriminatory language that reinforces stigma must cease, in particular, use of the term ‘leper’ and its equivalent in other languages. This term is offensive for the reasons stated above and also because it defines a person by his or her illness. Use of the term “leprosy” in a metaphorical sense should be avoided.

Five Recommendations

1. Given their important role in their respective communities of believers, the leaders of all religions—and this is an important and urgent matter—should, in their teachings, writings and speeches, contribute to the elimination of discrimination against persons affected by leprosy by spreading awareness that leprosy is curable and stressing that there is no reason to discriminate against anyone affected by leprosy or members of their families.
2. States and governments should be encouraged to make great efforts to implement the ‘Principles and Guidelines’ accompanying the resolution adopted by the General Assembly of the United Nations in 2010 on Elimination of discrimination against persons affected by leprosy and their family members. These ‘Principles and Guidelines’ must be fully implemented, otherwise they will remain just empty proclamations.

3. There should be a modification or abolition of all laws and regulations that discriminate against persons affected by leprosy. Policies relating to family, work, schools, or any other area which directly or indirectly discriminate against persons affected by leprosy must also be changed, recognising that no one must be discriminated against because of the fact that he or she has, or once had, leprosy.

4. There is a need for further scientific research to develop new medical tools to prevent and treat leprosy and its complications, and to achieve better diagnostic methods.

5. In order to achieve a world free of leprosy and the discrimination it causes, the efforts of all the Churches, religious communities, international organizations, governments, major foundations, NGOs, and associations of persons affected by leprosy which have hitherto contributed to the fight against this disease should be unified and joint plans of cooperation should be developed. ■