

ABSTRACT BOOK



Pontifical Academy for Life

**PALLIATIVE CARE:
EVERYWHERE &
BY EVERYONE**

Palliative Care in every region.
Palliative Care in every religion or belief

Rome February 28th - March 1st 2018

WORKSHOP PROGRAM

Wednesday, 28 February 2018

09.00 - Opening address and introduction

Archbishop Vincenzo PAGLIA

President of the Pontifical Academy for Life. Vatican City

FIRST SESSION: The value of palliative care

Chairs: Carlos CENTENO

University of Navarra, Pamplona, Spain.

Liliana DE LIMA

International Association for Hospice & Palliative Care.

Houston, Texas, USA

09.20 - **Palliative care improves symptoms**

Eduardo BRUERA

University of Texas MD Anderson Cancer Center, Houston, Texas, USA

09.50 - **Palliative care improves society**

David CLARK

University of Glasgow, Glasgow, UK

10.20 - **Palliative care improves health**

Marie-Charlotte BOUESSEAU

Service Delivery and Safety, World Health Organization, Genève, Switzerland

10.50 - Coffee Break

11.20 – **Palliative care improves medicine**

Kathleen FOLEY

Memorial Sloan-Kettering Cancer Center, New York, USA

11.50 - **Palliative care requires communication**

Christoph FUHR

Department of Health Policy, Springer Medizin, Aerzte, Zeitung, Germany

12.10 - Discussion

12.45 - Conclusion

SECOND SESSION: Palliative care everywhere

Chairs: M.R. RAJAGOPAL

Pallium India, Thiruvananthapuram, India

Daniela MOSOIU

Hospice “Casa Sperantei”, Bucarest, Romania

14.00 - **The way to integration: palliative care in Europe**

Philip LARKIN

- University College Dublin, Dublin, Ireland
- 14.20 - **Research and evidence to improve medicine: palliative care in North America**
Egidio DEL FABBRO
Virginia Commonwealth University, Richmond, Virginia, USA
- 14.40 - **Poverty, development, and human rights: palliative care in South America**
Tania PASTRANA
Latin American palliative Care Association, San Nicolás, Argentina
- 15.00 - **Spirituality and professional awareness: palliative care in Asia**
Jinsun YONG
Catholic University of Korea, Seoul, South Korea
- 15.20 - **Excellence and originality from necessity: palliative care in Africa**
Emmanuel LUYIRIKA
African Palliative Care Association, Kampala, Uganda
- 15.40 - Coffee Break
- 16.10 - **Cultural factors enriching palliative care: palliative care in Arabic Countries**
Azza HASSAN
National Center for Cancer Care and Research, Doha, Qatar
- 16.30 - **The involvement of the community: palliative care in India**
Joby KAVUNGAL
Catholic Health Association of India, Cochin, Kerala, India
- 16.50 - **The work of international institutions advocating for palliative care as a human right**
Katherine PETTUS
International Association for Hospice & Palliative Care, Houston, Texas, USA
- 18.10 - Discussion
- 18.30 - Conclusion

Thursday, March 1, 2018

THIRD SESSION: Palliative Care by Everyone

- Chairs: Ferdinando CANCELLI
Fondazione F.A.R.O. Onlus, Torino, Italy
Daniela MOSOIU
Hospice "Casa Sperantei", Bucarest, Romania
- 09.00 - **The graceful gift of mercy: Christian perspective**
Monika DÜLLMANN
Saint Louis Hospital, Jerusalem, Israel
- 09.20 - **Sanctity of Life: Islam perspective**
Dariusch ATIGHETCHI
University of Lugano, Lugano, Switzerland
- 09.40 - **Embracing life, facing death: Hindu perspective**

Vidya VISWANATH

Pallium India, Andhra Pradesh, India

10.00 - **A good life, a good death: Hebrew perspective**

Barry M. KINZBRUNNER

Vitas Healthcare Corporation, Miami, Florida, USA

10.20 - Coffee Break

10.50 - **The cherry or the yeast? Contributions of the chaplain in spiritual care**

Anne F. VANDENHOECK

Catholic University of Leuven, Leuven, Belgium

11.20 - **Integrating spiritual care into palliative care**

Christina PUCHALSKI

The George Washington University, Washington D.C., USA

11:50 - **The vision behind the Religions of the World Charters for Palliative Care for Children and for Older People of the Maruzza Foundation.**

Franca BENINI

Paediatric Palliative Care - Pain Service, Department of Women's and Children's Health, University of Padua, Italy

12.00 - Discussion

13.00 - Conclusion

FOURTH SESSION: Policy and Financial perspective

Chairs: Eduardo BRUERA

University of Texas, MD Anderson Cancer Center, Houston, Texas, USA

Thomas SITTE

Deutsche PalliativStiftung, Fulda, Germany

14.30 - Charles NORMAND

Trinity College, Dublin, Ireland

14.50 - Fr. Thomas VAIKATHUPARAMBIL

Lisie Hospital, Kerala, India

15.10 - Howard KOH

Harvard T.H. Chan School of Public Health, Boston, Massachusetts, USA

15.30 - Frank NIGGEMEIER

Federal Ministry of Health, Germany

15.50 – Discussion

FIFTH SESSION: PAL-LIFE activities and perspectives

Chairs: Rev. Renzo PEGORARO

Pontifical Academy for Life, Vatican

Nunziata COMORETTO
Pontifical Academy for Life, Vatican

16.00 - **White paper for global palliative care advocacy**

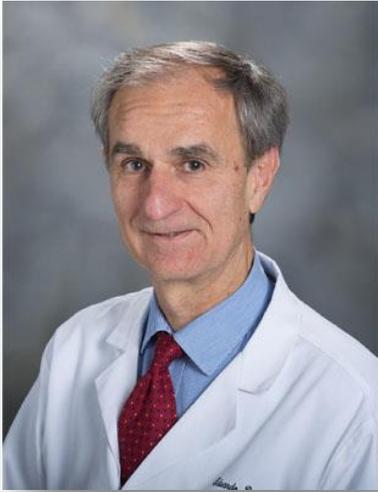
Liliana DE LIMA & Carlos CENTENO

16.15 – **Social capital and community participation in palliative care**

M.R. RAJAGOPAL

Pallium India, Thiruvananthapuram, India

16.30 – Conclusion



Eduardo BRUERA

University of Texas MD Anderson Cancer Center, Houston, Texas, USA

PALLIATIVE CARE IMPROVES SYMPTOMS

Patients with chronic progressive diseases develop a number of devastating physical, psychosocial and spiritual symptoms. Their primary caregivers and family members suffer severe emotional distress. Hospitals, universities and health care systems are organized and funded around disease treatment they have not developed the structures and processes to care for the persons affected by those diseases.

Palliative care teams have emerged as a response to the unmet need to patients and families. Interdisciplinary teams led by palliative care specialists have demonstrated efficacy in the inpatient, outpatient, and home care settings.

Patients report improved control of physical symptoms, psychosocial and spiritual symptoms and quality of life after palliative care encounters. Institutions with palliative care services have better end of life care quality outcomes. These outcomes are better when patients are referred early as outpatients. Palliative care decreases the cost of care for inpatients and outpatients. Although the clinical and financial outcomes strongly support palliative care, there has been very limited adoption of these services by health care systems and universities.

The adoption of palliative care by organized health care will require a major cultural change. Some of the cultural challenges and how to address them will be discussed in this presentation.



David CLARK

Welcome Trust Investigator, School of Interdisciplinary Studies, University of Glasgow, Glasgow, UK

PALLIATIVE CARE IMPROVES SOCIETY

Can palliative care improve society? Cicely Saunders thought it could. In 1961 she observed: 'A society which shuns the dying must have an incomplete philosophy'.

For Saunders, palliative care spoke to things forgotten and neglected in medicine, matters diminished within modern culture and issues eroded within contemporary values. She believed palliative care could be a beneficial force not only for patients and families, but also for the wider good. Today palliative care is much expanded, but at times appears undecided about its core purpose. Not only are there debates about where it begins, ends and to whom it applies, but palliative care also seems torn between two broad orientations: that of a medical specialty on the one hand, and that of a social movement on the other. It is confronted by a 'zero sum' game. If palliative care gains ground as a specialty, it is eroded as a movement. If it seeks the expanded influence of a movement, it loses credibility as a specialty.

What conditions are necessary for the relationship between palliative care and society to become a 'win win' game? To borrow philosopher John Rawls's evocative phrase, the answer might lie in an *overlapping consensus*ⁱ that identifies the principles and concepts of palliative care that all stakeholders can share, when thinking through the complex challenges we now face. I take the view that palliative care *can* improve society, but not until it is clearer in its messaging and more confident of its efficacy.



Marie-Charlotte BOUËSSEAU

Adviser, Service Delivery and Safety World Health Organization, Genève, Switzerland

PALLIATIVE CARE IMPROVES HEALTH

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

There is an ethical duty of all health professionals to take care of the most vulnerable, a responsibility in alleviating suffering even when the curative treatments are not effective anymore. However in the definition of palliative care, it is clear that this responsibility starts very early in the evolution of the disease and is not limited to the end of life care. Palliative care aims to address the needs of all patients with life-threatening illnesses, it is a pillar of health care; in complement to curative interventions, palliative care improves physical health (symptom control), it also addresses psychological and spiritual needs. In that sense, palliative care is emblematic of integrated people centred care; illustrating the responsibility to take care of a person in an holistic manner and not only to treat diseases. People are not isolated and the support provided to families during the disease and for the bereavement is a key component. The specificities of palliative care are related to the complexity of the needs it aims to address; the provision of palliation to people suffering from life-threatening diseases represents a crucial cultural change for health services and health care workers, probably also for societies. Because it is not based on a disease approach, palliative care has to answer very different kinds of needs and expectations, sometimes contradictory, of children or adults, during months. The strengthening of palliative care programs is a challenge for health systems, around the globe and there is not a unique model to be promoted but good and bad experiences to learn from. Palliative care aims to improve health as defined by WHO i.e. the physical, mental and social well-being and not merely the absence of disease or infirmity. To do so health systems must work on different components. The resolution adopted in 2014 by the World Health Assembly

is the first global commitment calling for the strengthening of palliative care as a component of comprehensive care throughout the life course (http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf); it provided an important tool to the WHO 194 Member States in their work to consolidate palliative care programs under the umbrella of the Universal Health Coverage.

Building strong palliative care programs is like building a house. The basement of the house, the first requirement, is a clear policy on access to medicines; regulations have to be in place to allow the availability, equitable access and appropriate use of controlled medicines. It is estimated that more than 80% of the people around the world do not have access to pain relief, while more than 40,000 people die every year from opioids overdoses in the US. This situation is not acceptable and requires urgent actions as indicated in the WHA resolution. The walls of the “palliative care house” are made with good educational programs for health care workers fighting against “*opiophobia*” on one hand preventing over prescriptions of opioids in some countries. Beyond the capacity to prescribe medicines health professionals need to be trained in many other aspects: managing symptoms of the disease and complications of the treatments, addressing psychological and spiritual needs of the patient and his/her family, providing information and facilitating advance care planning with an active participation of the patient and his/her family, coordinating interventions at all levels of care and task shifting within care providers, including family members. The door of the “palliative care house”, the entry point, is made of national policies ensuring that palliative care is not limited to some specific programs but delivered across disease and age groups. The house of palliative care also has many windows, multiple approaches to the complex needs and expectations of patients have to be addressed on the basis of a multidisciplinary approach; chaplains working with nurses, family care givers interacting with pain specialists, physicians collaborating with psychologists, etc. Finally the roof of the palliative care house could be represented with the public debate which has to be fostered to take on board cultural, societal and ethical issues. The tension between universal principles such as the respect of human dignity, the imperative to optimize the risk/benefit ratio in all interventions, the requirement to provide equitable access to medicines and quality health services, might be in tension with particular values depending on the cultural setting and singular aspects of the decision to be taken. This tension has to be managed through prudent decision making processes from an early stage, until the end of life and even after the patient’s death (bereavement). Health teams must be prepared to go through this processes ensuring the active involvement of patients and family caregivers.

WHO has a role in supporting its Member States in the strengthening of all the components of palliative care programs. To do so, it provides guidance documents such as the guide for programme managers published in 2016 (see <http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf?ua=1&ua=1>) . In 2018 three new publications will be available: the first one will describe palliative care at primary care level, the second one is dedicated to paediatric palliative care and the third one to palliative care in the context of humanitarian emergencies and crisis. During the year a pilot study will be conducted in Uganda, Zimbabwe and India to evaluate the potential use of mobile

application to facilitate the communication between family care givers and palliative care teams. WHO is also developing tools to facilitate the exchange of experience between countries and experts and the dissemination of information. The Organization is also working with experts on the development of indicators for the monitoring of the quality of palliative care programs.

Palliation is a key component of health systems and access to palliative care is a fundamental right; it is thus a shared responsibility for health providers, at all levels of care, to ensure that good palliative care is available everywhere for everyone.



Kathleen M. FOLEY

Emeritus Professor of Neurology, Weill Cornell Medical College and Emeritus Member, Memorial Sloan-Kettering Cancer Center, New York, USA

PALLIATIVE CARE IMPROVES MEDICINE

There is increasing evidence from a clinical, ethical and moral perspective to support a positive response to the question “Does palliative care improve medicine?” For purposes of this discussion the term medicine includes the principles and practice of medical care and those who provide such care. Palliative care which embraces a bio-psycho-social-spiritual approach is defined by the World Health Organization as “an approach that improves the quality of life of patients and families facing those problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms, physical, psychological and spiritual.” Palliative Medicine has developed over the last 30 years with standards, protocols and guidelines that describe primary and specialist palliative care and, in a number of countries, is recognized with specialty certification for physicians, nurses, social workers, chaplains. Palliative Medicine as a new field is still evolving and it is now partnering with specialty and primary care medicine in resource rich and resource poor countries to show that when used concurrently with old and new technologies, like standard therapies in cancer, such as lung cancer chemotherapy or stem cell transplant for leukemia or in Phase I trials and in patients with advanced cardiac disease receiving implanted cardiac devices or in HIV/AIDS patients receiving antiviral therapy, such a model of care improves quality of life for patients and their families, improves symptom control and mood, addresses spiritual concerns, facilitates communication about goals of care, and supports shared decision making and bereavement support. In some studies, palliative care may provide a survival benefit and reduce healthcare costs. The interdisciplinary team of physician, nurse, social worker, chaplain, psychologist, and pharmacist embrace the domains of whole person and patient-centered care emphasizing the need to be present to the sick person and their loved ones, providing unconditional support and solidarity, helping the patient achieve a sense of completion in life and finding opportunities for reconciliation, forgiveness, intimacy and peacefulness. Palliative

medicine is focused on treating those suffering with compassion and competence in an ethical and dignified paradigm that focuses on patients' living well with serious illness, modeling a way of caring that embodies the professionalism of medicine and constantly challenging medicine to be better.



Christoph FUHR

Department of Health Polity, Springer Medizin, Aerzte Zeitung, Germany

PALLIATIVE CARE REQUIRES COMMUNICATION

Palliative Care requires communication

- What does the media say about PC?
- Problems and strategies to increase public awareness
- PC and social media
- PC and health professionals: awareness of the benefits of PC and how and when to access it.



Philip LARKIN

University College Dublin, Dublin, Ireland

THE WAY TO INTEGRATION: PALLIATIVE CARE IN EUROPE

There is evidence that palliative care is becoming increasingly integrated into health care systems across Europe. The data from (for example), the EAPC ATLAS on Palliative Care, soon to be in its third edition, demonstrates how the vision and scope of palliative care is becoming more visible with positive outcomes for all European citizens. The WHA 69.14 resolution and WHO leadership in embedding palliative care as a public health issue at a global level provides a strong framework for better outcomes for those in need of palliative care across the European region. Key to this is a belief in the value of integration and how partnership and collaboration can make the difference for optimal palliative care. There are also quality demonstration projects which show the potential of integration for palliative care.

However, there are challenges to this, not least the fact that Europe is not a single entity, but a conglomeration of nations, cultures, beliefs and systems which global health ideals need to understand. Issues of social inequality, rural isolation, access to essential medications and immigration/migration are equal challenges for some European countries as the wider international community. The future integration of palliative care needs to be mindful of the future generation of practitioners to deliver on this particularly in terms of opportunity of education and training and employment in the field.

This presentation will consider the issues that integration raises for palliative care in Europe and consider what solutions may be possible to support this important development into the future.



Egidio DEL FABBRO

Virginia Commonwealth University, Richmond, Virginia, USA

RESEARCH AND EVIDENCE TO IMPROVE MEDICINE: PALLIATIVE CARE IN NORTH AMERICA

Over the past 30 years, Palliative Care researchers in North America have produced landmark studies that affirm the importance of Palliative Care (PC) in improving the medical care experienced by patients and their families. Palliative care is an interdisciplinary approach that improves the quality of life of patients and their families when facing life-threatening illness. Preventing and relieving suffering due to physical pain, burdensome symptoms, psychosocial and spiritual distress are the foundation of the discipline. The delivery of palliative care to patients during any period of their illness and in all settings is another important objective. PC research has led to advances in management of symptoms such as pain, nausea, fatigue, poor appetite, and delirium. PC researchers also identified the risks of an opioid-centric approach to pain management, underscoring the need for a multidimensional assessment and interdisciplinary management in PC. Additionally, evidence shows patients with greater spiritual support may experience improved quality of life and fewer non-beneficial medical procedures near the end of life; skilled clinician communication regarding goals of care results in greater patient satisfaction and avoidance of mechanical ventilation and intensive care units; and a comprehensive clinical model of care that includes inpatient palliative care units and outpatient clinics improves patient and family satisfaction, quality of life, and decreases symptom burden. Studies have also identified challenging areas that will require increased resources, including a future PC workforce shortage and regions where access to PC is currently lacking, such as rural areas and those serving minorities.



Tania PASTRANA

Latin American Palliative Care Association, San Nicolás, Argentina

POVERTY, DEVELOPMENT, AND HUMAN RIGHTS: PALLIATIVE CARE IN SOUTH AMERICA

People living in extreme poverty are one of the most vulnerable groups and often have limited or no access to health services, including palliative care and the relief of severe health related suffering. The poorest have a shorter life expectation and often die with excruciating pain and suffering. Access to pain treatment is a component of the right to health and the denial to the access to the pain relief constitutes “Cruel, Inhuman or Degrading Treatment”. Latin America is one of the regions with the largest economic and social development gaps, including those related to access to health. In this presentation I will explore and describe the inequities in access to palliative care in the Region and the strategies and possible solutions to meet these challenges.



Jinsun (Julianna) YONG

The Catholic University of Korea; WHO Collaborating Centre for Training in Hospice & Palliative Care, Seoul, South Korea

PALLIATIVE CARE DEVELOPMENT IN ASIA: RAISING PROFESSIONAL AWARENESS THROUGH SPIRITUALITY

The level of hospice & palliative care development in Asia remains low. A survey conducted by the WHO CC for Training in Hospice & Palliative Care in four countries of the Asia-Pacific (Mongolia, Vietnam, Solomon Islands, and South Korea) revealed that the healthcare professionals' perception of hospice & palliative care is rudimentary, while the cancer patients' needs remain high. It is thus necessary to transform the professionals' awareness to adequately address these needs, especially since cancer patients reported a high level of emotional and spiritual needs that are often neglected.

While a top-down approach to development requires much time and effort to materialize, professional training can bring some immediate changes within healthcare settings. In the Asia-Pacific, however, there is a general lack of such training. An attempt has thus been made to offer a spirituality-based training program to Korean middle manager nurses, which showed significant improvements in the participants' spiritual and psychosocial well-being. The meditation program also showed positive effects on cancer patients, demonstrating that enhancing spirituality can improve both the professionals' and patients' quality of life.

By training healthcare professionals to develop attitudes and qualities to address patients' multi-dimensional needs through self-care and spiritual intervention, quality care can be provided despite limited resources and lack of policies. In the Asia-Pacific, where most countries remain under such situation, providing holistic training to foster professional awareness on holistic care will have fundamental and sustainable effects for future development.



Emmanuel LUYIRIKA

*Executive Director African Palliative Care Association,
Kampala, Uganda*

EXCELLENCE AND ORIGINALITY FROM NECESSITY: PALLIATIVE CARE IN AFRICA

Africa has 54 countries and a population of over 1 billion people. It has the highest burden of palliative care need. This is happening when health budgets in most countries have not reached 15% of the national budgets as they committed in the Abuja Declaration. Despite this challenges some progress is being made on the continent.

According to the 2017 APCA Palliative Care Atlas, at least 38 countries have some sort of palliative care service using different models. Uganda had 229 such services, South Africa 160 and Kenya 70. Only 16 countries have pediatric palliative care services. Swaziland has 10.88 hospice services per million of population, Uganda 5.87, Gambia 5.02 while South Africa 2.91 per million of population.

28 countries have home-based palliative care services with South Africa topping with 109 home-based services, Tanzania 26, Zimbabwe with 25, and Uganda with 13 and Kenya 12.

For the countries that have the data, the number of patients in palliative care services per year, South Africa stood at 40,000, Zimbabwe at 5000, Zambia 4000, Botswana at 3210 and Kenya at 3000.

25 countries have hospital based PC services with highest coverage being Swaziland at 100% of all hospitals, Gambia 83%, Uganda 20% Kenya 14% and Senegal, Tanzania and Botswana at 10%.

The challenges facing palliative care in Africa are inadequate to no funding in most countries, poor access to controlled medicines including morphine, few trained palliative care providers, not including palliative care professionals in the health establishment and lack of universal health coverage schemes including palliative care.

Opportunities exist through partnerships to expand the discipline and access to palliative care on the continent where the governments, the church and other religious bodies, the private sector and civil society can work together to improve access.



Azza HASSAN

National Center for Cancer Care and Research, Doha, Qatar

CULTURAL FACTORS ENRICHING PALLIATIVE CARE: PALLIATIVE CARE IN ARABIC COUNTRIES

Each year, an estimated 40 million people are in need of palliative care, 78% of them people live in low- and middle-income countries. Worldwide, only about 14% of people who need palliative care currently receive it. Overly restrictive regulations for morphine and other essential controlled palliative medicines deny access to adequate pain relief and palliative care. Lack of training and awareness of palliative care among health professionals is a major barrier to improving access. Palliative Care is focused on improving quality of life for patients and their families. For most clinicians and patients, the discussion of palliative care is a difficult topic. It is complicated by both the clinician's and patient's belief systems, which are frequently heavily influenced by cultural and religious upbringing. Several different religions and cultures have been evaluated for their impact on perceptions of palliative care including end of life discussions. The effect of religion, sense of destiny, quality of life, and process preferences regarding end-of-life decision-making varies from nation to nation. Although the need for comfort, peace, dignity, and the presence of loved ones at the end of life is universal. Still, unique aspects of culture & beliefs can play a significant role in how the palliative team handles the dying process. Many factors influence a person's culture and, therefore, choices about end-of-life care: worldview, ethnicity, geography, language, values, social circumstances, religion/spirituality, and gender. For example, there are certain culture influencing the choices about types of support at the end of life, such as whether or not to use resuscitation measures, medications, medical interventions, or feeding tubes or whether or not to withhold nutrition and fluids. The culture can influence who is with the one at the time of death and whether the patient wants to die at home, in the hospital, or in a hospice facility. Some cultures treat death with the utmost reverence while others prefer to celebrate the life before it. Other cultures fear death. Communicating with the patient and the family regarding their cultural beliefs will help the palliative care team to provide more efficient support.

The Eastern Mediterranean region as defined by the World Health Organization includes 22 countries that extend from Pakistan in the east to Morocco in the west. These countries have significant variability in population, size, income, Human Development Index (HDI), health outcomes, and health expenditure.

In many of the developed countries in North America, Western Europe and Oceania, great strides have been made in the treatment of cancer. Public awareness has increased, treatment modalities improved and consequently the number of survivors is rapidly increasing. Concomitantly, advances in palliative care have also taken place, albeit at a slightly lower pace. Unfortunately, that is not the case in most of the low- and middle-income countries. Most of the countries in the Middle East belong to the latter category, where the majority of cancer patients are diagnosed with advanced stage disease. For these patients, the only realistic treatment option is pain relief and palliative care. In Western societies death has become medicalized and curative procedures are often prioritized ahead of palliative care. The 'cure at all cost' attitude of physicians, along with the strong religious views that many families hold on the sanctity of life often complicate end-of-life management. Also, in Western culture there is a recognizable lack of acceptance of death, leading to reluctance in seeking end-of-life care; as Western culture often tries to deny death as a natural process. This may create an atmosphere where some people are unprepared for their own death or the death of a loved one. By contrast, Islamic societies, unlike several Western societies, are more death accepting, and live in coexistence with the realization of the inevitability of death. Such an attitude has an impact as to how a patient and his family may view death, also knowing what lies beyond it.

Islam is the dominant religion in the Middle East, and observant Muslims believe that having an illness represents an opportunity to enhance the Muslim's degree or expiating personal sins. Yet, Islamic teaching encourages Muslims to seek treatment when they fall sick, as it is believed that Allah did not send down a sickness but rather a medication for it. Example: The concept of euthanasia which is a accepted practice in the west is not a acceptable practice and seen with great distress in the region Muslim's beliefs attribute to occurrence of pleasure and suffering to the will of Allah, and that every effort should be made to relieve suffering. Moreover, Islamic teaching considers the relief of suffering to be highly virtuous. According to Islam, adults of both genders are granted the full right to accept or decline medical intervention. In reality, close family members are more often directly involved with the decision-making process. Generally, parents, spouses and older children, in descending order, have greater decision-making power than the other members of the family. Islamic teaching encourages the community members to visit the sick and the sick to welcome their guests. Patients, therefore, may entertain a larger number of visitors during their hospitalization. The use of drugs that might affect consciousness is strictly prohibited in Islam. However, medically prescribed opioids are generally permissible because of their necessity. Usually, patients and families accept the use of opioids for symptom management, provided the rationale for their use is clearly explained to them. Of great importance is to explain patients and their relatives the possible side effects, as there are great concerns about an imposed drowsiness. Issues that relate to end-of-life are compounded spiritually and ethically, and are open for interpretations. While discussing the prognosis of the loved one, Muslim families are often skeptical about

receiving clear cut messages from the treating physician. The former are for the most part more comfortable receiving less concrete information and quite often would respond with: 'This is in Allah's (God's) hands, and we are not to predict the fate of the patient'. Such a response is largely due to the Islamic belief that the life expectancy of every person is only up to Allah, who is the one to determine the timing of death. Families, however, are very appreciative being updated as to the patient's condition, in order to enable them to carry out the traditional funeral rites. Taking all of the above into consideration, caregivers in Middle East exercise all the precautions and sensitivity while talking to terminally ill patients and their families.

Finally, as per WHO's recommendation for Palliative Care (PC) development, the country should start by asking where they are now. It is important to assess the number of people in need of cancer PC, the needs of patients, health-care providers and family caregivers, the existing PC plan and activities and finally, understand its social context. 2 Secondly, the country should decide where they want to be, i.e. the end goals of its PC program. It is important to define the target population for PC, identify gaps in PC services, set goals and objectives for PC, assess feasibility of intervention and consider ethical and religious issues. Last but not least, the country should determine how they could reach these goals. To be more exact, this can be broken down into smaller questions such as: how to bridge the gaps in PC, how to raise the necessary resources, how to create PC teams, how to educate caregivers, how to educate the general public and policy-makers, how to ensure the availability of essential drugs, how to develop PC standards and how to evaluate and monitor the PC plan and activities.



Joby KAVUNGAL

Catholic Health Association of India, Cochin, Kerala, India

THE INVOLVEMENT OF THE COMMUNITY: PALLIATIVE CARE IN INDIA

Jesus elucidated his mission in this world, as he said, “I have come that they may have life and have it in fullness.” (John 10:10). Life witness accompanied Jesus’ verbal communication i.e., he brought fullness of life through his words, and actions: through healing, washing of the feet and even to point of dying on the cross. From this Mission Jesus’ optics, ‘Health’ is holistic - a harmony of the physical, psychological, spiritual and social faculties of a person. Therefore, in Pratyasha, we approach palliative care from this holistic standpoint.

Genesis & Current Status of CHAI:

In 1940s, the health indicators across the country, especially among the marginalized communities and the vulnerable were appalling. There existed not even minimum accessible maternal and child health services. Soaring maternal and infant mortality, acute malnutrition, diseases burden due to Tuberculosis, Malaria, gastrointestinal diseases like Cholera and diarrhea, etc., lack of health literacy/preventive awareness combined with abject poverty and famine among the masses, ruled the day. The number of qualified women (nurses and doctors) working in health sector, especially among women religious, was negligible. These factors intertwined with superstitions and socio-cultural-religious taboos and gross inequalities in distribution of social health determinants made the health context even worse. The sheer shortage of women health professionals resulted in preventable deaths of women and children in thousands as many of the communities do not permit women to be medically examined by male doctors.

Responding to the situation, CHAI was established on 29th July 1943 by Sr. Dr. Mary Glowrey, an Australian medic and nun, along with 15 other sisters of various religious congregations, working in various hospitals. The objective was to coordinate/unite the efforts of various Catholic hospitals and other health care facilities to create a greater impact – making quality healthcare accessible and affordable even to the poorest, especially in the rural/hard-to-reach medically under-served areas. For CHAI, this Mission continues today responding to the

newly emerging challenges including the growing commercialization of health 'ministry' as 'industry', exploiting in the midst of suffering.

Currently, CHAI is one of the world's largest private not-for-profit Faith-Based Healthcare Networks, with a membership base of 3537 Member Institutions (MIs) - Over 90% of them are headed by women. Over 80% of CHAI member institutions, including 2331 health centres, 628 small, secondary and tertiary hospitals spread across all States – with a total of over 50,000 beds, etc. serve in the medically underserved areas where many a time not even primary public health facilities exist.

CHAI MIs altogether has a team of 1000 Sister-Doctors; 25,000 Sister-Nurses; 10,000 plus Sister-paraprofessionals and over 5,000 Sister Social Workers, along with a huge number of lay employees. CHAI MIs render curative services to over 21 million patients a year. These apart, there are rehabilitation, care and support centres for PLHIV and CLHIV, the children/youth with disabilities, the elderly and the terminally ill, mentally ill; schools/colleges of nursing and allied health with 8700 personnel passing out annually, etc.

These aforementioned efforts of CHAI and its MIs, contribute towards strengthening of equitable distribution of healthcare services with community participation in collaboration with health and various other line Depts. of Govt. and other NGOs/FBHNs. These measurers, in turn, contribute towards country achieving Sustainable Development Goal – 3: "Ensure healthy lives and promote well-being for all at all ages", including the Universal health coverage.

Immediate Context - Paradigm Shift to Holistic Palliative Care:

The realization of the external and internal challenges faced by the Catholic Healthcare Network forced the Catholic Health Association of India (CHAI), to initiate the Strategic Planning Process (SPP), in collaboration with the Catholic Bishops' Conference of India (CBCI) Office for Healthcare, in 2013. The goal of SPP is to strengthen the Catholic Healthcare Network at the National, Regional, Diocesan and Institutional levels, to foster collaboration with the other Christian networks and people of goodwill, towards achieving universal access to compassionate, affordable, rational and quality health care, with special emphasis on the socio-economically vulnerable people. SPP is also a retrospective process of revisiting CHAI's Vision of 'Health for All'.

The key to repositioning of Catholic health ministry is to enable women religious, who own/manage most of the Catholic healthcare facilities, to *revisit* their health ministry, *rediscover* their place and role in the emerging context and *reposition* themselves accordingly.

This repositioning also means to meet the external challenges like demographic and epidemiological transition. This includes mainly a paradigm shift to establish and maintain centres to take care of the elderly and the terminally ill, with special emphasis on the marginalized and vulnerable.

It is estimated that, in India, about 6 million people need palliative care in a year. Only less than 2% of these people have access to palliative care that can relieve suffering. Moreover, there is also a tendency to exploit in the midst of sickness and dying, due to the growing commercialization of healthcare.

Responding to the situation, in collaboration with its member Institutions CHAI has launched the project *Pratyasha* - with a Model 25-bed Holistic Palliative Care Centre in Hyderabad with 6 Holistic Palliative Care Units (HPCUs) covering three states on a pilot hub & spokes model.

Currently CHAI now plans to scale up *Pratyasha* model of holistic palliative care as a national movement through its member institutions, in order to reach maximum people who suffer due to lack of palliative care.

In this regard, CHAI and its Member Institutions has started focusing on building a new cadre of health professionals to render palliative and geriatric care with a 'whole' person/holistic approach. So far, CHAI has capacitated over 250 sister nurses / social workers in holistic palliative care in collaboration with MNJ Regional Cancer Centre in Hyderabad; also, over 200 in geriatric care.

Pratyasha - a Unique CHAI Model Of Holistic Palliative Care:

Currently CHAI is in the process of developing its Holistic Palliative Care Centre (HPCC) at Hyderabad as the Hub of *Pratyasha* movement - a unique CHAI Model of holistic palliative care. It is a combination of palliative and end-of-life Care - with a 'whole person' - patient – family centered approach, compassionate touch and communication, socially-culturally-faith linked psycho-spiritual support in a pluralist context, not only confined to Cancer but non-malignant chronic illnesses, ensuring adding life to days and peaceful death, care for the caregivers and bereavement support.

The project intends to replicate 'Pratyasha' model in patient homes/home-based care, embedded/inserted in neighboring communities / institutions, nurturing local volunteers (Community Home Based Care) through *Ecclesia Optics (come, see and experience)* involving local community elders & youth, PRIs & Other Govt. line depts., religious leaders / communities, local schools and other Institutions/organizations.

Pratyasha model believes that Nature has the power to heal, and hence, tries to create nature-rich healing ambiance - catering to 5 senses: smell, taste, sound, touch, and sight, with seasonal-fruit and vegetable gardens, greenish and flowery indoor plantation, water bodies (sound of water flowing), aquariums, pet garden: meant for pet therapy, soothing music, biblio-therapy – books & audios & videos - inculcating positive thinking & meaning in life, etc. It encourages patients and caregivers for free self-expression through group/individual

sharing/counselling for patients and close caregivers in a prayerful atmosphere, painting, drawing, clay modeling, etc.

As a Centre of Excellence, HPCC gives hands on training to doctors, nurses and local community volunteers – inculcating pratyasha cadre/‘Pratyasha Architects’ of holistic palliative care providers. As a Hub, it provides technical assistance to HPCUs/Spokes - including telementoring by skilled/technical experts. It intends to undertake research and advocacy (including drug availability).

CHAI also gradually builds Pratyasha into a national movement, replicating/customizing/mainstreaming CHAI brand of Holistic Palliative care, including Pratyasha wing in its member hospitals and health centers, facilitating the start of new HPCUs - with uniform standards of care, focusing on health care facilities by CHAI MIs in rural/remote areas. In this regard, currently it collaborates with Misereor – Germany, 2Worlds Cancer Collaboration – Canada, Pontifical Academy for Life (PAL) – Rome, Pallium India and other organizations.



Katherine PETTUS

*International Association for Hospice & Palliative Care
Advocacy Officer, Houston, Texas, USA*

THE WORK OF INTERNATIONAL INSTITUTIONS ADVOCATING FOR PALLIATIVE CARE AS A HUMAN RIGHT

Global advocacy for palliative care is subversive praxis, a stumbling block to health systems oriented towards cure, a call to *metanoia*, and therefore to evolutionary systems change. Palliative care clinicians are natural advocates for their patients in the public square: as witnesses to the existential distress and total pain of their patients, clinicians are their legitimate representatives, the voice of the voiceless. Palliative care advocacy requires clinicians to take the long view, the patient, faithful, eschatological perspective, maintained even as the sharp thorn of untreated patient and caregiver suffering drives us relentlessly on. It is quintessential mustard seed practice: leaven in the dough of health systems, international organisations, and of modern society itself. The palliative care ethos challenges contemporary global health ideology, which is fixated on making populations *fit* to contribute to “development,” discarding those who don’t make the cut, abandoning them to die in agony. From the development perspective, which requires financial returns on investment, the palliative care ethos is perverse: its promises of social and spiritual returns on investment are unquantifiable, and therefore appear invalid. Palliative care advocacy humbly requests public resources to care for people who don’t contribute to the bottom line, as a matter of justice, not of charity. We welcome guests who can’t reciprocate with their own party invitation. Such absurd petitions fly in the face of rational public policy and budgeting, particularly in this era of “scarcity” and “crisis.”



Monika DÜLLMANN

Saint Louis Hospital, Jerusalem, Israel

THE GRACEFUL GIFT OF MERCY – CHRISTIAN PERSPECTIVE

Among the founders and promoters of Palliative Care all over the world are many Christians.

Christian FAITH teaches the sanctity of life as a gift of God, a value which is not reduced by sickness and limitations. It also points to the coming world, and sees the earthly death not only as an end, but also as a beginning.

Christian ethics of LOVE urges to reduce suffering as Jesus taught and did, and to see in the suffering person Jesus himself.

Christian spirituality of HOPE believes in God's active presence in the life of each person. It calls the care giver to respect the individual with his and her faith, culture and personal convictions, and to accompany the dying person on his or her way.

Providing loving care and accompanying people on the last journey with all its physical and psychological limitations, sufferings and fears, is a strong witness for the Christian way of approaching life and death with mercy.

An example for this is St. Louis Hospital in Jerusalem, one of the main Palliative Care providers in Israel. Patients, Families and Care Givers, may they be Jews, Christians or Moslems, live and work together peacefully in a society torn by conflict and violence. They share a common aim, and experience a unique form of interreligious and intercultural dialogue.

Palliative Care accompanies people to the bridge between Life and Death, and it builds bridges of Peace.



Vidya VISWANATH

Pallium India, Andhra Pradesh, India

EMBRACING LIFE, FACING DEATH: HINDU PERSPECTIVE

In the journey with a person facing grief and loss, as a palliative care physician my endeavour is to ease transitions, keep hope alive in the face of despair and maintain the delicate balance between holding on and letting go. As I counsel patients at the crossroads, I need to be gentle in truth -telling and firm in establishing goals of care. I do need something more than evidence based medicine. Growing up with stories of the Hindu pantheon, each with their unique attributes, I am inspired to draw parallels to deal with the turmoil around with equanimity and serenity. When faced with ethical dilemmas, the “*Bhagwad Gita*” reminds me to do my duty to the best of my ability without expectations. It is the intention behind the action, not the fruit of the action says the “*Gita*” akin to the principles of bioethics we strive to follow. Accepting the Hindu principles of assimilation, plurality and tolerance, it is easier to integrate and work as multidisciplinary teams building bridges across barriers. I have learnt life lessons in the hospice, which, like the temple is more than just a structure. Finding solace in “*Karma*” and considering death as an evolution of the soul is how some caregivers try to cope. The emphasis in Hinduism is on awakening the soul and having faith in one’s own self. I am grateful that the practice of palliative care is a process of introspection and reflection which has brought me closer to my own faith.



Barry M. KINZBRUNNER

Vitas Healthcare Corporation, Miami, Florida, USA

A GOOD LIFE, A “GOOD DEATH”: THE HEBREW PERSPECTIVE

Judaism teaches that life is of almost infinite value, yet the Book of Ecclesiastes (3:2) tells us that “...there is a time to live and a time to die...” The latter is perhaps best illustrated in the first book of the Bible, Genesis, which vividly describes in its last few chapters the final illness and subsequent death of the Jewish Patriarch Jacob, during which Jacob had the opportunity to bless his children, following which he passed away peacefully in his own bed. Ancient Jewish sources teach us that Jacob actually asked God to create terminal illness in order to allow one to have time to settle one’s affairs before death. So, in some sense, the Jewish Patriarch Jacob may have experienced the first palliative care or hospice death in recorded history.

Interpretation of Jewish texts and prior Rabbinical rulings, from the ancient to the most modern, has provided and continues to provide Jewish patients and the Rabbis who advise and counsel them with the knowledge and understanding to make medical decisions in various end-of-life and near end-of-life situations that are both appropriate for patients and their families and are consistent with Jewish law. Key areas impacted by this that will be explored include overall decision making near the end of life, the management of pain, do-not resuscitate orders vs. cardiopulmonary resuscitation, and artificial nutrition and hydration. Jewish mourning and bereavement customs as a model for a healthy survivor response to loss will also be briefly discussed.



Anne F. VANDENHOECK

Catholic University of Leuven, Leuven, Belgium

THE CHERRY OR THE YEAST? CONTRIBUTIONS OF THE CHAPLAIN IN SPIRITUAL CARE

Palliative Care has been a blessing regarding the integration of spiritual care and the honoring of whole person care. Within the palliative context every patient is seen as having spiritual resources and spiritual needs and every clinician is expected to integrate this into the care plan. So what is the role and contribution of the chaplain then? Is he or she just a cherry which makes the pie look nicer or is he or she the yeast in the dough which is essential to bake the pie? In this lecture we will explore what chaplaincy can mean in the context of palliative care and the palliative care team and how the chaplain can counsel clinicians in spiritual care.



Christina PUCHALSKI

The George Washington University, Washington D.C., USA

INTEGRATING SPIRITUAL CARE INTO PALLIATIVE CARE

Built on over twenty years of consensus building, research, educational and policy programs, Spirituality and Health is increasingly becoming a field in the US and in many countries around the world particularly in the context of caring for patients with serious and chronic illness. Two consensus conferences in the United States and an international conference in Geneva, Switzerland resulted in a model for interprofessional spiritual care and recommendations for its implementation. Participants gathered to bring their collective knowledge, wisdom, and passion for improving health care systems to discussions of strategies and standards for creating more spiritually-centered compassionate systems of care through the integration of spirituality, in the broadest sense, in diverse health systems globally. The findings were published in 2014 --- *Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus*, published in the Journal of Palliative Medicine.

Models for interprofessional spiritual care are based on the ethical guidelines in palliative care that all healthcare professionals have an obligation to attend to their patient's suffering--- psychosocial as well as spiritual and that they should work with spiritual care professionals such as chaplains who are the experts in spiritual care. ISPEC, a global train the trainer program in interprofessional spiritual care will be discussed as well as partnerships with professional associations of spiritual care professionals in helping countries develop culturally appropriate professional spiritual care leadership in their health settings.



Charles NORMAND

Emeritus Professor, Centre for Health Policy and Management, Trinity College, Dublin, Ireland. Professor of the Economics of Palliative Care, Cicely Saunders Institute, Kings College London

ACHIEVING VALUE FOR MONEY IN PALLIATIVE AND END OF LIFE CARE

Despite significant methodological and practical challenges, there is a growing body of evidence regarding the cost-effectiveness of palliative care. Palliative care is a complex intervention for people who have complex needs, and therefore does not fit easily into the commonly used frameworks for assessing cost-effectiveness. Interventions are personalised and varied, many of the services support other care providers, and beneficiaries include families and caregivers. Particular challenges can be to cost and value aspects of services such as accessibility and availability (even for services that are not used). Widely used quality of life tools appear not to be very sensitive in the end of life context, and may significantly undervalue improved care.

This presentation will briefly review the challenges in assessing cost-effectiveness and value for money in palliative care, and will report on the growing evidence on benefits and costs. Some studies show that palliative care can be cost-saving despite achieving better outcomes. This is largely from better support for decision making that reduces use of services that have little or no value, but high costs and some worsening of quality of life. In other cases there is evidence that good palliative care is valued highly. We need to expand the evidence using tools that allow comparison with other healthcare, but which are sensitive to the measurement challenges in palliative care.



Thomas VAIKATHUPARAMBIL

Director Lisie Institutions, Kerala, India.

PALLING UP FOR PALLIATIVE CARE

“GOD HAS CHOSEN US TO HELP ONE ANOTHER” (SMITH WIGGLESWORTH)

The timing, demand and opportunity to expand access to palliative care are unprecedented. The public and private health care markets are under pressure to provide higher quality care for the growing number of chronic and terminally ill patients. We need policy initiatives that address workforce needs, research and payment models linked to quality measures. Also we need legislations to facilitate research, professional development and public education in palliative care. Formulation and implementation of certain policies by the governing bodies can help in the successful development of Palliative Care Services in the society.

In this presentation, we discuss the various policies that need to be formulated by governing bodies to achieve an effective palliative care program. The various funding models are discussed. The role of Catholic Church and Lisie hospital as a role model too has been discussed. What the future holds for palliative care and how to build resources and train manpower as we enter palliative era also has been briefly touched upon “Think personal act global”, is the new mantra for palliative care.



Howard KOH

Harvard T.H. Chan School of Public Health, Boston, Massachusetts, USA

POLICY DIMENSIONS OF SPIRITUAL CARE IN THE UNITED STATES

The United States is engaged in a vigorous national debate on the future of health and health care. A major national goal is to move toward a better system for addressing fundamental health needs through patient-centered care, person-centered care and quality improvement. This presentation will review how these and other themes currently relate to policy dimensions of spiritual care, both as a specific part of palliative care and more broadly.



Frank NIGGEMEIER

Federal Ministry of Health, Germany

POLITICAL POSSIBILITIES TO IMPROVE AND EXPAND PALLIATIVE CARE – EXPERIENCES FROM GERMANY

What can policy do to ensure that people can spend the last phase of their life in dignity? In Germany, based on a broad public debate about how we want to live and die, a comprehensive approach was taken which implies in particular:

- generally improving the situation of persons in need of long-term care, particularly the elderly, and of their families,
- ensuring patients' rights to an informed decision about their medical treatment, including the option of self-determined limitation or termination of life-prolonging treatment,
- further developing palliative care abilities of health professionals and diminishing legal obstacles for adequate palliative care,
- specifically supporting and expanding palliative and hospice care facilities throughout the country, in particular team-based approaches,
- strengthening suicide prevention and
- banning organized and businesslike suicide assistance.

Policy can only set the legal and financial framework. Such a framework is a necessary, but not a sufficient condition. To establish and maintain palliative care as an essential part of a humane society, it also takes public awareness and the engagement of many – individuals, groups, institutions. This kind of approach could be taken into account and adapted, as appropriate, to the specific national and cultural conditions of other countries if citizens there decide to develop a similar framework.



Liliana DE LIMA

International Association for Hospice & Palliative Care, Houston, Texas, USA



Carlos CENTENO

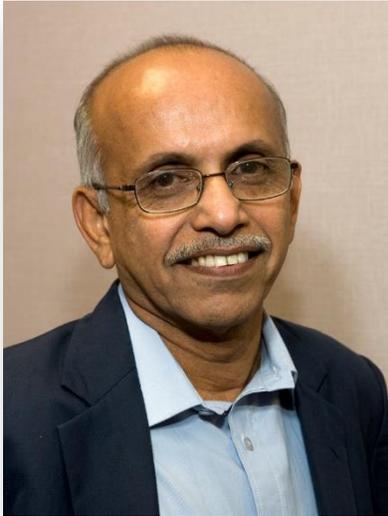
*Palliative Medicine and Symptom Control
Titular Professor Faculty of Medicine,
University of Navarra, Pamplona, Spain*

WHITE PAPER FOR GLOBAL PALLIATIVE CARE ADVOCACY

The Pal-Life project was convened by the Academia Pro Vita (Pontifical Academy for Life) a Pontifical Academy of the Roman Catholic Church that does related research on bioethics and Catholic moral theology. Palliative Care (PC) experts from around the world (“the ad hoc group”) were invited to prepare recommendations for the global development of palliative care. Members of the ad hoc group were selected based on their expertise, leadership and experience in advancing policies and programs.

Thirteen key stakeholder groups were identified as key advocacy partners in the advancement of palliative care in the world: pharmaceutical authorities, policymakers, university (Academia), professional associations, mass media, international organizations, religious institutions, spiritual and ethics groups; hospitals and health care centers, patients and patients groups, health care workers, philanthropic organizations and charities; and professional associations and societies focusing on specialties other than PC. Members of the ad hoc group were assigned to a stakeholder group and requested to provide two or three recommendations on how that specific stakeholder group could contribute to the advancement of palliative care. All recommendations were shared and ranked by the members of the ad hoc group. Recommendations with the highest importance rankings were selected. The ad hoc group prepared a total of 43 recommendations. All members rated the recommendations and selected thirteen as being the most important.

The white paper represents a position statement of the Pontifical Academy of Life with regard to PC, which will be useful for advocacy with local governments, healthcare organisations, opinion leaders, and faith-based communities, among others. The recommendations are useful as a checklist for countries or regions in the process of identifying and implementing basic strategies to improve public policy and care provision for patients and families with PC needs. It may also serve as the basis for development of a more comprehensive list of recommendations adapted to the institutions or groups within its stakeholder's category, or a specific geographical context.



M.R. RAJAGOPAL

Pallium India, Thiruvananthapuram, India

MEMORANDUM OF UNDERSTANDING CHAI & PALLIUM INDIA

World Health Organization says that health is “not only absence of disease or infirmity, but a state of complete physical, mental and social well-being”. Paradoxically, the evolution of health care distanced health care from the person and suffering. Today, the focus is on diseases, especially its diagnosis and cure, often abandoning the person and family when cure is not possible. Often it results in inappropriate, hi-tech, expensive disease-focused treatment even at the end of life.

Palliative care is one stream of medicine which brought the focus of treatment back on the person, the family and suffering, including the domain of spiritual suffering.

Based on the premises that health care should be a partnership between the patient and the family on the one hand and the care system on another, and that the care system needs to include anyone who is able to provide social, psychological or spiritual support, the palliative care system in Kerala involves the community in the form of trained lay volunteers. This system declares that health care is the responsibility of the whole community and that everyone has the responsibility to help his neighbor in suffering. Volunteers perform the following roles:

- a. Be a link between the patient and family and the care system.
- b. Provide basic nursing care to patients and impart nursing skills to the family.
- c. Fund-raise for palliative care.
- d. Initiate and manage palliative care programs.
- e. Advocate for patients and families and for palliative care.

However, monitoring of the system is needed because such utilization of the social capital can open the door to negative influences like vested interests of members of the community.

POSTERS

CLINICAL ETHICS CONSULTATION IN CASE OF TRUTH TELLING IN PALLIATIVE CARE SETTINGS IN BULGARIA

Silviya Aleksandrova-Yankulovska¹, Nikolay Yordanov², Maria Kostova²

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²*Palliative care ward, Comprehensive Oncological Center-Vratsa*

This poster presentation aims at discussion of ethical and legal aspects of truth telling to terminally ill patients in Bulgaria through a real palliative care case.

The case is retrieved through the application of METAP methodology for clinical ethics consultation (CEC) in the palliative care ward in Vratsa, North Bulgaria. Adapted METAP instruments were applied at the ethics meeting and participants' feedback was analyzed through originally developed questionnaire.

The case: A 65-year old female patient with colon cancer and poor prognosis was hospitalized and palliative care was provided. The patient was not informed about the diagnosis. The relatives had disagreed over truth telling which was the reason for organizing the ethics meeting.

Results and Discussion: Three staff members and three relatives took part in the ethics meeting. Relatives' wish to withhold information from the patient collided with patient's legal right to be informed. The meeting contributed to the clarification of legal and ethical aspects (50%) of the situation which led to the final decision of two of the relatives to reveal the truth to the patient with the assistance of the team. Participants agreed that the moral problem was well defined (100%) but partially solved (50%). Each participant had equal opportunity to share their opinion and the satisfaction with the meeting was 100%.

Conclusion: The issue of truth telling is still debatable in Bulgaria. Legal provisions for withholding of information do not exist but paternalistic views are still strong among health professionals and patients' relatives. Earlier studies showed that 78.8% of patients in palliative care units were aware of their diagnosis against 50.4% of in-hospice patients. Existing clinical guidance for care of terminally ill patients, which requires registration of information for the patient, is not equally binding for hospices as for hospital units. CEC is often indicated in such cases.

THE PALLIATIVE CONVERSATION FOR EVERYONE TAKING CARE: THE RESPONSIBILITY OF THE PROFESSIONALS

Dr. Kathleen Benton

Director of Clinical Ethics and Palliative Care, St. Joseph's / Candler Health System, Savannah, Georgia, USA

Silos are inherent to medical care. The disciplines work together yet are miles apart. The social worker is not speaking to the physician, and the nurse is not speaking to the respiratory team. The goal of charting, rounds, and electronic medical records has begun to close these gaps. However, the tenuous and demanding nature of healthcare, along with the inherent hierarchy that exists, inhibits a crossover of clear communication. And thus, a patient and his or her family are faced with the unorthodox challenge of understanding a message from multiple professionals with multiple spectrums and spans of knowledge and with varying opinions on how far treatment should proceed. The continuum of care is broken, gapped, and challenged, particularly when the ability to heal is no longer likely and when the care that can be achieved is only one of compassion and comfort. Thus, it is more important than ever that palliative communication be a team approach.

It only takes one allied professional who feels the need to give inaccurate or false hope to throw the family into confusion. When a member of the care team is communicating clearly that the end is near, that individual can quickly become the 'bad guy' if other more hopeful opinions challenge a terminal likelihood, and generates discontent for a family struggling with grief. It is left to the professionals working together to speak to the moving parts of a terminal acceptance, and a positive transition towards a comfortable end. Thus, the team must all be delivering the same prognostic message. Daniel was my brother; his end of life lasted two years and followed 110 surgeries and thousands of hospitalizations. Life was a battle for breath until the end came and dignity and peace accompanied that end. When everyone taking care stood in silos, his acceptance was unnecessarily disillusioned.

DEVELOPING THE ALL-IRELAND INSTITUTE OF HOSPICE AND PALLIATIVE CARE (AIIHPC) PALLIATIVE CARE RESEARCH NETWORK STRATEGIC PLAN 2017 – 2022

Dr Jackie Boylan, Dr Mary Rabbitte, Karen Charnley, Assoc Prof Suzanne Guerin, Professor Sonja McIlpatrick, Brendan O'Hara

All Ireland Institute of Hospice and Palliative Care (AIIHPC), Second Floor, Education & Research Centre, Our Lady's Hospice, Harold's Cross, Dublin 6W, Ireland.

Background: In 2012, AIIHPC established the Palliative Care Research Network (PCRN) to address the need for collaborative multidisciplinary palliative care research on the island of Ireland. The PCRN is governed by the Strategic Scientific Committee (SSC) whose membership includes representatives from the PCRN, people with life limiting conditions and their family/carers* and national funding bodies.

Aim: Develop a Strategic Plan, setting out the main objectives of the PCRN and implementation actions required over next five years.

Method: Three phase development: (1) Identification of activity areas by SSC members via open agenda meeting and email review; (2) Refinement of plan created by SSC with support of AIIHPC via email/ phone review; (3) Prioritization to inform the actions required for implementation via stakeholder workshop. Participants (17) from: academic/clinical institutions; policymaking/funding organizations; Voices4Care research panel; AIIHPC.

Results: Five strategic objectives were identified: (1) Collaborative and coherent research environment and culture; (2) Deliver outstanding, innovative, internationally relevant research; (3) Develop research leaders and research capacity; (4) Advance knowledge and practice for hospice and palliative care through interdisciplinary collaborations and meaningful involvement of people with life limiting conditions and their carers; (5) Effective translation of knowledge on the island of Ireland and internationally; aligned to five activity areas and individual actions. Further prioritisation identified three activity areas and 14 corresponding key actions; with key activity for successful implementation to focus on building research leadership and capacity; and key action to actively seek opportunities to influence and inform policy and strategy in palliative care to effectively disseminate knowledge from research.

Conclusion: The PCRN Strategic Plan 2017 - 2022 sets out the direction and actions required to develop the PCRN network over the next five years to uphold our vision that as the leading Network for palliative care research on the island of Ireland.

*Members of the Voices4Care Research Panel

297 words (excluding title and authors, affiliation)

THE “CRA” PROJECT: INVOLVE GP TRAINEES IN NURSING HOME TO LEARN PALLIATIVE APPROACH IN ELDERLY PATIENTS

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¹¹ Nursing Home Coordinator “O.P. Castiglioni” Formigine, Friends for Life Association

AIM: General Practitioners will face the alarming global aging problem in the near future. Available hospices are insufficient to satisfy the palliative care (PC) needs among the non-oncological patients. But why don't we consider Nursing Homes as a resource for GP's education?

GOALS: Educate doctors to care for Non-Oncological patients nearing the end of life. Describe the “core curriculum” for employees in Intermediate Care and the program for students. Transform Nursing Home into Educational Centers for both healthcare professionals and citizens. Promote Research in the field of palliative care (for oncological and non-oncological patients).

METHOD: The project was developed by: identifying resources, sponsors and stakeholders; training a pool of GPs that will serve as tutors for the next generations of family doctors, defining the learning objective for healthcare professionals. Nursing Homes are open to welcoming undergraduate students from different faculties and also post-graduate specialists.

RESULTS: So far we have:

- Trained 4 GPs between 2015 and 2017 (3 Italians and 1 Turkish)
- Increased research activity (6 abstracts presented at National and International conferences)
- Held the first multi-professional class (nurses and doctors together)
- Defined the learning objective (Frailty, 4-D assessment, PC scales, Advanced care plan, narrative medicine, bereavement, spiritual care) and recorded data in patient summary.
- Improved the standards in all Nursing Homes in our Province
- Started supporting On-site learning in practice

- Introduced Audit methodology, SWOT analysis and reflective learning from GP trainees (they fill a report at the end of the residency describing what they have learned)
- Improved the use of Social Media

CONCLUSION: GPs and Nurses must be ready to face to the ageing global population and the increasing PC needs. Nursing Homes are an option to spread PC approach in young generations of GPs and represent an occasion to build on-site education in a real teamwork and cost effectiveness environment.

ATENCIÓN PALIATIVA Y UNIDAD CUIDADOS PALIATIVOS EN BIKOP (CAMERUN)

Dra Ana Gutierrez, Dra Rosi Garcia, Dr Milton Arango, Dr Wilson Astudillo,

Centro de Salud Bikop (Selva) Camerun. Paliativos Sin Fronteras (PSF)

Iniciamos una colaboración formativa de PSF en 2011 con Cursos específicos Medicina Paliativa (Dr M.Arango) y Material Docente a las responsables en Camerún en zona de Bikop (Selva) Dras Ana Gutierrez y Rosi García de la Congregación Esclavas del Sagrado Corazón de Jesús, con un Centro de Salud con camas de hospitalización y personal de Salud, y en Yaundé Dra Cristina Antolín directora Hospital San Martín de Porres hasta finales 2017, y su personal de Salud. Hasta esa fecha se desconocía la Medicina y Atención Paliativa y se carecía de Morfina para el tratamiento del dolor en fases avanzadas. Se nombra a Dra Ana G Representante de PSF.

Desde entonces hasta 2018:

- Se ha formado a 3215 Profesionales Salud en Centro, Sur y Litoral de Camerún,
- Creación 1ª Unidad Soporte Domiciliario y Hospitalización y Centro de Día en CS Rural Bikop con atención de 148 pacientes, Consulta Psicológica, Acompañamiento al Duelo. Crea 2 Grupos de Escucha para Enfermos y Familiares en CP
- Creación 1ª Unidad CP en el Hospital S. Martín de Porres, Yaundé(capital) 2014 <http://youtu.be/H0Oe3DLae5A>, con consulta de Psicología.
- Provisión Morfina en Polvo ☑ Elaboración Guía Nacional CP y 3 Folletos: Cáncer, Acompañamiento y Trabajo en Equipo ☑ Organizan Jornada Anual Paliativa (2015-2017)
- En 2016 se introduce Docencia Reglada de Cuidados Paliativos a nivel de Licenciatura y Máster en las Escuelas de Enfermería: Católica de Yaundé e Insóláfrica de Kribi.
- Envío 4 becarios a España perfeccionamiento en UCP
- Formación Anual Voluntarios de PSF (Personal Sanitario) in situ
- Realización Documental (56 minutos) MAS ALLÁ DE LA COLINA Y LA SELVA por A.Torrescalles (2015)

PALIATIVOS SIN FRONTERAS (PSF): SOLIDARIDAD INTERNACIONAL PARA EL DESARROLLO CP.

Dr Wilson Astudillo, Dra Carmen Fuente-Hontañón, Dr Antonio Salinas

Objetivos

- Conseguir que CUIDADOS PALIATIVO y TRATAMIENTO DOLOR se consideren dos derechos humanos esenciales en todos los países
- Ayudar a reducir brecha entre países ricos y pobres
- Facilitar la cooperación inter institucional educativa: cáncer, paliativos, dolor en España y otros países.
- Apoyar proyectos de investigación y Guías en CP y TD
- Promover convenios cooperación en oncología y CP
- Ayudar a integrar los CP en Planes Nacionales de Salud

Iniciativa de 2009, (España) fruto experiencia de Fundadores de Sociedad Vasca Cuidados Paliativos –Dr.Wilson Astudillo- y Sociedad Castellano Leonesa de Cuidados Paliativos (PACYL)- Dra Carmen Fuente-Hontañón- junto al Dr Montiano Cooperante en África y la ayuda Dr Elias Diaz-Albo Cooperación Internacional.

Aceptados en 2015 por Agencia Española de Cooperación Internacional (AECI) como ONG de Salud nº2834 y declarada ONG de Utilidad Pública por el Ministerio del Interior.

Enviados 12 Médicos y Enfermeras como Cooperantes a Camerún, Marruecos, Nigeria.

Promovido creación 4 Unidades de Cuidados Paliativos, una Yaundé (2014Camerún), dos Perú (2011-2017Cuzco y Lima) y una de CP Pediátricos en España (2017). 3 Equipos de CP Domiciliarios en Bikop (2011 Camerún), Marruecos (2016-Nador) y Haití (2017).

Acuerdos Docentes con 10 Hospitales de España y proporcionado 33 estancias formativas de tres meses en CP, Oncología, Unidad del Dolor y Anatomía Patológica a profesionales de África (Camerún), Haití y Latinoamérica.

Editado 25 libros de CP y el último de CP Pediátricos en Niños y Adolescentes, traducido al francés. Curso On-Line de CPP para 100 Pediatras de CYL.

Red de 17 Representantes en Latinoamérica y África

Premio Fundación-Sociedad Española de Dolor www.sedolor.es (2015) por Acciones formativas Latinoamérica y África. Premio Fundación ANESVAD (www.anesvad.org), 2017, Innovación en Cooperación Internacional Camerun

ATENCIÓN PALIATIVA Y SOPORTE DOMICILIARIO DESDE MELILLA (ESPAÑA) A NADOR (MARRUECOS):“LOS QUE SUFREN NO PUEDEN ESPERAR”

Diego Santamaría Amat, Montserrat Jimena Garcia, Wilson Astudillo, Carmen Fuente-Hontañón

En octubre de 2015 recibimos este email:

“Buenas tardes: Me llamo Diego y me dirijo a ustedes para comentarles un proyecto que está surgiendo en esta ciudad. Somos un grupo de médicos y enfermeros que tenemos la intención de realizar Cuidados Paliativos en Marruecos.

Trabajamos en el Hospital Comarcal de Melilla, y todos los días se acercan familiares y pacientes con la necesidad de estos cuidados. En Marruecos la sanidad se paga, y cuando se acaba el dinero cruzan la frontera para pedir continuar con el tratamiento, pero al no tener papeles no se les puede ayudar.

Igualmente muchas veces en ese país se acaba la medicación (por motivos desconocidos), y los pacientes se pueden quedar sin mórficos, quimioterapia... durante semanas.

Por estos motivos, este grupo de profesionales hemos decidido lanzarnos a realizar esta tarea en ese país. Algunos médicos de la SECPAL nos hablaron de ustedes y tras visitar su página web hemos decidido entrar en contacto.....

Un saludo

Diego Santamaría

Desde PSF iniciamos colaboración y apoyo y desde 2016:

- creación de un Grupo de Voluntarios Sanitarios para Atención Domiciliaria de Cuidados Paliativos y dotación material docente y asistencial
- Inicia Cuidados Domiciliarios a Pacientes de Nador (Marruecos)
- Se nombra a DIEGO SANTAMARÍA AMAT representante de PSF
- Jornada de Formación de Voluntarios
- Rotación de un Voluntario en UCP de Hospital de Cruces (Bilbao)
- Desde 2016 se han atendido a 78 pacientes
- Convenio con Farmacéuticos Sin Fronteras y Hospital Donostia para envío material
- Convenio con Servicio de Oncología Pediátrica (Rabat) para Formación y asistencia pediátrica domiciliaria

IMPACTO ECONÓMICO DE LAS UNIDADES DE CUIDADOS PALIATIVOS

Esmeralda Alonso Sandoica

Del Pozo Valdés, Covadonga

INTRODUCCIÓN: En diversos países se están haciendo estudios sobre la eficiencia de los cuidados paliativos.

MATERIAL Y MÉTODOS: Se realizó una búsqueda utilizando “cuidados paliativos impacto económico” y “cuidados paliativos eficiencia” en Etheria y Pubmed y se estructuró la información ordenándola por países.

CANADÁ: El Programa Regional de Cuidados Paliativos de Edmonton supuso un ahorro de 1.650.689 dólares anuales entre 1995 y 1997.

ESTADOS UNIDOS: Se demostró una reducción de coste sanitario en pacientes atendidos por equipos de cuidados paliativos en gastos de farmacia, laboratorio y cuidados intensivos, especialmente si esta atención tenía lugar de forma precoz.

ESPAÑA: La atención por equipos de cuidados paliativos supuso una reducción de estancia hospitalaria, incremento del número de fallecimientos en domicilio y menor uso de urgencias hospitalarias, con una reducción de costes del 61% en el cuidado de pacientes en las seis últimas semanas de vida.

El coste de una cama de cuidados paliativos es entre un 30 y un 40% menor que una cama en un hospital de agudos.

Por cada paciente con cáncer se produjo un ahorro de 2250 euros. En Cataluña se ahorraron en 2005 aproximadamente 48000000 de euros por cuidados paliativos (28000000 euros en pacientes con cáncer), con un ahorro neto de 8 millones de euros.

CONCLUSIONES: Se demuestra una importante reducción de costes directos utilizando programas de cuidados paliativos reduciendo visitas a urgencias, ingresos hospitalarios y menor duración de estos ingresos. El coste de ingreso en una cama específica de cuidados paliativos es menor que en una cama de un hospital de agudos y se produce una reducción importante de gasto en laboratorio, pruebas diagnósticas invasivas y farmacia.

Implementar programas de cuidados paliativos, además de los resultados clínicos, supone reducción de gasto sanitario.

PROGRAMA VIDA DIGNA PARA PROMOCIÓN DE CUIDADOS PALIATIVOS

Esmeralda Alonso Sandoica

Del Pozo Valdés, Covadonga

OBJETIVO: Promover y compartir la documentación existente sobre las cuestiones clínicas, éticas, legislativas y de atención sanitaria al final de la vida, favoreciendo un acceso organizado a la información disponible sobre ellas.

METODOLOGÍA: Se ha realizado una página web, registrada con el dominio <http://www.vida-digna.org/>, que posibilita el estudio de modo organizado.

FORMATO: Los temas se proponen con finalidad de ofrecer una información clarificadora y son englobados dentro de apartados: aspectos médicos, aspectos políticos, experiencias reales, documentos/docencia y noticias.

El bloque de docencia se divide en: algoritmo ético de casos del final de la vida (diagrama de flujo ético), análisis de casos prácticos (deliberación ética, método de los cursos de acción) y artículos relevantes (formación continuada sobre las cuestiones del final de la vida).

Existe una cuenta de *Twitter* que permite comunicar las actualizaciones de los contenidos de la web, aportando informaciones relevantes con documentación enlazada para los seguidores.

APLICACIÓN DEL PROYECTO: La web es dada de alta en abril de 2013 y se posibilita su localización a través de los diferentes buscadores de Internet.

La incorporación de la cuenta de *Twitter* permite contribuir a la difusión de los contenidos.

REFLEXIÓN FINAL: La puesta en marcha de este programa, y su buena recepción posicionando la página en los primeros lugares según diferentes ítems de búsqueda en los principales portales de Internet, hace concluir que el programa responde a una necesidad de sistematización de la información sobre la atención al final de la vida hasta ahora escasa o fragmentariamente diseñada.

El *Programa Vida digna para la Promoción didáctica de los Cuidados Paliativos* es una herramienta válida de referencia al servicio de profesionales sanitarios, unidades docentes en facultades de ciencias biosanitarias así como legisladores especializados en derecho sanitario.

INSTITUTIONAL LOGICS OF DANISH HOSPICE PRACTICE

Vibeke Graven

Videncenter for Rehabilitering og Palliation, Syddansk Universitet, Danmark

Provisional results from an ongoing ethnographic study exploring core elements of Danish hospice palliative care practice.

In Denmark the first hospice opened 25 years ago and the still young hospice tradition is inspired by the early international pioneers of the modern hospice movement. Traditionally hospice philosophy is based on values such as reconciliation, fulfillment and meaning combined with a holistic approach to suffering however these values are under review within contemporary palliative care practice.

Danish hospices today are an integrated part of specialized palliative care within the public health care service and are thus regarded as part of mainstream healthcare. Hospice palliative care enjoys a good reputation amongst the public. But neither the history of Danish hospices nor the practice of palliative care are well-researched. The goal of the project is to identify a cultural understanding of the core elements of hospice practice with a view to identifying which ought to be maintained/developed further.

Drawing on institutional logics as an analytical framework the project explores the hypothesis that there are at two main logics driving hospice care: 1. A philosophical palliative care logic aiming at relief of 'total pain' (physical, psychological, social and spiritual) of persons diagnosed with life-threatening illness. 2. A *medical* palliative care logic with a more focused aim of delivering evidence-based relief of specific symptoms.

The research employs participant observation and interviews with professionals, patients and families at three hospices in different areas of Denmark. Initial findings are beginning to disclose a range of ways in which (the) different logics are at play within different aspects of hospice practice such as the variety of ways in which death and dying are managed. The project is a collaboration between REHPA, Danish Knowledge Center for Rehabilitation and Palliative Care and Danish Hospice Managers.

HABLAR DE LA MUERTE A LOS PACIENTES TERMINALES EN UNA CULTURA AFRICANA ANIMISTA Y ANCESTRAL. ESTUDIO DE 8 CASOS

A. Gutiérrez, R. Garcia, S. Lyeb

*Centro de Salud Católico de Bikop, Camerún. Esclavas del Sagrado Corazón de Jesús
Paliativos sin Fronteras*

Introducción: En 2017 hemos seguido 27 pacientes con Hepatitis crónica y fallo hepático severo en etapa terminal, 8 (29.6%) con acompañamiento psicológico al final de la vida. Hablar de la muerte es un desafío personal y cultural, pero necesario para que puedan afrontar la muerte inminente y prevenir un duelo patológico en sus familiares

Objetivos: Dialogar con los pacientes y sus familias del final de la vida. Detección temprana de síntomas de angustia. Evaluación del entorno familiar del paciente en busca de apoyos. Prevenir el duelo patológico familiar en una cultura dominada por las prácticas animistas y de brujería

Método: Identificación de los pacientes en la consulta médica y referencia al psicólogo. Serie de entrevistas con el paciente y / o su familia en un entorno empático, sobre sus necesidades, conocimiento y experiencia de la enfermedad. Detección temprana de síntomas de angustia psicológica. Evaluación del apoyo familiar. Desarrollar líneas de trabajo para el control de dicha angustia. Caminar con el paciente en sus respuestas de adaptación psicológica a su estado terminal, en equipo interdisciplinar

Resultados: 8 casos seguidos en 2017. Creación de un espacio para expresar experiencias, expectativas, necesidades, ansiedades, reducción de la angustia existencial en relación con el final de la vida. Libertad de expresión, lugar de afirmación y confianza en sí mismo, comunicación sobre tabúes (fin de la vida, funeral, testamento, herencia, etc.). Mejora de su calidad de vida. Acogida de la muerte como un proceso natural y normal.

Conclusión: El acompañamiento psicológico es importante al final de vida. Permite un seguimiento global del paciente y su familia. Aporta calidad de vida al paciente y libera carga emocional tanto al paciente como a sus cuidadores

BENEFICIOS DEL SEGUIMIENTO DE LAS CIRROSIS DESCOMPENSADAS EN CUIDADOS PALIATIVOS EN CAMERÚN. ESTUDIO RETROSPECTIVO.

A. Gutiérrez, R. Garcia, F. Kizimba, S. Lyeb, I. Fernandez

*Centro de Salud Católico de Bikop, Camerún. Esclavas del Sagrado Corazón de Jesús
Paliativos sin Fronteras*

Objetivos:

- Identificar los pacientes con cirrosis descompensada y su origen y enviarlos al equipo de soporte de cuidados paliativos
- Identificar problemas psicológicos asociados a dicha enfermedad
- Aplicar cuidados de confort además del tratamiento farmacológico

Material y Métodos:

- Identificación de todos los pacientes vistos entre el 01/01/2013 y el 21/12/2017
- Datos estudiados:
 1. Causas de cirrosis
 2. Presencia de ascitis de media o gran abundancia que produce molestias
 3. Laparacentesis evacuadoras como un recurso médico útil para aliviar sufrimiento
 4. Evaluación de problemas psicológicos

Resultados:

- 33 casos tratados en 4 años (3 en 2014; 4 en 2015; 8 en 2016 ; 18 en 2017). 69 % mujeres, 31 % hombres. Edad media 42 años
- Origen: 69 % de origen viral (73 % debidas a hepatitis B; 21 % debidas a hepatitis C, 1 caso de coinfección B y C). 1,6 % de origen alcohólico y un 29,4 % su origen no fue determinado
- 14 personas (42 %) se beneficiaron de laparacentesis periódicas como acto médico de confort
- Se detectan los siguientes problemas psicológicos: rechazo de los cambios corporales; alteración de la autoimagen; pérdida de autoestima; sentimientos de culpabilidad o de agresividad; estados depresivos; sufrimiento global; estado de crisis existencial

Conclusión:

1. La cirrosis descompensada en los países emergentes es una enfermedad a seguir en cuidados paliativos.
2. El soporte en equipo interdisciplinar en los casos de cirrosis descompensada aporta ventajas importantes en la calidad de vida de los enfermos

3. Mejorar una identificación temprana y un seguimiento regular para detectar y aliviar los síntomas de malestar puede mejorar considerablemente la calidad de vida de los enfermos y aumenta la supervivencia.

LA INTEGRACIÓN DE LOS CUIDADOS PALIATIVOS EN ZONA RURAL EN CAMERÚN: UN ESTUDIO RETROSPECTIVO.

A. Gutiérrez, R. García, F. Kizimba, S. Lyeb

*Centro de Salud Católico de Bikop, Camerún. Esclavas del Sagrado Corazón de Jesús
Paliativos sin Fronteras*

Objetivos:

- Proporcionar una visión general de los cuidados paliativos en una zona rural de Camerún.
- Definir áreas de trabajo para mejorar la atención

Material y Métodos:

- Estudio retrospectivo. Recolección de datos de años consecutivos, entre el 01/01/2013 y el 21/12/2017
- Todos los pacientes hospitalizados o vistos en consulta para cuidados paliativos. Ambos sexos y más de 15 años
- Datos estudiados:
 1. Enfermedad presente
 2. Si paciente oncológico, tipo de cáncer
 3. Duración hospitalización
 4. Lugar de fallecimiento

Resultados

- Se identificaron 147 pacientes (24 en 2013, 35 en 2014, 31 en 2015, 21 en 2016, 36 en 2017). 63% de mujeres
- Edad promedio = 50.1 años [15-92]. 7 casos pediátricos de 10-14 años
- Duración promedio de la hospitalización = 10.7 días
- Resultados:
 - El cáncer 30 % seguido del Sida 29 % son las enfermedades más frecuentes, seguido de cirrosis e insuficiencia cardiaca
 - 78% murieron en el hospital, 16% en casa
 - 16% se perdieron de vista después de su salida.
- El uso de analgésicos de nivel 2 o 3 se informó en sólo el 21.5% de los casos. Hubo 2 sedaciones terminales
- El 80% de los pacientes con cáncer llegaron al momento del diagnóstico con 2 meses de retraso antes del fallecimiento
- El tratamiento de la cirrosis descompensada y avanzada -la mayoría debido a hepatitis virales-, está aumentando la supervivencia de estos pacientes

Conclusión

1. Los cuidados paliativos existen en las zonas rurales de Camerún y el aumento de la incidencia del SIDA y el cáncer sugiere un crecimiento de esta realidad.
2. Fortalecer una identificación temprana y un seguimiento regular para detectar y aliviar los síntomas de malestar podría ayudar a prevenir la muerte en el hospital.
3. Se necesita mejorar el acceso a los opioides. Los cuidados paliativos son necesarios por tanto en todas partes, a cualquier edad y para cualquier enfermedad

A PARALLEL BETWEEN JESUS' SUFFERING ON THE WAY OF THE CROSS AND THE SUFFERING THAT HEALTH CARE PROFESSIONALS DEAL WITH IN PALLIATIVE CARE

Anne Marie Horgos

Background: Health care professionals that attend patients in palliative care have to deal with the patients' and their families' terrible suffering every day. There are many images, faces, wounds, smells, sounds, sentences that prove hard to process.

Methods: The purpose of this study is to share with others the personal way of processing the suffering encountered in palliative care as a christian physician doctor.

This study represents a personal reflection. First I wrote down the flashbacks I had with the patients under my care during 24 months and with their families, while praying the Way of the Cross (grouped on the 14 stations). After gathering all of the taken notes I have taken, I continued with enlisting the correlations between: 1) Jesus' physical suffering and the patients' one; 2) Jesus' psycho-emotional, spiritual and social suffering and the patients' one; 3) the suffering and feelings of those who met Jesus during His passion and that of the relatives of the patients or of the health care professionals.

Results: The features of Jesus' suffering and of those who met him during His passion were reproduced and the suffering that health care professionals deal with in palliative care, grouped on the 14 stations and the 3 studied categories.

Conclusions: Pope Francis wrote on 23rd of July 2015 in his twitter post that „the one who helps the sick and needy touches the flesh of Christ, alive and present in our midst.” As health care professionals that attend in palliative care, we can recognize, meet, serve, touch Christ, the Son of God, every day in our patients.

VALIDAZIONE ITALIANA ED IMPLEMENTAZIONE DELLA PAPAS SCALE, TEST VOLTO AD IDENTIFICARE PRECOCEMENTE BISOGNI DEL BAMBINO E DELLA SUA FAMIGLIA IN UN PERCORSO DI CURE PALLIATIVE

Luca Manfredini

Istituto Giannina Gaslini, Genova, Italia

Negli ultimi decenni si è evidenziato un netto incremento della prevalenza dei neonati, bambini e adolescenti portatori di malattia inguaribile e/o disabilità grave con complesse necessità assistenziali

Si è creata pertanto una nuova tipologia di pazienti con precoce necessità di cure peculiari (Cure Palliative precoci). L'identificazione precoce di neonati, bambini ed adolescenti affetti da patologie inguaribili con bisogni assistenziali complessi e il loro inserimento in un percorso di cura adeguato permette di offrire loro un miglioramento della qualità di vita, un minor numero di ricoveri ospedalieri, fornendo un efficace sostegno alla loro famiglia.

L'utilizzo di uno strumento validato (PaPaS Scale) è indispensabile per identificare in modo oggettivo, preciso, omogeneo e soprattutto precoce i bisogni del paziente, in modo da inserire i bambini e le loro famiglie in un percorso di cure palliative pediatriche

Obiettivi: Validare (lingua, cultura, costruito) ed adattare alla realtà italiana una scala di valutazione che possa aiutare i professionisti ad identificare i pazienti che potrebbero trarre beneficio dall'inserimento precoce in un percorso di Cure Palliative Pediatriche, per facilitare la presa in carico e la pianificazione di Percorsi Diagnostico-Terapeutico Assistenziali per neonati, bambini e adolescenti affetti da patologie inguaribili ad alta complessità di Cura.

Individuazione di criteri per l'eleggibilità alle cure palliative generali o specialistiche tramite la valutazione dell'entità dei "problemi di bambino e famiglia e l'analisi dei bisogni di cura da esso innescati

Identificazione precoce di pazienti bisognosi di cure palliative pediatriche.

Predisposizione di Percorsi Diagnostico-Terapeutico Assistenziali individualizzati e condivisi con le differenti strutture ospedaliere e territoriali presenti nella Rete di Cure Palliative Pediatriche Regionali.

Miglioramento della qualità della vita dei pazienti (riduzione dei sintomi disturbanti, aumento delle relazioni sociali, miglioramento del funzionamento psicologico) e dei loro familiari.

Ridurre i costi della prestazione sanitaria (limitando i ricoveri impropri attraverso una più efficace ed efficiente gestione in rete)

WEAVING SACRED THREADS: PALLIATIVE CARE AT THE BEGINNING OF LIFE.

Daniel Nuzum

Healthcare Chaplain and Clinical Pastoral Education Supervisor, Cork University Maternity Hospital, Cork, Ireland; Lecturer, Department of Obstetrics & Gynaecology, University College Cork, Cork, Ireland.

Introduction: The diagnosis of a life-limiting condition or fetal anomaly brings expectant parents from a journey of joy to one of uncertainty as their baby faces an anticipated death either before or shortly after birth. Parents are challenged with the liminal conflicts of saying 'hello' and goodbye' to their baby in a very short timeframe. How parents are cared for during this period will shape their overall grieving experience and recovery.

Perinatal Palliative Care: The principles of palliative care provide an important approach to the care of a baby whose life-span is limited. This approach of perinatal palliative care attends to the physical, psychological and spiritual needs of parents and their baby. Chaplains have a particular role in this care and working alongside other professionals they can provide meaningful opportunities for parents to acknowledge and honour the life of their baby as he/she lives their short life. From a Christian perspective and drawing from Church teaching this approach to care affirms each baby –even in illness- as bearing the *Imago Dei*. In addition this vulnerable population are important in the drive to provide 'Palliative care: everywhere and for everyone'.

Each member of the healthcare team has a role to play in perinatal palliative care and valuable opportunities of support should be made available to parents during what is a very challenging time. Drawing on the experience of the author who works in an Irish tertiary university maternity hospital, this poster highlights the various 'strands' of palliative care at the beginning of life and gives examples of memory making, spiritual care, ritual, and support. This holistic approach provides meaningful and supportive care for bereaved parents and families and at the same time honours the dignity of the baby who will die.

PALLIATIVE CARE: THE ROLE OF THE WHOLE HEALTHCARE TEAM IN THE PROVISION OF SPIRITUAL CARE.

Daniel Nuzum

*Healthcare Chaplain, Marymount University Hospital and Hospice, Curraheen, Cork, Ireland;
Clinical Pastoral Education Supervisor, Cork University Maternity Hospital, Cork, Ireland.*

Introduction: Palliative care at its heart is person-centred as healthcare professionals attend to the physical, psychological and spiritual needs of the human person with a life-limiting illness. During illness spiritual questions often present as patients face existential questions and reflect on their mortality and faith.

Objective: Spiritual care is recognized as being a core dimension of palliative care provision. Although chaplains are the professional providers of spiritual care this study set out to explore how other disciplines saw their role in meeting the spiritual needs of patients and their families in an Irish specialist palliative care inpatient setting.

Study Design: A modified *Spiritual Care Perspectives Scale* was administered amongst healthcare assistants (n=5), household staff (n=3), nurses (n=14), physicians (n=10), physiotherapists (n=2) and social workers (n=2).

Results: All participants recognized that their discipline had a role in helping patients to use their spiritual and religious resources to cope with illness. All disciplines except household staff expressed that patients share religious or spiritual thoughts with them on a daily basis. Nine participants felt that their ability to provide spiritual care was weak or limited. These same staff expressed that they felt uncomfortable providing spiritual care. 60% of physicians and nurses expressed that they felt very comfortable addressing spiritual matters: 40% of physicians scored in the median point between very comfortable and very uncomfortable whereas 15% of nurses felt very uncomfortable.

Conclusion: This study highlights the importance placed on how all staff meet the spiritual needs of palliative care patients. The data revealed that non-clinical staff felt inadequately trained to provide spiritual care even though patients shared spiritual/ religious thoughts with them and furthermore they recognized that they had a role in responding to spiritual need. This study highlights the importance of spiritual care education for all staff working in palliative care.

THE LEGACY OF THE NORTHERN IRELAND CONFLICT IN PALLIATIVE CARE

Brendan O'Hara

All Ireland Institute of Hospice and Palliative Care, Second Floor, Education & Research Centre, Our Lady's Hospice, Harold's Cross, Dublin 6W, Ireland.

Background: Understanding the impact of the Northern Ireland 'Troubles'/'conflict' on a particular area of health care – palliative care – which has received little, if any, previous research focus. The research was carried out for a dissertation submitted in partial fulfilment for the degree of Master of Philosophy.

Aim(s): To investigate how the legacy of the Northern Ireland conflict may be encountered by professionals providing palliative care - to those they are caring for who may have been directly/indirectly affected (victims/survivors) and those involved in inflicting damage, death and/or injury. To investigate how the distinct context of Northern Ireland has impacted on palliative care practice.

Method: Interviews were carried out with nine professionals with experience and interest in the provision of support to people with palliative care needs.

Participants reflected experience across a wide geography of Northern Ireland including the region's two major cities, four of the region's five health and social care trust areas, and four of the five inpatient hospice facilities. Participants included: three nurses; two doctors; a social worker; a chaplain; a complementary therapist and a welfare officer.

Results: This research opened up a dialogue between the disciplines of peacebuilding and palliative care. The language of legacy, narrative, life story and peacebuilding is one which the palliative care community understands. The impact of the Troubles has had an effect on the delivery of palliative care, through the attitudes and influences on those who provide the care and those they care for.

Conclusion: The influences of the religious divide, the silencing, and the traumas of the past are not something that the care giver is apart from - they are very much influenced by them. The sensitivities around the Catholic/Protestant divide, the silencing, and restricting opportunities to talk about 'Troubles'-related trauma, could prevent people from having appropriate palliative care.

SPIRITUAL SUPPORT OF SERIOUSLY ILL CHILDREN: A SURVEY OF THE LITERATURE AND FUTURE DIRECTIONS

Regina Okhuysen-Cawley, MD, Taryn Schuelke, CCLS, Taylor Baumann, MD, and Kirstin Springmeyer, M.Div.,

Department of Pediatrics, Baylor College of Medicine and Pediatric Advance Care Team, Texas Children's Hospital, Houston, Texas, USA

Introduction: Spiritual care is a fundamental aspect of high-quality palliative care. Even very young children may be highly spiritually aware. The special needs of seriously ill children and families, and the special role that chaplains, interdisciplinary team members, and bedside clinicians play in this domain of care is increasingly recognized.

Methods: A literature review was performed, utilizing the PubMed search engine through January of 2018.

Results: There is an emerging body of literature regarding spiritual support of seriously ill children. Dominant themes include the importance of honest, sensitive inclusion of the child in discussions regarding their illness and expected trajectory. This may clarify misconceptions, help reframe hope, address fears about dying, provide reassurance about Heaven, may redirect existential distress into spiritual meaning, and empower collaborative medical decision-making in difficult cases. Timely spiritual support may decrease overall symptom burden by mitigating emotional suffering, thus promoting a peaceful, dignified death. Spiritual support facilitates bereavement and may prevent complicated grief in survivors.

Conclusions: Although the need for spiritual support is universal, significant barriers exist and access remains limited, especially, when persons are displaced for any reason. Early, longitudinal integration, with appropriately timed rituals such as Christenings, naming ceremonies, and other, religion-specific ones (such as Catholic Sacraments) may offer excellent opportunities to lend strength, accompany and support the seriously ill child, family, faith community and healthcare team. Small celebrations associated with these events afford the opportunity for meaningful interaction, legacy building and the formation of strong, comforting memories.

Awareness, coupled with attitudes of mindfulness, cultural sensitivity and aperture may permit any healthcare provider to be spiritually supportive when chaplains are unavailable. Spiritual assessment skills and competencies may also be augmented in all healthcare settings using institutional, conference and web-based training. Further research may inform strategies to facilitate Spiritual Care at a global level.

LA PRÁCTICA DE LA COMPASIÓN EN CUIDADOS PALIATIVOS: UN CAMINO QUE HUMANIZA Y DA SENTIDO A LA PRÁCTICA CLÍNICA

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RESUMEN

Antecedentes: La práctica de la compasión en la práctica clínica, es recomendada por numerosos autores, pero no se han encontrado estudios multifocales (de pacientes, familiares, profesionales, profesores y estudiantes) sobre la compasión en Cuidados Paliativos.

Objetivo: Describir el concepto y manifestaciones de la compasión en la práctica asistencial con pacientes al final de la vida, teniendo en cuenta la perspectiva de todos los miembros integrantes.

Diseño: Investigación Cualitativa. Los datos se recolectaron a través de entrevistas en profundidad y grupos focales, analizados y codificados usando la técnica de la teoría fundamentada. Se obtuvo la aprobación de un Comité de Ética.

La muestra intencionada estuvo constituida por 29 participantes, entre ellos: pacientes y familiares de pacientes con enfermedad avanzada, profesionales expertos en bioética, profesores universitarios y estudiantes de Ciencias de la Salud. Los datos se recolectaron en un Hospital de Cuidados Paliativos en Madrid, España.

Resultados: La compasión se presentó como un proceso complejo que requiere gran profundización. Se explica a través de 4 categorías emergentes. La compasión es (I) un concepto que precisa ser clarificado, que (II) implica estar con disposición de atención frente a las necesidades de los otros, (III) sensibilizarse con el dolor y actuar con intención de ayudar y (IV) deja consecuencias positivas de satisfacción y agradecimiento en los pacientes, familiares y profesionales sanitarios.

Conclusión: El concepto de la compasión en su término en castellano, no es bien entendido por la sociedad actual, si bien sus características y manifestaciones encontradas en la literatura, son requeridas y muy valoradas por los enfermos y familiares. La práctica de la compasión puede ayudar al bienestar de las personas que sufren a causa de la enfermedad, a mejorar la calidad de la práctica clínica y a desarrollar futuras investigaciones.

MINDFULNESS AS A SPIRITUAL SUPPORT IN PALLIATIVE CARE

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Introduction: According to literature, pain is one of the most common experience in cancer patients, especially in terminal cancer patients. Conventional treatment do not always satisfactorily relieve this symptoms. Complementary therapies such as mind-body techniques, massage, and other methods can help relieve symptoms and improve physical and mental well-being. Relaxation techniques can help to reduce procedural pain.

This study demonstrates that mindfulness can help patients to relieve pain and other similar symptoms present at the end of life.

Patients and methods: The study was conduct at the home of a terminal cancer patient. The techniques used were colouring mandala listening soft music, breathing exercises, and counselling.

Tools: The patient was assessed with Minnesota Multiphasic Inventory (MMPI-2) Cognitive Behavioural Assessment (CBA), an Italian Questionnaire of Pain (QUID) was weekly measured. The Oncological medical care was a pain relieving drug.

Results: After five weeks the data analysis of the QUID, the perception of pain changed from lancinating and persistent to intermittent and bothersome, the patient improved his self-control and level of humour. A better quality of life with an increment in the quality of relationships was observed. The posology for pain management was reduced. The colouring of mandala gave the opportunity to the patient to discover his interiority, decreased the tension for pain and created a relaxed environment.

Conclusion: Mindfulness techniques do not resolve the problem of cancer patients, however they help the patient to considere himself in the totality of his dimensions: mind, spirit and body according to an holistic approach. The mandala can be considerate as an instrument that helps the patients to concentrate on him self, with the aim to get back his normal internal equilibrium.

SPIRITUALITY IN THE PATIENT'S NETWORK: DESIGNING A RESEARCH PROJECT AT A PAEDIATRIC CARDIAC INTENSIVE CARE UNIT (PCICU) IN ITALY

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It is widely acknowledged that the patient's wellbeing has a positive effect on the outcome of medical treatment. Scholars have started to study the effect that spirituality has on the patient's well-being. While existing research focuses on the effect of spirituality of the patient, the effect of spirituality in the patient's network, such as medical staff or family members, is still understudied. Therefore, the goal of this research project is to address this research gap by studying the effect of spirituality in the patient's network on the patient's well-being and the underlying mechanisms of this effect. Our research setting is the PCICU at Bambino Gesù Children's Hospital in Rome, one of the leading paediatric hospitals in Europe accredited by the Joint Commission International. In our sample we include paediatric patients affected by congenital heart disease and their families which have to undergo an elective heart operation with cardiopulmonary bypass. The findings of this research project, which is ongoing, are expected to contribute to the spirituality literature by exploring the role of spirituality in the patient's network and to provide useful insights to practitioners interested in increasing patient's wellbeing by promoting spirituality.

CARE TIPS. PALLIATIVE CARE

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Euthanasia and assisted suicide are discussed more and more in palliative care because of fear for suffering. This raises questions about the palliative care options. Is palliative care sufficient for patients for pain relief or symptom control in the final phase of life? Palliative sedation can be used as a method of choice indicated if other measures of symptom control do not work or are not desired. Is assisted suicide also used in palliative care?

We asked medical specialists in 49 of specialized outpatient palliative care teams (PCT) in Germany about their opinions and practice concerning euthanasia and assisted suicide.

The response of the specialists was high (86%). Of all patients, who were cared for by these teams and died in 2013-2014, 8% of the patients and/or their relatives (i.e. 1.452 times) had expressed the wish for life-shortening actions in form of assisted suicide or euthanasia, mostly at the beginning of palliative care. No euthanasia was applied. 17 patients committed suicide. In none of these cases the reason had been physical suffering, which could not be alleviated.

We conclude that – accordingly to the reports of the medical specialists – assisted suicide and euthanasia are not necessary in palliative care patients with physical suffering because alternative options for alleviation of suffering are present. The study indicates that effective suicide prevention at the end of life is possible when palliative care is provided by specialized outpatient palliative care teams.

SPIRITUAL CARE AT THE END-OF-LIFE. DOES EDUCATIONAL INTERVENTION FOCUSED ON A BROAD DEFINITION OF SPIRITUALITY INCREASE UTILIZATION OF CHAPLAIN SPIRITUAL SUPPORT IN HOSPICE?

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Objectives: Research shows that religion/spirituality is very important in coping with significant and life-threatening illness. Patients who receive good spiritual care report greater quality of life and better coping, and such support is strongly associated with patients' greater well-being, hope, optimism and reduction of despair at the end of life. Despite the benefits of spiritual care, evidence shows that a significant number of patients/caregivers refuse it when offered by hospice teams, resulting in unnecessary suffering. This study aimed to better understand what contributes to the spiritual support acceptance rate in hospice care.

Methods: Quasi-experimental study with 200 participants admitting to hospice divided equally into an intervention and controlled arm. The participants in the controlled group received standard information about the availability of chaplain support and an offer to make a referral to chaplain services. The participants of the intervention arm received an educational intervention aimed to explain hospice chaplain services and the benefits of spiritual support, evidenced by research. Statistical analysis was employed to seek correlation of the results with patients' age, disease, church affiliation and support, sex, bereavement risk and place of residence.

Results: 64 % ($n=64$) of the participants in the intervention arm accepted spiritual support and 36% ($n=36$) declined it, vs. 52% ($n=52$) who accepted it and 48% ($n=48$) who declined it in the controlled group. The acceptance rate in either group did not seem to significantly correlate with sought variables except for place of care and nature of the disease.

Conclusions: This research suggests that a specific educational intervention aimed to better explain spiritual care in hospice and its benefits, in a statistically significant way, contributes to a greater acceptance rate and allows patients/caregivers to gain the benefits spiritual support offers in end-of-life care.

UNDERSTANDING PALLIATIVE CARE AS CARRYING ON CHRIST'S COMPASSIONATE CARE FOR THE SERIOUSLY ILL: THE ARCHDIOCESE OF BOSTON TAKES ACTION

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Abstract: The Archdiocese of Boston is entering into the fourth year of a strategic initiative, unique in the US and perhaps globally, designed and implemented at the request of Cardinal O'Malley, whose sole purpose is to educate about and promote Palliative Care and Advance Care Planning, with the understanding that, in today's health care environment, a society of educated/'demanding' consumer-patients could bring pressure to bear on the health care provider community and private/public payor to provide and support Palliative Care for the seriously ill in a more efficient and efficacious way than 'mere' policy discussions have done to date.

The ***Initiative for Palliative Care and Advance Care Planning***, a direct outgrowth of the paucity of information noted among Catholics when the Archdiocese led efforts to resist a 2012 Massachusetts ballot referendum to legalize Physician-Assisted Suicide, consists of three foci:

I. Education and Outreach

- educational sessions delivered to parishes throughout the Archdiocese: an overview of Palliative Care and its consistency with Church teaching, followed by series of workshops on specific topics, such as pain management and the principle of Double Effect, Church teaching on Medically-Administered Nutrition and Hydration, Morally Licit Refusal of Treatment, and so on
- Palliative Care Resource Groups are formed, receiving ongoing education to work with parish ministries to the sick and parish nurses, to provide families with serious illness diagnoses information about Palliative Care for discussions with health care providers

II. Ethics

- work with other ethicists/moral theologians to articulate in an accessible way Church teaching on issues in Palliative Care

III. Advocacy

- serve as model or resource to other Catholic dioceses and organizations planning to develop Palliative Care programs for their communities
- promote public policy that supports/champions Palliative Care, with media, state/national legislatures, and others

HOSPITAL PALLIATIVE CARE TEAM: MEANING, DEVELOPMENT AND FUTURE PERSPECTIVES.

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Background: Hospital Palliative Care Team (HPCT) has been realized in November 2016 for caring patients with end-stage diseases. The multidisciplinary team is composed by medical doctors and nurses specialized in palliative care. The aim of this service is helping clinicians, patients and their family to approach the end stage of ill and to organize a safe discharge integrating local services offered by Hospice Services.

Aim: We want to describe as a multidisciplinary approach of HPCT increase the quality of life and the quality of care for the patients and their family. Outcomes include hospital length of stay, hospital costs and discharge disposition.

Methods: A case manager dedicated has collected, from November 2016 to November 2017, the data of the patients managed by our unit care. We have created a database with data assessments, we have analyzed this data using excel program.

Results: The patients assessed are 423: 212 are female (50,1%), 211 are male (49,9%). 298 patients (70,4%) have an oncological disease while 125 (29,6%) have a non-oncological disease. The mean age of oncological patients is $69,7 \pm 13,5$ SD while non-oncological patients have a mean age of $78,8 \pm 13,1$ SD. The time between the admission in hospital and the request of palliative care is approximately 12,1 days for oncological patient and 14,7 days for non-oncological patient. The time of discharge from our consultation is approximately 8,8 days for oncological patients and 14,0 days for non-oncological patients.

CONCLUSION: In the next years we will have an increasing number of older people affected by chronic pathologies and terminal ill failure. In our experience oncological and non-oncological requests for palliative care reach similar numbers; this is a demonstration of the importance of HPCT for all end-stage diseases.

INTEGRATED AND COORDINATED HOSPITAL DISCHARGE PLANNING FOR PATIENTS WITH MORE COMPLEX NEEDS.

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Background: The Integrated and Coordinated Hospital discharge planning (ICHDP) has been realized in November 2016 to organize safe discharge in complex patients. The multidisciplinary team is composed by medical doctor and nurse specialized in management of post-acute stage. We have 5 possible destination for continuing the care after the discharge:

1. Rehabilitation: dedicated to patients which need motor rehabilitation after an orthopedic or neurological illness.
2. Long-Term Hospitalization: dedicated to patients which have had an acute illness and need to continue the treatment in a medical center.
3. Home care services (Nursing and/or Nutrition Support Home Care): dedicated to patients which need a nurse for continuing medical treatment including nutrition.
4. Nursing Home: dedicated to patients which can not to live in own home for medical and social issues.
5. Palliative care: dedicated to patients affected by end-life disease.

Aim: We want to describe as the importance and the benefit of an effective discharge planning process.

Methods: A dedicated case manager has assessed, from November 2016 to November 2017, the data of the patients managed by our care unit. We have created a database with data assessments, we have analyzed this data using excel program.

Results: We analyzed 1404 requests coming from November 2016 to November 2017; 544 (38,7%) have an oncological pathology while 860 (61,3%) have a non-oncological pathology. The post-discharge destinations are: 423 (30,1%) Palliative Care, 381 (27,1%) Home Care Services, 341 (24,3%) Rehabilitations, 23 (1,6%) Long Term Hospitalizations, 21 (1,5%) Nursing Homes. We obtained an important reduction in length of stay in hospital from 28,0 gg in November 2016 to 21,3 gg in November 2017.

Conclusions: A safe and organized discharge is associated to a reduction of hospitalization days, rehospitalization and mortality. The early identification of the patient and the multidimensional evaluation of his needs, the meeting/interview with family and/or caregiver, are essential assessing for choosing the best patient destination. We want to promote this discharge assessment in other hospitals and we hope will be other studies about this argument.

VALORES Y PREFERENCIAS SOBRE EL FINAL DE LA VIDA EN PACIENTES CON ENFERMEDAD CRÓNICA COMPLEJA (PCC) Y ENFERMEDAD CRÓNICA AVANZADA (MACA)

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Introducción: El Go Wish Card(GWC) es una herramienta desarrollada para facilitar las conversaciones acerca del final de la vida. Se han explorado los valores y deseos de los pacientes MACA y PCC.

Objetivo: Identificar los valores y deseos de los pacientes MACA y PCC en una entrevista acerca del final de la vida usando el GWC como instrumento.

Método: Se incluyeron pacientes MACA y PCC atendidos en la unidad de convalecencia y larga estancia de la Fundació Santa Susanna. Se registraron datos sociodemográficos, nivel de instrucción, nivel de competencia mediante la Escala Móvil de Drane(EMD) y estado cognitivo mediante la escala de Pfeiffer. Se usó el GWC como instrumento para explorar los deseos y valores. Los pacientes seleccionaron entre las cartas, lo importante y no importante, de las importantes, se les pidió que seleccionaran las 10 más importantes. Se evaluó la utilidad y adecuación de la entrevista. El análisis estadístico se realizó con el SPSS:21.0.

Resultados: Se incluyeron 34mujeres y 19hombres, edad media:82,7±7,5; pacientes MACA:23 y PCC:30. Grado de instrucción: No saben leer ni escribir:1,89%, saben leer y escribir:50,9%; estudios primarios:39,6%; estudios secundarios:7,55%, EMD: Nivel I:5,66%; Nivel II:52,8%; Nivel III:41,5%. Pfeiffer ≤ 2 errores:43,4%; Pfeiffer ≥ 2errores:56,6%. Los deseos más importantes fueron: *no ser una carga para mi familia*:90,6%; *no estar conectado a maquinas*:71,7% y *“estar sin dolor”* :67,9%. Los deseos menos importantes fueron: *“Poder hablar sobre lo que significa morir”*:81,1%;*“Hablar con un sacerdote, pastor, rabino, capellan”*:73,6% y *“estar consciente de lo que está pasando”*:71,7%. La entrevista fue útil y adecuada en un 96%.

Conclusión: No ser una carga para la familia, evitar la instrumentalización y morir sin dolor, fueron los deseos más importantes para los pacientes MACA y PCC. El GWC fue un instrumento útil y adecuado para explorar los deseos y valores acerca del final de la vida.

ⁱ Rawls, John R. (1993) *Political Liberalism*. New York: Columbia University Press.