White Book for Global Palliative Care Advocacy

Recommendations from the PAL-LIFE expert advisory group of the Pontifical Academy for Life, Vatican City

PONTIFICIA ACADEMIA PRO VITA

White Book for Global Palliative Care Advocacy

Recommendations from the PAL-LIFE expert advisory group of the Pontifical Academy for Life, Vatican City

WRITTEN BY

CARLOS CENTENO, THOMAS SITTE, LILIANA DE LIMA,
SAMY ALSIRAFY, EDUARDO BRUERA, MARY CALLAWAY, KATHLEEN FOLEY,
EMMANUEL LUYIRIKA, DANIELA MOSOIU, KATHERINE PETTUS,
CHRISTINA PUCHALSKI, MR RAJAGOPAL, JULIANNA YONG,
EDUARDO GARRALDA, JOHN Y. RHEE, NUNZIATA COMORETTO

PONTIFICIA | PRO
ACADEMIA | VITA

Index

Authors:
Carlos Centeno, Thomas Sitte, Liliana De Lima,
Samy Alsirafy, Eduardo Bruera, Mary Callaway, Kathleen Foley,
Emmanuel Luyirika, Daniela Mosoiu, Katherine Pettus,
Christina Puchalski, MR Rajagopal, Julianna Yong,
Eduardo Garralda, John Y. Rhee, Nunziata Comoretto.

Editors:
Carlos Centeno and Eduardo Garralda,
University of Navarra, ATLANTES Research Program,
Institute for Culture and Society (ICS),
Campus Universitario, 31080 Pamplona, Spain

Preface

Archbishop Paglia

A marked increase in the proportion of older people in the West and the associated economic costs that accompany advanced age have given a new urgency in recent years to end-of-life questions. These are questions debated much more frequently and go beyond medical discussions, which often deal with purely clinical matters, to family concerns, i.e., the contexts and environments enveloping decisions at the end-of-life. The "right to die" movement has become a major discussion of contemporary culture, but unfortunately one that does not consider the larger framework of human existence, the context of every condition and relationship in which a person may find him or herself. A serious consideration of "death with dignity" thus means going back to find, and contribute to implementing, a new culture of life and relationships in order to avoid the major tragedy of our time: an increased life expectancy often accompanied by and associated with greater loneliness, often dying alone, with no one at the person's side. This has resulted in a radical cultural shift that moved from empathy and being with a person at the end of life to a "merciful death." The request for euthanasia often begins there, from loneliness that is always negative, that in moments of weakness and sickness becomes even more intense, to the point of becoming unbearable. It is then that one prefers death to suffering alone.

The value of palliative care is that it offers accompaniment, therefore, helping create an environment for a "good death" by building freedom from the fear of unbearable suffering lived out in loneliness.

"Palliative care, […] in fact, points the way to a rediscovery of the most important aspect of the medical profession, which is taking care of people, even when a cure is not possible. Certainly, the medical profession is tireless in its commitment to acquiring new knowledge and to overcoming an ever greater number of diseases. Palliative care, however, recognizes in clinical practice that while the limits of medicine are to be challenged and overcome, they are also to be recognized and accepted when they cannot be overcome. This means not abandoning the sick, but rather being close to them and accompanying them in the difficult trials that mark the end of life. When all the resources of "acting" appear to be exhausted, the most important aspect of human relations emerges, that of "be-

ing": being present, being close, being welcoming. This also means sharing the helplessness of those who come to the end of their lives. It is then that "limit" takes on a new meaning. It is no longer a moment of separation and solitude, but an occasion for encounter and communion. Death itself takes on a new and symbolic meaning where it appears not so much as a barrier, against which life presses but to which it must yield, but rather as the fulfillment of a life that was freely received and lovingly shared."[1]

The truly crucial point that I would like to highlight concerns the "debt" that the human community owes to palliative care for its "rediscovery" of a fundamental, indispensable approach, that of taking care of one another. The Good Samaritan has been the inspirational model of professional medical ethics for many centuries, a telling image, perhaps, because the Samaritan's behavior mirrored the care often attributed to medical professionals. After all, for a long time, medicine could not often do anything but take care of the sick person through support, accompaniment, presence, and comfort. Over the course of many centuries, it has only partially relieved

pain and suffering caused by disease, only rarely been able to treat the disease in a truly effective manner, arresting its course and bringing recovery to the patient. Today, however, it seems that the Good Samaritan is not the model most often followed in medical care. Today, the image of a hospital is one where there is lots of technology and intensive care—a scenario that puts the emphasis on scientific means rather than on a human attitude of caring. In fact, 'healing," which for many centuries represented only a marginal possibility for medicine, today plays a preponderant role, to the point of expropriating the exclusive focus of contemporary medicine. There is however a risk in shifting from the goal of "taking care of" to that of "treating" in the sense of "healing." The risk is that, especially in highly technological contexts, we tend to look at recovery as the only goal to be pursued, the only worthwhile outcome. This attitude has two consequences: first is the risk of unreasonableness in the use of medical capabilities aimed at a cure, something that "must" be obtained at all costs, because any failure to cure is seen as a defeat for medicine. This is how we arrive at what some authors

call 'therapeutic obstinacy," which actually ends up burdening the patient with sufferings produced by the means used, often invasive, without their use being related to any overall benefit to the patient. "Do everything possible" (within the known limits of medicine) can mean, today, doing too much (i.e., falling into an excess that damages the patient). The second risk is abandoning the patient when he or she cannot be cured, i.e., if I cannot cure, I have ended my relationship with the patient, I have nothing more to offer, I cannot do anything more for this patient. It is not true! If we cannot cure, we can still relieve suffering and take care of that person. This should not seem like nothing to us. In the incurable patient we can still see that unconditional value, that absolute human dignity that is the indispensable justification for all medical activity. We cannot speak seriously about the humanization of medicine unless we have a true, full, convinced understanding of the dignity of the human person, of each human person, especially the sick, the seriously ill, or the dying. However, this is precisely the risk that the incurable patient runs today, given the mentality of the medical profession in the West. This leads to

lack of concern, to saying "there's nothing we can do;" "it's not worth the trouble." This is dangerous talk and it leads to abandonment.

Pope Francis urges us in a different direction.

"Medical interventions have become increasingly effective, but they are not always definitive: they can support biological functions that have become insufficient, or even replace them, but this is not the same as promoting health. We need wisdom because today the temptation to insist on treatments that have powerful effects on the body, but do not benefit the integral good of the person is insidious. Responsibly recognizing the limits of the human condition requires recognizing when further intervention is useless." 'Here, one does not will to cause death; one's inability to impede it is merely accepted.' is what the Catechism of the Catholic Church says at Number 2278. This different perspective restores humanity to the accompaniment of the dying and does not provide support for the elimination of life. The personal and relational dimension of life—and of dying itself, which is after all just one extreme moment of life— must, in caring for and accompanying the patient,

Authors´ Presentation

provide adequately for the dignity of the human being. It can be said that the categorical imperative is to never abandon the patient. Our anguish at the condition that takes us to the threshold of our human limits and to the difficult choices that must be made, tempt us to flee from relationship. But this is the precisely the place where we are asked for love and closeness, more than anything else, recognizing the limits that we all share and that leads us to solidarity. Each one gives love in the way that he or she can: as a father or mother, son or daughter, brother or sister, doctor or nurse. Just give it! If we know that we cannot always guarantee a cure, we can and must always take care of the living person, without shortening life, but also without unnecessarily urging resistance to death. This is the path that palliative medicine is taking, and that is culturally important as well

as we struggle to oppose what makes dying more painful and frightening— loneliness and suffering. It is of great importance, on a cultural level as well, to commit oneself to resisting all that makes dying more dreaded and unwelcome, namely pain and loneliness." [2]

With this in mind, the Pontifical Academy for Life has launched the PAL-LIFE Project, establishing an international committee of experts, which can support the project in its initiatives for the development and spread of palliative care throughout the world and in the promotion of a culture that accepts death as the final but important stage of life and cares for the dying person. With this spirit, we welcome the White Book, a document that can serve as a working tool for healthcare personnel as they implement palliative care in the various regions of the world.

This book presents the consensus of 13 PC experts from around the world, in line with the PAL-LIFE objectives, on what are considered the most important recommendations to 13 groups of stakeholders to help advance PC development. Some of the recommendations are applicable to several stakeholder groups (ie.: recommendation for pharmaceutical authorities on morphine availability should also be directed to lawmakers, administrators, pharmaceutical manufacturers, dealers and PC advocates; or recommendation to universities should also be presented to "health care workers and educators)".

Many of the items presented here require a coordinated approach. Globally, a majority of patients die with severe pain without having ever received a single dose of morphine or other opioid analgesic. To address this tragic situation, it is important to harmonize the need for increased access to opioids for pain treatment, while taking in consideration the abuse potential and adverse effects. This requires a coordinated approach among policymakers, universities, pharmacists and professional associations so that safety measures are put in place for the goals to be achieved.

The recommendations in this White Book focus on crucial issues. However, optimal situations may require more comprehensive and broader recommendations (ie: the recommendation for pharmaceutical authorities on morphine availability should be accompanied by a statement clarifying that more than one low priced opioid is needed since up to 80% of patients may need opioid rotation at some point, even though only morphine is specifically recommended here). The critical issue is that governments should take the necessary steps to ensure access to PC medicines included those on the WHO Model List of Essential Medicines, including morphine as the gold standard and all the others in the List. Similarly, some recommendations may not capture the importance of spiritual care that is equally important to the physical and psychosocial domains. Spiritual, religious, and existential concerns are also dimensions which require care and should be addressed, registered, monitored and managed by the PC team.

The group of authors strongly recommends considering the recommendations broadly, while taking into account all agreed-upon recommendations, not just most important ones.

---

1. Letter from the Cardinal Secretary of State to the President of the Pontifical Academy for Life on the occasion of the Conference on palliative care organized by the Academy (Rome, February 28-March 1 2018).

2. Message of the Holy Father to the particepants in the Europeam Regional Meeting of the World Medical Association dealing with end-of-life questions. (Vatican City, Synod Hall, November 16-17, 2017).

Abstract

Background
— The Pontifical Academy for Life (PAV) is an academic institution of the Holy See (Vatican) which aims to develop and promote Catholic teachings on questions of biomedical ethics.
— Palliative care (PC) experts from around the world professing different faiths were invited by the PAV to develop strategic recommendations for the global development of PC ("PAL-LIFE group").

Design
— Thirteen experts in PC advocacy participated in an online Delphi process. In four iterative rounds, participants were asked to identify the most significant stakeholder groups and then propose for each, strategic recommendations to advance PC.
— Each round incorporated the feedback from previous rounds until consensus was achieved on the most important recommendations.
— In a last step, the ad hoc group was asked to rank the stakeholders' groups by order of importance on a 13 points-scale and to propose suggestions for implementation.
— A cluster analysis provided a classification of the stakeholders in different levels of importance for PC development.

Results
— Thirteen stakeholder groups and 43 recommendations resulted from the first round and, of those, 13 recommendations were chosen as the most important (one for each stakeholder group).
— Five groups had higher scores.

— The recommendation chosen for these top five groups were 1) Policy Makers: Ensure universal access to PC; 2) Academia: Offer mandatory PC courses to undergraduates; 3) Health care workers: PC professionals should receive adequate certification; 4) Hospitals and health care centers: Every healthcare center should ensure access to PC medicines, and 5) PC associations: National Associations should be effective advocates and work with their governments in the process of implementing international policy framework.
— Not chosen recommendations for both this higher scored group, plus for the remaining eight groups, are also presented in order of importance.

Conclusion
This white paper represents a position statement of the PAV with regards to advocacy and promotion of PC.

Keywords
Palliative Care, development, advocacy, global, position statement.

Running Title
PAL-LIFE White Paper for Global Palliative Care Advocacy.

Introduction

Background

Every year, over 25.5 million people die with serious health related-suffering (SHS) associated with life-limiting and life-threatening conditions. An additional 35 million live with these conditions and SHS (1). Yet the vast majority of the world does not have access to adequate treatment and care and social support.

Palliative care (PC) helps relieve SHS by providing physical, psycho-social, and spiritual care to patients and their families*. PC relieves "total pain" by shifting the often overly technical modern medical model to a holistic person-centered model of care (2).

Estimates of unmet PC needs worldwide are around 26.8 million per year (3). Other data suggest an even greater need of up to 40 million people per year (4), with estimates reaching 61 million people around the globe suffering from SHS (1). Various additional studies have shown a deficit of PC demand to PC supply (5-9), highlighting a lack of access to PC as a major global health inequity issue (10)(11).

There has been a rising burden of non-communicable diseases (NCDs) worldwide, and globally, NCDs cause 70% of all deaths (12) and generate 93% of adult PC need, and nearly 80% of the global PC need is in low-to-middle income countries (3)(5). Furthermore, the global population is ageing, and this, partnered with the increased prevalence of NCDs and the persistence of other debilitating chronic and infectious diseases reflects an alarming increase in need for PC provision at the global scale (4). In fact, studies estimate that by 2040, the proportion of people worldwide in need of PC will increase from 25% to 47% (13).

---

* In the annex, an updated definition of Palliative Care based on a rigorous global consensus process that has been endorsed by the PAL-LIFE group is offered.

25,5

MILLION PEOPLE DIE APPROXIMATELY WITH SERIOUS HEALTH RELATED-SUFFERING ASSOCIATED WITH LIFE-LIMITING AND LIFE-THREATENING CONDITIONS

80%

NEARLY THIS PERCENTAGE OF THE GLOBAL PC NEED IS IN LOW-TO-MIDDLE INCOME COUNTRIES

This growing need is recognized by global health organizations; the World Health Organization (WHO) recently approved the 13th General Program of Work recognizing the "limited availability of [PC] services in much of the world and the great avoidable suffering for millions of patients and their families" (4)(14) and concluded with several recommendations for further PC development and support for global PC advocacy campaigns. Though research has shown that PC has steadily grown at the global level, the demand far outstrips supply, and this growth has been very uneven, with some countries having progressed very little over the past decade (4-9).

The Catholic Church's appreciation for the PC as an approach to take care of the vulnerable is evident in its catechism, which includes the following statement "[Palliative care] represents a special form of disinterested charity, and as such, should be encouraged" (Catechism of the Catholic Church, n. 2279). Recently, Pope Francis shared with health professionals meaningful words on PC: "I encourage professionals and students to specialize in this type of assistance which is no less valuable for the fact that it is not life-saving. [PC] accomplishes something equally important: it values the person" (15).

The Pontifical Academy for Life (PAV) is an academic institution of the Holy See (Vatican) dedicated to the promotion of human life, and, among other specific topics, the study issues in medical ethics. In 2017, the PAV launched an international project called "PAL-LIFE: An International Advisory Working Group on diffusion and development of palliative care in the world" to advise on how the Catholic Church could assist in continued PC development at the global level (16). This white book represents a position statement of the PAV regarding PC, intended to be used for advocacy with local governments, healthcare organizations, leaders on-the-ground, and faith-based communities.

" Though research has shown that PC has steadily grown at the global level, the demand far outstrips supply, and this growth has been very uneven"

Design

A process was developed to generate consensus among 13 PC experts on key recommendations for major stake-holders' groups, including ranking both the recommendations and the stakeholder groups by importance, as well as providing suggestions for implementation.

The study was submitted and approved by the Clinical Research Ethical Committee of the University of Navarra.

Selection of experts and definition of the process

The expert group was selected considering and balancing diverse geographical regions and professional backgrounds. Members included clinicians, ethicists, and health administrators working in academic centers or international and regional PC organizations and professing different faiths. The PAV initially chose three experts in PC advocacy with global expertise in PC development. In a second step, additional experts were added to the group through a snowball process of recommendations by at least two peer experts reaching a total of thirteen persons considered to be experts in PC advocacy ("ad hoc group"). Two additional experts were invited in the last stage of the process based on the suggestion of several members of the group.

"

A process was developed to generate consensus among 13 PC experts"

An initial face-to-face meeting was conducted at the venue of the PAV in Rome, on March 2017. The purpose of the meeting was to define the strategy and methodology for identification of the key recommendations to be determined by the ad hoc group. It was outlined the project for a draft of a position statement ("white paper") on PC advocacy containing recommendations for health policy planning and providing guidance to different stakeholder groups on how to advance the development of PC in countries and regions.

Table 1. Members of the PAL – LIFE ad hoc group.

NAME	TITLE, INSTITUTION	CITY	COUNTRY
Alsirafy, Samy	Head of the Palliative Medicine Unit, Kasr Al-Ainy School of Medicine, Cairo University	Cairo	Egypt
Bruera, Eduardo	Chair, Dept. of Palliative Medicine and Supportive Care - UT MD Anderson Cancer Center	Houston	USA
Callaway, Mary V.	Board of Directors, IAHPC	Houston	USA
Centeno, Carlos	Director, ATLANTES Research Group, University of Navarra	Pamplona	Spain
De Lima, Liliana	Executive Director, International Association for Hospice and Palliative Care (IAHPC)	Houston	USA
Foley, Kathleen M.	Attending Neurologist Emeritus, Memorial Sloan Kettering Cancer Center	New York	USA
Luyirika, Emmanuel	Executive Director, African Palliative Care Association (APCA)	Kampala	Uganda
Mosoiu, Daniela	Director, Casa Sperantei, Assoc Prof. Transylvania University	Brasov	Romania
Pettus, Katherine	Advocacy Officer, IAHPC	Houston	USA
Puchalski, Christina	Director, The George Washington University's Institute for Spirituality and Health (GWish) Professor of Medicine GWU	Washington	USA
Rajagopal, MR	Director Pallium India, WHO Collaborating Centre for Training and Policy on Access to Pain Relief	Trivandrum	India
Sitte, Thomas	CEO Deutsche PalliativStiftung	Fulda	Germany
Yong, Jin-Sun	Director, The Catholic University of Korea (CUK), WHO Collaborating Centre for Training in Hospice and Palliative Care. Professor of Nursing, CUK	Seoul	South Korea

"
Members of the ad hoc group suggested new stakeholder groups or modified ones already in the list, resulting in a final list of 13 groups"

For the purposes of this project, the ad hoc group used the WHO definition of PC. The group also adopted the WHO public health strategy framework for PC (17).

Identification of Stakeholder Groups

In Round 1, experts of the ad hoc group were invited by e-mail to identify the most relevant stakeholder groups to which the recommendations would be directed to. These stakeholder groups were identified based on their key roles in their ability to promote PC development at national or regional levels in healthcare and/or society. From the initial list, through a Delphi consensus process, members of the ad hoc group suggested new stakeholder groups or modified ones already in the list, resulting in a final list of 13 groups. Based on the field of expertise, each expert was assigned to a specific stakeholder group.

Table 2. Assignment of members of ad hoc group to stakeholder groups.

MEMBER	STAKEHOLDERS
Samy Al-Sirafy	Pharmaceutical authorities
Eduardo Bruera, Daniela Mosoiu	Policymakers
Carlos Centeno, Jin-Sun Yong	University (Academia)
Liliana de Lima	Pharmacists
Emmanuel Luyirika	Professional associations and societies
Daniela Mosoiu	Mass media
Katherine Pettus	International organizations
Christina Puchalski	Religions, religious institutions, spiritual and ethics groups
M. R. Rajagopal	Hospitals and health care centers
Thomas Sitte	Patients and patients groups
Jin-Sun Yong	Health care workers
Mary Callaway	Philanthropic organizations and charities
Kathleen Foley	Other professional associations and societies than Palliative Care

Consensus process for the recommendations

In Round 2, each member was contacted by e-mail and requested to provide 2-3 recommendations for his/her corresponding stakeholder group. Each recommendation was accompanied by a statement, including rationale for the proposal, up to a maximum of 200 words. Recommendations were built upon the previous work and experience of the experts within their own or several other institutions to ensure best possible recommendations per stakeholder group.

In Round 3, all the recommendations were shared with the entire ad hoc group through an online survey tool (https://es.surveymonkey.com/) and each member of the ad hoc group was asked to rank each recommendation on a Likert scale from 1 to 5 (1 being "not important at all" and 5 "extremely important"). The average number of points for each recommendation was calculated.

The results were preliminarily presented in a PC conference organized by the PAV in Rome in March 2018, and subsequently discussed by the ad hoc group in a new face-to-face meeting with a subset of the experts. During this meeting, a thorough review of the recommendations and suggestions for implementation was conducted to improve wording.

In Round 4, twelve members of the ad hoc group reviewed their previous ratings and conducted another round of rankings of the stakeholder groups based on their perceived importance for PC development. Using a 13-point scale, points were assigned to each, according to the ranking given by each member [range: 12 (worst = one point per expert) to 156 (best = 13 points per expert)]. An exploratory K-means cluster analysis provided a classification of the stakeholders in different levels of importance for PC development. As final step in this round 4, members of the ad hoc group were asked to provide suggestions for implementation for each of the recommendations.

1/5

EACH MEMBER OF THE AD HOC GROUP WAS ASKED TO RANK EACH RECOMMENDATION ON A LIKERT SCALE FROM 1 TO 5

PAV endorsement of the recommendations and presentation of outcomes

The resulting recommendations from each stakeholder group were revised and agreed upon, then endorsed by the Board of Directors of the PAV. The endorsement was announced during the plenary session of the annual meeting of the PAV (June 2018) as the official position of the Academy and as the recommendations of PAL-LIFE.

Some considerations about the recommendations

In this book we present all the recommendations divided in chapters for each stakeholders´ group. The order is given by their importance for palliative care advocacy according to the ad hoc group´s consensus.

> "The resulting recommendations from each stakeholder group were revised and agreed upon, then endorsed by the Board of Directors of the PAV"

(1) Scores on relative importance (range 1 to 156) and K-means for cluster analysis. The K-means cluster analysis confirmed the existence of two levels in the ranking of the stakeholders' groups: five groups had higher scores (closer to K-mean 103.4) and nine stakeholder groups lower ones (closer to K-mean 52.4).

Table 3. Ranking of Stakeholder groups (1).

STAKEHOLDER GROUP	POINTS	GROUP K-MEAN
Policymakers	122	103.4
Universities (academia)	111	
Health Care Workers	103	
Hospitals and Healthcare Centres	92	
Palliative Care Associations	89	
International Organizations	71	52.4
Mass Media	69	
Philanthropic Organizations and Charities	62	
Pharmaceutical Authorities	59	
Patients and Patient Groups	53	
Spiritual Care Professionals	50	
Associations other than Palliative Care	29	
Pharmacists	26	

Within each chapter, recommendations chosen as the most important will be shown first. All the recommendations are accompanied by a rationale/reflection, and bibliographic references. Additionally, the five highest ranked recommendations will also show suggestions for implementation.

Bibliography

1. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report [Internet]. Vol. 391, The Lancet. 2018. Available from: http://dx.doi.org/10.1016/S0140-6736(17)32513-8

2. Richmond C. Dame Cicely Saunders. Bmj [Internet]. 2005;331(7510):238–238. Available from: http://www.bmj.com/cgi/doi/10.1136/bmj.331.7510.238

3. World Palliative Care Alliance. Global atlas of palliative care at the end of life [Internet]. World Health Organization (WHO), editor. London: Worldwide Hospice Palliative Care Alliance and World Health Organization; 2014. 111 p. Available from: http://www.who.int/cancer/publications/palliative-care-atlas/en/

4. World Health Assembly. WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course [Internet]. Sixty-seventh World Health Assembly. Geneva; 2014. Available from: http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf%5Cnhttp://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf

5. The Economist Intelligence Unit. The 2015 Quality of Death Index Ranking palliative care across the world. Econ [Internet]. 2015;71. Available from: http://www.apcp.com.pt/uploads/2015-EIU-Quality-of-Death-Index-Oct-6-FINAL.pdf

6. Centeno C, Lynch T, Donea O, Rocafort J, Clark D. EAPC Atlas of Palliative Care in Europe 2013. Full Edition. [Internet]. European Association for Palliative Care. 2013. 1-410 p. Available from: http://www.eapcnet.eu/Themes/Organisation/DevelopmentinEurope/EAPCAtlas2013.aspx

7. Rhee JY, Luyirika E, Namisango E, Powell RA, Garralda E, Pons JJ, et al. APCA Atlas of Palliative Care in Africa. Houston: IAHPC Press; 2017. 48 p.

8. Pastrana T, De Lima L, Pons JJ, Centeno C. Atlas de Cuidados Paliativos en Latinoamérica- Edición Cartográfica 2013 [Internet]. Houston: IAHPC Press; 2013. 1-72 p. Available from: www.cuidadospaliativos.org

9. Osman H, Rihan A, Garralda E, Rhee JY, Pons Izquierdo JJ, De Lima L, et al. Atlas of Palliative Care in the Eastern Mediterranean Region [Internet]. Houston: IAHPC Press; 2017. Available from: http://hdl.handle.net/10171/43303

10. Radbruck L, Foley K, De Lima L, Praill D, Fürst CJ. The Budapest commitments: Setting the goals a joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and help the hospices. Palliat Med [Internet]. 2007;21(4):269–71. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17656401

01

Recommendations for Policymakers

11. Gomez-Baptiste X, Connor S. Building Integrated Palliative Care Programs and Services. Xavier Gomez-Batiste and Stephen Connor(eds.), editor. Barcelona: Liberdúplex; 2017. 384 p.

12. World Health Organization (WHO). Noncommunicable diseases and their risk factors [Internet]. [cited 2018 Feb 22]. Available from: http://www.who.int/ncds/management/palliative-care/palliative-care-NCDs/en/

13. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med [Internet]. 2017;15(1):102. Available from: http://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2

14. Dye C, Boerma T, Evans D. The World Health Report 2013: Research for universal health coverage [Internet]. Luxembourg; 2013. Available from: http://www.who.int/whr/2013/report/en/

15. Vatican Radio. Pope Francis: We must not abandon the elderly. [Internet]. Vatican Radio; Available from: http://en.radiovaticana.va/news/2015/03/05/pope_francis_we_must_not_abandon_the_elderly/1127144.

16. Comoretto N. PAL-LIFE Project: International Advisory Working Group on Diffusion and Development of Palliative Care in the World: First Meeting Report. J Palliat Med, 20.9 (2017), 913–14.

17. Stjernswärd J, Foley K, Ferris F. The public health strategy for palliative care. J Pain Symptom Manage 2007;33:486–493.

1st Recommendation

Policymakers must recognize the societal and ethical value of palliative care and modify the existing health care structures, policies and outcome measures to ensure universal access to Palliative Care for all patients in need. They must also take the steps to ensure an integrated health system, to allow a smooth flow of patients between the different levels of care, so that patients with complex problems may be referred to secondary and tertiary levels, as needed, and referred back to home care, if possible.

Rationale

Patients with chronic progressive diseases such as cancer, congestive heart failure, chronic obstructive pulmonary disease, and HIV/AIDS, develop severe physical, psychosocial, and spiritual symptoms before death [1][2]. There is strong evidence that PC is beneficial in reducing much of this suffering in patients as well as psychosocial and spiritual or existential distress in families [3].

There is strong evidence that these benefits are accompanied by a reduction in the total cost of care [4]. Cost savings are achieved mainly by preventing unnecessary disease-oriented investigations and treatments as well as hospitalizations in acute care hospitals and intensive care units [5-8]. Value in healthcare results from the balance between benefits and costs. PC has demonstrated impact on both components of value.

Suggestions for implementation

— Involve national associations to advocate for PC.
— Advocate with local policymakers for access to Palliative Care as a human right.
— Link advocacy to other initiatives such as the movement of whole-person care, preventive medicine and health promotion.
— Carry out a public awareness campaign focusing on needlessly suffering and the ethical responsibility of the government.

— Include Palliative Care as a component of Non-communicable Diseases National Plans or strategies.

2ⁿᵈ Recommendation

Policymakers must ensure that universal palliative care access is provided and integrated with disease-oriented treatment.

Rationale

There is strong evidence that the value of palliative care (benefits in the reduction of suffering and cost savings from unnecessary disease-oriented interventions) is increased when patients access palliative care early (integrated with disease-oriented treatment) rather than late (after the failure of disease-oriented treatment).

3ʳᵈ Recommendation

Policymakers must ensure universal palliative care training among healthcare professionals who treat patients with chronic progressive diseases. They must also modify structures, processes and outcomes in the healthcare system to allow patients with more complex problems access to secondary and tertiary palliative care.

Rationale

Palliative care should be delivered at primary level (by community based healthcare professionals and disease-oriented professionals such as oncologists, cardiologist, etc.); at secondary level (primary healthcare professionals in consultation with palliative care specialists for patients with more complex problems); and at tertiary level (palliative care specialists for the patient with the most complex problems and who will be in charge of education and research in the region).

Bibliography

1. World Health Organization (WHO). Palliative Care [Internet]. World health Organisation website. 2018 [cited 2018 Apr 30]. Available from: http://www.who.int/en/news-room/fact-sheets/detail/palliative-care.

2. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report [Internet]. Vol. 391, The Lancet. 2018. Available from: http://dx.doi.org/10.1016/S0140-6736(17)32513-8

3. Boston PH, Mount BM. The Caregiver's Perspective on Existential and Spiritual Distress in Palliative Care. J Pain Symptom Manage. 2006;32(1):13–26.

4. Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: A literature review. Palliat Med. 2014;28(2):130–50.

5. Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, Hager MA. A High-Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End-of-Life Care Costs. J Palliat Med [Internet]. 2003;6(5):699–705. Available from: http://www.liebertonline.com/doi/abs/10.1089/109662103322515202

6. Elsayem A, Swint K, Fisch MJ, Palmer JL, Ready S, Walker P, et al. Palliative care inpatient service in a comprehensive cancer center: Clinical and financial outcomes. J Clin Oncol. 2004;22(10):2008–14.

7. Norton LA, Holloway RG, Temkin-Greener H, Buckley MJ, Quill TE. Proactive palliative care in the medical intensive care unit: effects on length of stay for selected high-risk patients. Crit Care Med. 2007;35(6):1530–5.

8. Ciemins EL, Blum L, Nunley M, Lasher A, Newman JM. The Economic and Clinical Impact of an Inpatient Palliative Care Consultation Service : A Multifaceted Approach. 2007;10(6):1347–55.

02

Recommendations for Academia (Universities & Colleges)

1st Recommendation

All academic institutions offering degrees in health-care-related fields should include mandatory Palliative Care courses as part of the undergraduate curricula.

————

Rationale

According to the UN Committee on Economic, Social and Cultural Rights (CESCR), Member States are required to ensure universal access to PC. This obligation includes the duty to ensure that healthcare workers meet appropriate standards of education (1). Accordingly, the WHO urges Member States to integrate basic PC training into all undergraduate medical and nursing professional education (2). In other words, international law stipulates that governments and universities of Member States provide adequate training of healthcare workers pursuant to the principles laid out by the WHO (3).

Studies also suggest that early and continuous student exposure to PC education is associated with positive attitudes and increased satisfaction towards PC among undergraduate medical students (4). Studies also demonstrate undergraduate nursing students' belief that PC training should be an essential component of their education, contributing favourably to both their personal and professional development (1).

Complete integration of PC courses into all undergraduate curricula for future healthcare workers is both an obligation under international law and an evidence-based educational strategy.

————

Suggestions for implementation

— Approve a national law where Palliative Care teaching is mandated.
— Develop standard curricula on team-based interdisciplinary Palliative Care.

— Palliative Care curricula must combine theoretical and practical components integrated at the primary care level.
— Teach Palliative Care by clinically-experienced faculties who have academic appointments.
— Funding for education programs should come from governments' healthcare educational budgets.
— When Palliative Care is not taught, invite Palliative Care experts to deliver lectures on Palliative Care to create the demand.

2ⁿᵈ Recommendation

To include palliative care as an independent, longitudinal subject in the curricula of medical and nursing schools.

Rationale

Training and formal education in palliative care is an essential component for all health care professionals and its inclusion in undergraduate curricula leads to better clinical care of patients. Palliative care education and training improves knowledge, skills, and competences (especially communication) and improves attitudes toward caring (5). Students who are taught Palliative Care at undergraduate level, report feeling better as professionals and more prepared to care for all patients at all stages of disease as well as at the end of life (6)(7). There is a trend to include mandatory teaching of Palliative Care in a number countries around the world (8). Recommendations for the development of undergraduate curricula in palliative medicine are available (9).

3ʳᵈ Recommendation

Rec. 3.1: All universities engaged in the training of healthcare workers (doctors, nurses, pharmacists, social workers, chaplains, etc.) should include courses on 'spiritual care' and 'spiritualty and health' as part of mandatory undergraduate coursework on palliative care.

Rec. 3.2: Mandatory undergraduate courses on palliative care for healthcare students should be team-based and interdisciplinary, while avoiding an exclusively theoretical approach.

Rec. 3.3: All universities engaged in the training of healthcare workers should train educators who are fully capable of delivering team-based interdisciplinary training on palliative care and employ them as tenured faculty members.

Rationale

The integration of palliative care courses as required undergraduate coursework is not sufficient to ensure the adequate training of healthcare workers. This needs to be accompanied by proper quality management of the content and method of education. In the U.S., as in other countries around the globe, palliative care is often taught merely as part of another course (10). Even when palliative care is included in the curriculum as a full course, undergraduate nursing students tend to show inconsistent degrees of self-efficacy and low confidence upon graduation (11). This calls for further development to deliver quality education.

Studies reveal that engaging medical students in clinical practices and real encounters with patients, while encouraging student reflection via reflective writing assignments, provides a deeper understanding of palliative care and even suggests life-changing experiences (12)(13). Undergraduate nursing students enrolled on a palliative care elective found that listening to the patients' narratives and being present with them, offered great educational values (14). These kinds of training programs comprise the emerging field of 'spirituality and health.' Healthcare students who have received

educational intervention in spirituality and health were shown to possess a greater degree of knowledge and skills as well as more positive attitudes, compared to students who were not offered such intervention (15). Similar effects have been demonstrated in a project which shows the importance of a critically reflective approach to professional training in healthcare (16). Providing a spirituality program to undergraduate nursing students has also shown positive effects on their competences (17).

It is in this context that the 2009 National Consensus Conference (Pasadena, California) recommends that all palliative care programs should integrate the domain of spiritual care into their overall quality improvement plans. This is because spiritual issues need to be considered as one of the patient's vital signs, since spiritual care should be integral to any patient-centered model of care (18). Moreover, since palliative care is essentially holistic, it necessarily calls for a team-based interdisciplinary approach. Palliative care training thus needs to develop the capacity for effective teamwork. Interdisciplinary, multi-professional undergraduate training has already been shown to improve the self-efficacy and knowledge of core palliative care issues among medical students (19). Hence the 2013 International Consensus Conference(Geneva, Switzerland) recommends that besides integrating palliative care education into undergraduate training for healthcare students, efforts should be made to continuously develop curricula that cover spiritual care, self-awareness, cultural sensitivity, and spiritual assessment (20).

Bibliography

1. World Health Assembly. WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course [Internet]. Sixty-seventh World Health Assembly. Geneva; 2014. Available from: http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf%5C-nhttp://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf

2. Gomez-Baptiste X, Connor S. Building Integrated Palliative Care Programs and Services. Xavier Gomez-Batiste and Stephen Connor(eds.), editor. Barcelona: Liberdúplex; 2017. 384 p.

3. A Lee, B Carlon, R Ramsay and TT. Integrating exposure to palliative care in an undergraduate medical curriculum: student perspectives and strategies. Int J Med Educ. 2017;151–2.

4. Ballesteros M, Centeno C, Arantzamendi M. A qualitative exploratory study of nursing students' assessment of the contribution of palliative care learning. Nurse Educ Today. 2014;34(6):e1-6.

5. Schulz C, Moller MF, Seidler D SM. Evaluating an evidence-based curriculum in undergraduate palliative care education: piloting a phase II exploratory trial for a complex intervention. BMC Med Educ. 2013;13(1).

6. Barclay S, Whyte R, Thiemann P et al. An important but stressful part of their future work: medical students' attitudes to palliatice care throughout their course. J Pain Symptom Manag. 2015;49:231–42.

7. Centeno C, Ballesteros M, Carrasco JM, Arantzamendi M. Does palliative care education matter to medical students? The experience of attending an undergraduate course in palliative care. BMJ Support Palliat Care. 2016;6(1):128–34.

8. Carrasco JM, Lynch T, Garralda E et al. . Palliative care medical education in European universities: a descriptive study and numerical scoring system proposal for assessing educational development. J Pain Symptom Manag. 2015;50(4):516–23.

9. Recommendations of the European Association for Palliative Care (EAPC) for the development of undergraduate curricula in palliative medicine at European medical schools. [Internet]. Available from: http://www.eapcnet.eu/Themes/Education/ Medical/CurriculumUpdate.aspx

10. Meghani SH, Hinds PS. Policy brief: the Institute of Medicine report Dying in America: Improving quality and honoring individual preferences near the end of life. [Internet]. Vol. 63, Nursing outlook. Washington DC: National Academies Press; 2015. 51-9 p. Available from: http://www.nursingoutlook.org/article/S0029655414002565/fulltext

11. Henderson A, Rowe J, Watson K, Hitchen-Holmes D. Graduating nurses' self-efficacy in palliative care practice: An exploratory study. Nurse Educ Today [Internet]. 2016;39:141–6. Available from: http://dx.doi.org/10.1016/j.nedt.2016.01.005

12. Roji R, Noguera-Tejedor A, Pikabea-Diaz F, Carrasco JM, Centeno C. Palliative Care Bedside Teaching: A Qualitative Analysis of Medical Students' Reflective Writings after Clinical Practices. J Palliat Med. 2017;20(2):147–54.

03

Recommendations for Health Care Workers

13. Borgstrom E, Morris R, Wood D, Cohn S, Barclay S. Learning to care: medical students' reported value and evaluation of palliative care teaching involving meeting patients and reflective writing. BMC Med Educ [Internet]. 2016;16(1):306. Available from: http://bmcmededuc.biomed-central.com/articles/10.1186/s12909-016-0827-6

14. Hold JL, Blake BJ, Ward EN. Nurse Education Today Perceptions and experiences of nursing students enrolled in a palliative and end-of-life nursing elective : A qualitative study. Ynedt [Internet]. 2015;35(6):777–81. Available from: http://dx.doi.org/10.1016/j.nedt.2015.02.011

15. Osório IHS, Gonçalves LM, Pozzobon PM, Gaspar Júnior JJ, Miranda FM, Lucchetti ALG, et al. Effect of an educational intervention in "spirituality and health" on knowledge, attitudes, and skills of students in health-related areas: A controlled randomized trial. Med Teach [Internet]. 2017;22:1–8. Available from: https://doi.org/10.1080/0142159X.2017.1337878

16. Cobb MR, Puchalski CM, Rumbold B. Oxford Textbook of Spirituality in Healthcare Healthcare spirituality: a question of knowledge Waterfalls and buckets. M Cobb, C Puchalski and BR., editor. Oxford: Oxford University Press; 2012.

17. Yong J, Kim J, Park J, Seo I, Swinton J. Effects of a Spirituality Training Program on the Spiritual and Psychosocial Well-Being of Hospital Middle Manager Nurses in Korea [Internet]. Vol. 42, The Journal of Continuing Education in Nursing. 2011. Available from: http://www.slackinc.com/doi/resolver.asp?doi=10.3928/00220124-20101201-04

18. Puchalski, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. J Palliat Med [Internet]. 2009;12(10):885–904. Available from: http://ecommons.luc.edu/socialwork_facpubs/22

19. Gerlach C, Mai S, Schmidtmann I, Massen C, Reinholz U, Laufenberg-Feldmann R, et al. Does Interdisciplinary and Multiprofessional Undergraduate Education Increase Students' Self-Confidence and Knowledge Toward Palliative Care? Evaluation of an Undergraduate Curriculum Design for Palliative Care at a German Academic Hospital. J Palliat Med. 2015;18(6):513–9.

20. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus. J Palliat Med [Internet]. 2014;17(6):642–56. Available from: http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.9427

1st Recommendation

Healthcare professionals working in Palliative Care should receive appropriate certification while actively participating in continuing education to maintain the adequate competency levels.

———

Rationale

In addition to requiring basic-level PC training for all undergraduate medical and nursing professional education, the WHO urges Member States to ensure intermediate-level training to all healthcare workers who routinely encounter patients with life-threatening illnesses and to fully integrate PC into health care in every setting, specifically highlighting community settings, and throughout the course of advanced illnesses. Member States are also required to provide specialist-level training to prepare healthcare professionals who will engage in more than routine PC practice (1). This means that healthcare workers must receive appropriate certification, acquiring competences that are required by the proper standards of certification. Specialist-level training is of particular importance in places where the role of PC specialists has not yet been institutionalized.

———

Suggestions for implementation

— Reach out to the national boards of medicine and nursing and the Ministries of Health and education through National Associations to advocate for the recognition of Palliative Care as a specialty.
— Establish a working group among members of the board of medicine and the board of nursing with Palliative Care experts in the country to determine the minimum level of competencies, knowledge and skills in Palliative Care, and years of dedication required to be recognized as Palliative Care professional.

— Standardize health professional education with basic and specialty certification programs according to each country's process of health care professional official certification.

2nd Recommendation

All healthcare workers engaging in palliative care should engage in ongoing education to develop knowledge and skills in other disciplines related to one's own profession, while readily applying an interdisciplinary team approach in practice.

Rationale

———

Healthcare workers must complement their specialized professional training with ongoing interdisciplinary education. Since holistic care is based on the ethical principles of patient-centeredness and holism, developing multidisciplinary competences is a moral obligation on the part of healthcare workers (2). According to one qualitative study, physicians themselves agree on the necessity of ongoing education that is practice-based and inter-professional, on the grounds that undergraduate level education is insufficient for real-life clinical settings (3). It is thus imperative that healthcare workers continue to acquire basic knowledge of other relevant disciplines, in addition to developing competences within their specialty. To incorporate this into practice, they need to develop capacities for interdisciplinary teamwork as well.

3rd Recommendation

All healthcare workers engaging in palliative care should promote the individual's spirituality by means of spirituality programs and self-care,

empowering the self to assess spiritual distress and provide an adequate level of spiritual care.

———

Rationale

The development of one's own spirituality constitutes a crucial element for this kind of team capacity. This is because team dynamics focuses on mutual respect and understanding, which in turn requires the ability to reflect on self and others (2). The 2013 International Consensus Conference thus recommends all palliative care team members be trained in spiritual care, voluntarily engaging in ongoing education to develop competences in self-care, self-reflection, and reflective practice (4). Studies demonstrate that a spirituality program can promote the psychological and spiritual wellbeing of nurses, which may contribute to forming a more effective care environment (5). Palliative care that is truly holistic and team-based also requires practitioners to engage in an appropriate level of spiritual assessment. Healthcare workers should therefore continue to care for themselves, so that they may always be vigilant and sensitive enough to properly recognize spiritual distress (3).

Bibliography

1. World Health Assembly. WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course [Internet]. Sixty-seventh World Health Assembly. Geneva; 2014. Available from: http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf%5Cn-http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf

2. Cobb MR, Puchalski CM, Rumbold B. Oxford Textbook of Spirituality in Healthcare Healthcare spirituality: a question of knowledge Waterfalls and buckets. M Cobb, C Puchalski and BR., editor. Oxford: Oxford University Press; 2012.

3. Pype P, Symons L, Wens J, Van den Eynden B, Stes A, Deveugele M. Health care professionals' perceptions towards lifelong learning in palliative care for general practitioners: a focus group study. BMC Fam Pract [Internet]. 2014;15(1):36. Available from: http://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-15-36

4. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus. J Palliat Med [Internet]. 2014;17(6):642–56. Available from: http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.9427

5. Yong J, Kim J, Park J, Seo I, Swinton J. Effects of a Spirituality Training Program on the Spiritual and Psychosocial Well-Being of Hospital Middle Manager Nurses in Korea. J Contin Educ Nurs [Internet]. 2011;42(6):280–8. Available from: http://www.slackinc.com/doi/resolver.asp?doi=10.3928/00220124-20101201-04

04

Recommendations for Hospitals & Health Care Centers

1ˢᵗ Recommendation

Every hospital and healthcare center should ensure affordable access to Palliative Care medicines included in the WHO Model List of Essential Medicines, particularly to immediate-release oral morphine. It also should accept Palliative Care provision as a moral and ethical imperative.

———

Rationale

Modern medical science, unfortunately, based increasingly on technology, has become so disease-oriented as to neglect the human being. Health-related suffering is often ignored.

Persistent attempts at treating the disease, even in the face of futility of treatment, causes, in addition to physical, social, and mental suffering, financial difficulties and spiritual distress. In his address to participants in the Plenary of the PAV (Clementine Hall, 5 March 2015) Pope Francis said, "I therefore welcome your scientific and cultural efforts to ensure that PC can reach all those who need it. I encourage professionals and students to specialize in this type of assistance, which has no less value on account of fact that it does not save lives. PC recognizes something equally important, the value of person (1)."

The World Health Assembly in its landmark Resolution of 2014 (2) called upon all Member States to integrate PC in Healthcare at all levels (primary, secondary, and tertiary) across the continuum of care (from the time health-related suffering starts until the death of the patient and continuing thereafter in the form of bereavement support for the family).

———

Suggestions for implementation

— Ensure training of all staff in the fundamentals of Palliative Care.
— Define a Palliative Care integration strategy for the hospital or Health Center.

— To stablish a minimum dataset to monitor the quality of care in advance disease and end of life.

2ⁿᵈ Recommendation

Rec. 2.1 Accept provision for palliative care as a moral and ethical imperative,

Rec. 2.2 Establish a palliative care service as part of its routine activity, primarily based on care in the home-setting with inpatient facility when necessary,

Rec. 2.3 Ensure training of all staff in the fundamentals of palliative care to ensure a palliative approach in all healthcare,

Rec. 2.4 Ensure availability of at least one doctor and nurse in every such institution with specialised training in palliative care.

————

Health, according to the World Health Organization, is not just absence of disease, but a state of complete physical, social and mental well-being. Unfortunately, modern medical science, based increasingly on technology, has become so disease-oriented that it may neglect the human being. Health related suffering is often ignored. Persistent attempts at attacking the disease, even in the face of the futility of treatment causes, in addition to physical social and mental suffering, financial destruction and spiritual distress. In his address on Vatican Radio dated 5-3-2015, titled "We Must Not Abandon The Elderly", Pope Francis said, "I therefore welcome your scientific and cultural efforts to ensure that palliative care can reach all those who need it. I encourage professionals and students to specialize in this type of assistance, which has no

less value on account of fact that it does not save lives. Palliative care recognizes something equally important, the value of person (1)."

The World Health Assembly in its landmark Resolution of 2014 (2) called upon all Member States to integrate Palliative Care in Healthcare at all levels (primary, secondary and tertiary) across the continuum of care (from the time health related suffering starts till death of the patient and continuing thereafter as bereavement support for the family).

Bibliography

1. Vatican Radio. Pope Francis: We must not abandon the elderly. [Internet]. Vatican Radio; Available from: http://en.radio-vaticana.va/news/2015/03/05/pope_francis_we_must_not_abandon_the_elderly/1127144.

2. World Health Assembly. WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course [Internet]. Sixty-seventh World Health Assembly. Geneva; 2014. Available from: http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf%5Cn-http://apps.who.int/medicine-docs/documents/s21454en/s21454en.pdf

05

Recommendations for Palliative Care Associations

1st Recommendation

Representatives of National Associations should be effective advocates and work with their governments in the process of implementing international policy framework, including Conventions, Resolutions and Declarations in their countries (i.e. UNGASS outcome document, Agenda 2030, WHA Resolution).

———

Rationale

Patients who require PC often have diverse and over-lapping illnesses, and may be staying at home, in long-term care facilities, nursing homes, and hospitals. Delivery of holistic services to patients requires mul-tidisciplinary teams which may work in the national/ public health system, the church or non-government sectors (1).

These teams need to plan their interventions based the needs of the patient, whether adult or child, and the patient's family (2). To develop the skills and improve their knowledge, the members of the multidisciplinary teams rely on guidelines and recommendations from PC associations and societies that often work with governments, other civil society agencies, donors and promoters of PC to set up functional capacity building, service delivery, and research networks (3). These build a system that can reach even the most disadvantaged communities not reached by conventional health care systems. (4)

———

Suggestions for implementation

— Implement advocacy workshops with representa-tives of national associations to empower represen-tatives of civil society so that they adopt the skills to do effective advocacy campaigns and strategies.
— National associations have the power and legitimacy to request and demand from their governments the

implementation of the international policies and frameworks which call for the inclusion of palliative care in the national policies and programmes, the strengthening of NCDs programmes and the adoption of the SDGs in the Agenda 2030.

— Work in order to set national standards in palliative care including primary and specialist palliative education and training and work with both governmental and nongovernmental stakeholders to develop a national palliative care strategy integrated into universal health care.

2nd Recommendation

Professional associations and societies and all non-government stakeholders need to exploit opportunities to work within countries and extend palliative care to patients in homes, communities, hospitals and hospices, even as national health systems evolve to include hospice and palliative care.

3rd Recommendation

The associations should also support capacity building and research as well as the development and documentation of best practices and peer-to peer learning in palliative care within the countries they work.

4th Recommendation

The associations should also work to tap alternative sources of funding for palliative care to complement government budgets. Funding agencies should not

exclude these associations as they often complement government efforts and in some cases they are the pioneers in advance of the implementation of government systems.

———

Rationale

Patients who require palliative care often have diverse and overlapping illnesses and may be found at home, in old age homes and in hospitals. Delivery of holistic services to such patients requires multidisciplinary teams, which may be part of a national/public health system, or from the church or non-government sectors (1). Such professional teams need to work in concert with the needs of the patient whether adult or child and the patient's family (5). To develop the professionalism of such multidisciplinary teams to offer services wherever they needed often depends on the existence of functional professional associations and societies that often work with governments, other civil society agencies, donors and promoters of palliative care to set up functional capacity building, service delivery and research networks (6). These then build a system that can reach even disadvantaged communities, not reached by conventional health care systems (7).

Bibliography

1. World Health Assembly. WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course [Internet]. Sixty-seventh World Health Assembly. Geneva; 2014. Available from: http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf%5Cnhttp://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf

2. Schulz C, Moller MF, Seidler D SM. Evaluating an evidence-based curriculum in undergraduate palliative care education: piloting a phase II exploratory trial for a complex intervention. BMC Med Educ. 2013;13(1).

3. Barclay S, Whyte R, Thiemann P et al. An important but stressful part of their future work: medical students' attitudes to palliatic care throughout their course. J Pain Symptom Manag. 2015;49:231–42.

4. Centeno C, Ballesteros M, Carrasco JM, Arantzamendi M. Does palliative care education matter to medical students? The experience of attending an undergraduate course in palliative care. BMJ Support Palliat Care. 2016;6(1):128–34.

5. United Nations General Assembly. Political declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Disease. Sixty-sixth session. A/66/L.1 [Internet]. 2011. Available from: http://www.un.org/ga/search/view_doc.asp?symbol=A%2F66%2FL.1&Lang=E

6. Parashar D. The role of non-government organizations in cancer control programmes in developing countries. Indian J Palliat Care [Internet]. 2016;10(79):2016. Available from: http://www.jpalliativecare.com/text.asp?2004/10/2/79/13891

7. Sustainable Development Goals [Internet]. Vol. 1. United Nations Development Program; 2015 [cited 2018 Jan 17]. Available from: http://www.undp.org/content/undp/en/home/mdgoverview/post-2015-development-agenda/

06

Recommendations for International Organizations
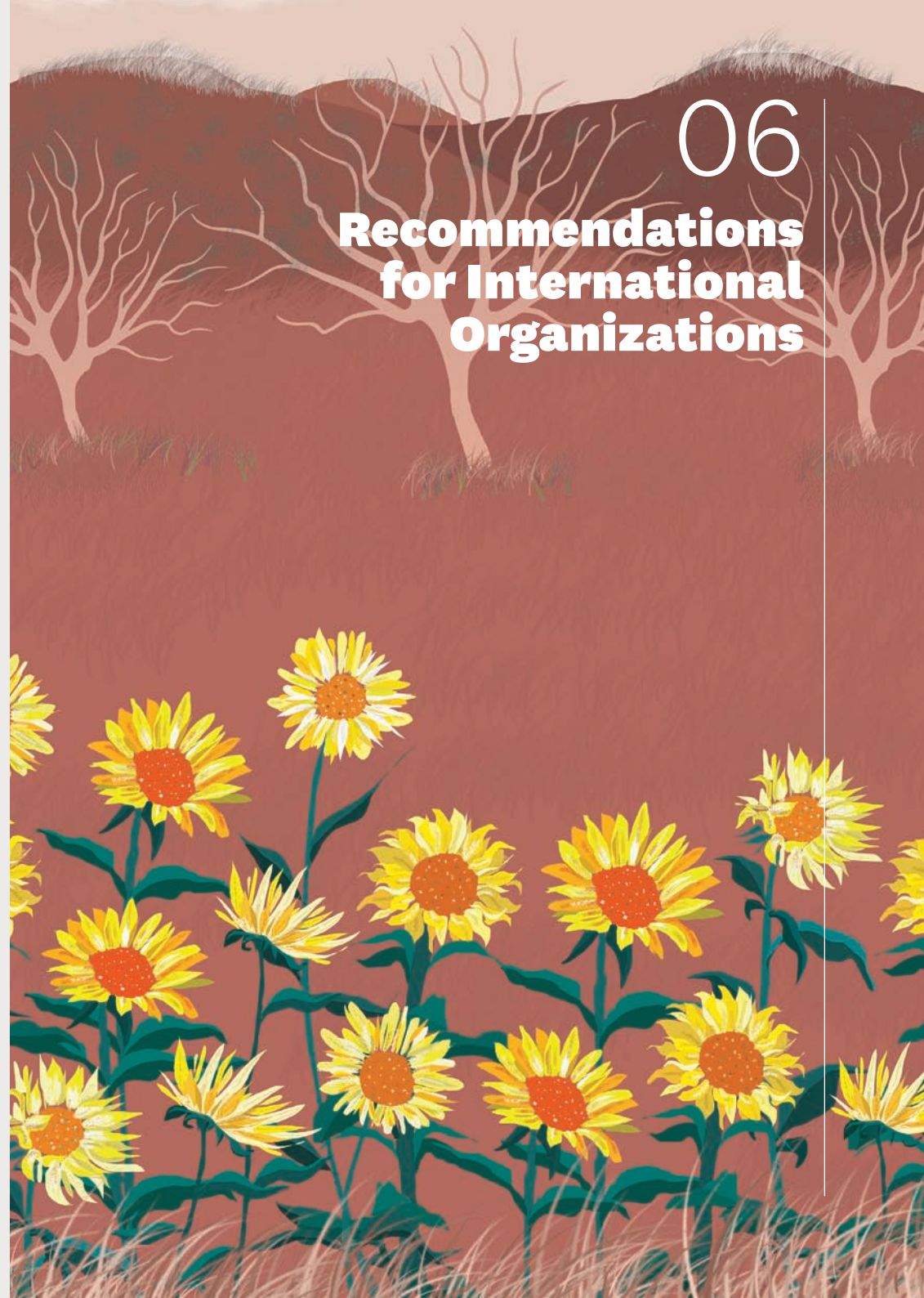
1st Recommendation

International organizations should encourage WHO Member States to develop policies and procedures to implement the WHA Resolution 67/19 as an integral part of their strategies, and to implement the Agenda 2030 for Sustainable Development Goals, paying specific attention to the needs of children and older persons.

———

Rationale

Recognizing that more than 75% of the world has no access to PC services, WHO Member States unanimously adopted WHA Resolution 67/19 in 2014. In 2015, UN Member States unanimously adopted Agenda 2030 for Sustainable Development in 2015 with the pledge to "leave no one behind." Leaving no one behind means that UN member states and agencies must collaborate to develop integrated, human rights-based policies and procedures in order to realise their key public health outcomes. Human rights based public health policies make integrated, person-centered services available to all citizens, migrants, and refugees of all ages in all settings: home, hostel or hospice, rural or urban clinic, hospital, and long term settings such as nursing homes and prisons (1)(2)(3)(4)(5)(6)(7)(8)(9)(10).

2nd Recommendation

That Holy See mission at UN Headquarters uses a prepared White Paper on the relevance of palliative care and controlled medicines to achieve Global Goals (2030 Agenda) as a basis for drafting contributions and prepared interventions at the UN Headquarters, ECOSOC functional organizations and subsidiary bodies.

———

Rationale

Goal 3 of the 2030 Agenda for Sustainable Development in 2015, "Healthy Lives for all at All Ages ," includes Target 3.8, Universal Health Coverage (UHC) and Access to

Medicines. The majority of UN delegations discussing Agenda 2030 do not know, however, that palliative care and palliative care medicines (because the text does not specify them) are included under UHC (WHO Definition), and that "essential medicines" include internationally controlled PC medicines such as morphine (WHO Model List). It is important to stipulate that achieving Target 3.8 entails integrating palliative care into public health systems as per WHA Resolution 67/19.

Rationale

As palliative care is a relatively new medical specialty and a new issue for the UN, few UN documents contain any "agreed language" referring to palliative care. This makes it difficult to introduce a new program! Developing agreed language requires the committed and informed participation of seasoned diplomats in missions that are able and willing to promote the new issue. The Holy See diplomats in all UN offices could play that role, once they are educated about the issue and have basic documents at hand. To date, the HS delegates in NY, Geneva, and Vienna have not produced statements of support for the inclusion of basic palliative care policies, including access to controlled medicines, in debates and discussions around inter alia healthcare, human rights, older persons, Agenda 2030. This may be because mission staff are unaware of the relevance of palliative care to the UN agenda and they do not have ready access to "agreed language" that they can suggest to add to text during drafting procedures or in prepared interventions. The Holy See missions might help to educate other missions at UN agencies through distribution of a White Paper containing definitions, explanations, agreed language and suggestions for proposed texts, as well as through technical briefings and sideline events at key conferences and High Level forums. The results will be 1) official meeting records that include Holy See statements on palliative care and medicines; and 2) a developing body of agreed language on palliative care and controlled medicines (11-17)

Bibliography

1. Carrasco JM, Lynch T, Garralda E et al. Palliative care medical education in European universities: a descriptive study and numerical scoring system proposal for assessing educational development. J Pain Symptom Manag. 2015;50(4):516–23.

2. Recommendations of the European Association for Palliative Care (EAPC) for the development of undergraduate curricula in palliative medicine at European medical schools. [Internet]. Available from: http://www.eapcnet.eu/Themes/Education/ Medical/ CurriculumUpdate.aspx

3. Meghani SH, Hinds PS. Policy brief: the Institute of Medicine report Dying in America: Improving quality and honoring individual preferences near the end of life. [Internet]. Vol. 63, Nursing outlook. Washington DC: National Academies Press; 2015. 51-9 p. Available from: http://www.nursingoutlook.org/article/S0029655414002565/fulltext

4. Henderson A, Rowe J, Watson K, Hitchen-Holmes D. Graduating nurses' self-efficacy in palliative care practice: An exploratory study. Nurse Educ Today [Internet]. 2016;39:141–6. Available from: http://dx.doi.org/10.1016/j.nedt.2016.01.005

5. Roji R, Noguera-Tejedor A, Pikabea-Diaz F, Carrasco JM, Centeno C. Palliative Care Bedside Teaching: A Qualitative Analysis of Medical Students' Reflective Writings after Clinical Practices. J Palliat Med. 2017;20(2):147–54.

6. Borgstrom E, Morris R, Wood D, Cohn S, Barclay S. Learning to care: medical students' reported value and evaluation of palliative care teaching involving meeting patients and reflective writing. BMC Med Educ [Internet]. 2016;16(1):306. Available from: http://bmcmededuc.biomedcentral.com/articles/10.1186/s12909-016-0827-6

7. Hold JL, Blake BJ, Ward EN. Nurse Education Today Perceptions and experiences of nursing students enrolled in a palliative and end-of-life nursing elective : A qualitative study. Ynedt [Internet]. 2015;35(6):777–81. Available from: http://dx.doi.org/10.1016/j.nedt.2015.02.011

8. Osório IHS, Gonçalves LM, Pozzobon PM, Gaspar Júnior JJ, Miranda FM, Lucchetti ALG, et al. Effect of an educational intervention in "spirituality and health" on knowledge, attitudes, and skills of students in health-related areas: A controlled randomized trial. Med Teach [Internet]. 2017;22:1–8. Available from: https://doi.org/10.1080/0142159X.2017.1337878

9. Vatican Radio. Pope Francis: We must not abandon the elderly. [Internet]. Vatican Radio; Available from: http://en.radio-vaticana.va/news/2015/03/05/pope_francis_we_must_not_abandon_the_elderly/1127144.

10. World Palliative Care Alliance. Global atlas of palliative care at the end of life [Internet]. World Health Organization (WHO), editor. London: Worldwide Hospice Palliative Care Alliance and World Health Organization; 2014. 111 p. Available from: http://www.who.int/cancer/publications/palliative-care-atlas/en/

11. The PGA Handbook General Assembly [Internet]. New York: Permanent Mission of Switzerland to the United Nations; 2011. Available from: https://www.unitar.org/ny/sites/unitar.org.ny/files/UN_PGA_Handbook.pdf

12. Transforming our World: The 2030 Agenda for Sustainable Development [Internet]. United Nations; 2015. Available from: https://sustainabledevelopment.un.org/post2015/transformingourworld

13. Holy See Statement on Agenda 2030. (Emphasises definitions on sexual and reproductive health. Could do something similar with UHC) [Internet]. Available from: http://en.radiovaticana.va/news/2015/09/03/holy_see_on_uns_2030_agenda_for_sustainable_development/1169218

14. Holy See Statement to HLPF July 2017. Quotes Pope Francis statement on compassion for "real men and women who live, struggle, and suffer and are often forced to live in great poverty, deprived of all rights. [Internet]. 2017. Available from: https://sustainabledevelopment.un.org/content/documents/21590holy-see.pdf

15. Turkson PC. Statement of His Eminence Peter Cardinal Turkson, Prefect of the Dicastery for Promoting Integral Human Development, Head of the Delegation of the Holy See to the United Nations Conference to Support the Implementation of SDG 14: Conserve and Sustainably [Internet]. New York; 2017. Available from: https://sustainabledevelopment.un.org/content/documents/24049holyseer1.pdf

16. World Health Organisation: Definition of Universal Health Coverage [Internet]. Available from: http://www.who.int/health_financing/universal_coverage_definition/en/

17. World Health Organisation. WHO model list of essential medicines [Internet]. WHO Press. World Health Organisation; 2013. Available from: http://www.who.int/medicines/publications/essentialmedicines/en/index.html

18. Seatzu F, Fanni S. The Right To Palliative Care: a "Mirage" in the Jurisprudence of the Ecthr and Iacthr? Cuad Derecho Transnacional [Internet]. 2016;8(Marzo):5–16. Available from: https://e-revistas.uc3m.es/index.php/CDT/article/viewFile/3016/1722

19. Seatzu F. On the Inter-American Convention on the Rights of Older Persons. Anu Español Derecho Int [Internet]. 2015;31(1):349–66. Available from: http://www.unav.edu/publicaciones/revistas/index.php/anuario-esp-dcho-internacional/article/view/4629

20. Stjernsward J, Foley KM, Ferris FD. Integrating Palliative Care into National Policies. J Pain Symptom Manage [Internet]. 2007;33(5):514–20. Available from: http://www.jpsmjournal.com/article/S0885-3924(07)00154-6/fulltext

07

Recommendations for Mass Media

1ˢᵗ Recommendation

Mass media should be involved in creating a culture of understanding around advanced illness and the role of palliative care throughout the life course and as a component of Universal Health Coverage (UHC).

———

Rationale

There is a misconception about PC both among the general public and among healthcare professionals that PC is synonymous with end-of-life care (1). PC is not just for the dying. With this understanding comes an imperative for patients to receive PC earlier in their disease trajectory (2). This requires a cultural shift that starts with physicians to the general population.

2ⁿᵈ Recommendation

Mass Media should use as sources of information, people that have experienced or somehow approached palliative care, whether providing or receiving it.

———

Rationale

Given the misunderstandings and confusion that often occur in the press and general media with regard to Palliative Care, a better source of information for mass media would be highly desirable. We know that normally, politicians are the agents for transmitting information regarding PC to newspapers, and to a lesser extent, health professionals when some kind of technical data is needed, and this usually concerns controversial situations (3). The references to PC are mainly related to socio-political debates linked to the proposals of lawmakers on end-of-life-care (4).

3rd Recommendation

Considering the overall potential benefit to mankind, mass media must give importance to healthcare and palliative care, emphasizing the value of total care providing physical, social, emotional and spiritual well-being, and highlighting inspiring positive stories from patients, families and caregivers.

———

Rationale

Normally mass media elsewhere approaches palliative care in a negative way, generally associating it with euthanasia, death and suffering; forgetting the improvement of the quality of life for those facing the end of their lives, the gratitude many patients and families feel and many other good qualities offered by palliative care providers (5)(6).

4th Recommendation

Mass media should increase presence in the news by all means, bringing Palliative Care to the top of the agenda at times.

———

Rationale

The general public and society hardly ever hears of palliative care. This is known to be one of the major challenges for Palliative Care development and integration in the health system (3). If mass media paid attention and informed about palliative care, given that the press media is one of the main generators of public knowledge and opinion, this would improve its presence in society (5).

Bibliography

1. Cobb MR, Puchalski CM, Rumbold B. Oxford Textbook of Spirituality in Healthcare Healthcare spirituality: a question of knowledge Waterfalls and buckets. M Cobb, C Puchalski and BR., editor. Oxford: Oxford University Press; 2012.

2. Yong J, Kim J, Park J, Seo I, Swinton J. Effects of a Spirituality Training Program on the Spiritual and Psychosocial Well-Being of Hospital Middle Manager Nurses in Korea [Internet]. Vol. 42, The Journal of Continuing Education in Nursing. 2011. Available from: http://www.slackinc.com/doi/resolver.asp?doi=10.3928/00220124-20101201-04

3. Centeno C, Garralda E, Carrasco JM, den Herder-van der Eerden M, Aldridge M, Stevenson D, et al. The Palliative Care Challenge: Analysis of Barriers and Opportunities to Integrate Palliative Care in Europe in the View of National Associations. J Palliat Med [Internet]. 2017;20(11):1195–204. Available from: http://online.liebertpub.com/doi/10.1089/jpm.2017.0039

4. Downing J. Using the media to promote palliative care. Int J Palliat Nurs [Internet]. 2010;16(3):107. Available from: http://search.ebscohost.com/login.aspx?direct=true&db=-jlh&AN=105163177&site=e-host-live

5. Carrasco JM. Social Representation of Palliative Care in the Media: A Qualitative Analysis of Spanish Newspapers. PLos One 2019.

6. Carrasco JM, Centeno C. What message do Spanish media convey about palliative care? Eur J Palliat Care. 2016;23(1):32–4.

08

Recommendations for Philanthropic Organizations and Charities

1st Recommendation

Individuals and organizations involved in palliative care must engage, educate and advocate for philanthropic organizations and charities to support palliative care development and implementation of services.

———

PC must be integrated into national health systems around the world. National governments have not provided adequate financing to support PC development and non-governmental organizations, professional organizations, foundations, faith-based organizations, charities, charitable trusts, and development agencies have played important roles in the development of hospice and PC at the international and community levels, providing both medical and social support.

With the potential for governments to provide universal health coverage (UHC) and a basic package for PC, all donor organizations must work with PC providers to develop innovative educational and social support systems (1-4).

2nd Recommendation

Hospice and palliative care donor mapping should be undertaken and presented at a meeting of existing and potential donors. Participating donors should present their program strategies, successes and lessons learned and develop an action plan to address unmet needs.

———

Palliative care is developing slowly around the world but organizations currently funding palliative care policy, services, education and training, awareness raising, and drug policy are not well known to palliative care

Rationale

Rationale

providers seeking support. A detailed mapping and description of funding from existing national and regional donors such as privately operating foundations, corporate foundations, national development agencies, charities and other organizations would serve as a resource database for palliative care programs (5-8).

3rd Recommendation

Donors who fund similar program areas such as education or service development, should come together to create a donors' collaborative to provide leverage for and an increase in program support.

Rationale

There is not sufficient funding for palliative care development and provision locally, nationally, or regionally. Donors coming together to support similar palliative care programs would find leverage for their funds and increase the amount of available funding for palliative care programs (9-14).

Bibliography

1. Puchalski, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. J Palliat Med [Internet]. 2009;12(10):885–904. Available from: http://ecommons.luc.edu/socialwork_facpubs/22

2. Gerlach C, Mai S, Schmidtmann I, Massen C, Reinholz U, Laufenberg-Feldmann R, et al. Does Interdisciplinary and Multiprofessional Undergraduate Education Increase Students' Self-Confidence and Knowledge Toward Palliative Care? Evaluation of an Undergraduate Curriculum Design for Palliative Care at a German Academic Hospital. J Palliat Med. 2015;18(6):513–9.

3. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus. J Palliat Med [Internet]. 2014;17(6):642–56. Available from: http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.9427

4. Pype P, Symons L, Wens J, Van den Eynden B, Stes A, Deveugele M. Health care professionals' perceptions towards lifelong learning in palliative care for general practitioners: a focus group study. BMC Fam Pract [Internet]. 2014;15(1):36. Available from: http://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-15-36

5. Robert Bosch Stiftung Foundation [Internet]. Robert Bosch Stiftung; Available from: http://www.bosch-stiftung.de/

6. European Society of Medical Oncology Working Group on Palliative Care. ESMO Designated Centres Working Group [Internet]. Available from: http://www.esmo.org/About-Us/Who-We-Are/Educational-Committee/Designated-Centres-Working-Group

7. Lynch T, Connor S, Clark D. Mapping levels of palliative care development: A global update. J Pain Symptom Manage [Internet]. 2013;45(6):1094–106. Available from: http://dx.doi.org/10.1016/j.jpainsymman.2012.05.011

8. Rhee JY, Luyirika E, Namisango E, Powell RA, Garralda E, Pons JJ, et al. APCA Atlas of Palliative Care in Africa. Houston: IAHPC Press; 2017. 48 p.

9. Murr M, Walker B, Kowel S, Pillsbury K. Funding Resources [Internet]. 2014. Available from: http://www.icpcn.org/funding-resources/

10. Hospices of Hope [Internet]. Available from: https://www.hospicesofhope.com

11. Hospice Casa Sperantei [Internet]. Available from: https://www.hospice.ro/en/

12. Nursing Practice Centers of Excellence [Internet]. Available from: https://www.bms.com/life-and-science/news-and-perspectives/building-palliative-cancer-care-nursing-capabilities.html

13. Global Health. USAID. Available from: https://www.usaid.gov/what-we-do/global-health

14. DFID Independent Palliative Care Funding Review. Available from: https://www.gov.uk/government/publications/independent-palliative-care-funding-review

09

Recommendations for Pharmaceutical Authorities

1st Recommendation

Morphine (preferably immediate release oral formulation) is the preferred medication for the treatment of moderate/severe cancer pain and palliative care and should be made available and accessible. No government should approve modified-release morphine, transdermal fentanyl patches, or slow release oxycodone without also guaranteeing widely available immediate-release oral morphine.

———

Rationale

Morphine is recommended by the WHO as the first-line strong opioid for the management of moderate-to-severe cancer pain in adults and children (1-4). Although it is available in different formulations (3-4), it is recommended that the availability of cheap immediate-release oral morphine is a priority due to reasons such as affordability and flexibility in use. Although other, newer, strong opioids should also be made available, availability of these newer opioids should not be considered as a replacement to availability of morphine.

2nd Recommendation

A list of essential medicines for palliative care, comprising affordable drugs should be made available.

———

Rationale

Patients with life-limiting illnesses, including cancer and non-cancer, may suffer due to pain and a wide range of other symptoms (5-6). The availability of medicines to control pain and other symptoms is an essential component of palliative care as many of the symptoms experienced by the terminally ill can be managed effectively using simple, affordable medications. The

2017, 20th edition of the WHO Model List of Essential Medicines and the 6th edition of the WHO Model List of Essential Medicines for Children includes a section dedicated to "Medicines for Pain and Palliative Care" (3-4). The medicines listed are essential to control pain and other common symptoms in palliative care patients. The IAHPC List of Essential Medicines for Palliative Care is a more comprehensive list (7). Such lists can be used to guide the development of model lists in countries, taking into consideration affordability.

It should be noted that making essential palliative care medicines available is a component of and not a replacement for, holistic palliative care.

3rd Recommendation

To ensure the availability and accessibility of controlled medicines necessary for palliative care patients, pharmaceutical authorities should work with concerned bodies to achieve a balance in national policies on controlled medicines.

————

Rationale

Restrictive regulations that limit the availability and accessibility to controlled medicines, including opioid analgesics, still represent a barrier to pain control in many countries (8). Similarly, the misuse of controlled medicines resulting from loose control or misleading marketing of new opioids/formulations has a negative impact on pain control. Pharmaceutical authorities are called upon to work in collaboration with concerned bodies to revise national policies that control opioid analgesics guided by the WHO recommendations (9).

Bibliography

1. World Health Organization: Cancer Pain Relief: A Guide to Opioid Availability, 2nd ed. Geneva: World Health Organisation, 1996.

2. World Health Organization: WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. http://apps.who.int/iris/bitstream/10665/4454011/9789241548120_Guidelines.pdf (last accessed July 4, 2018).

3. World Health Organization: WHO Model List of Essential Medicines, 20th ed. 2010. www.who.int/medicines/publications/essentialmedicines/20th_EML2017_FINAL_amendedAug2017.pdf?ua=1 (last accessed July 4, 2018).

4. World Health Organization: WHO Model List of Essential Medicines for Children, 6th ed. Geneva: World Health Organization, 2017.

5. Teunissen SC, Wesker W, Kruitwagen C, de Haes HC, Voest EE, de Graeff A. Symptom prevalence in patients with incurable cancer: a systematic review. J Pain Symptom Manage. 2007; 34(1): 94-104.

6. Moens K, Higginson IJ, Harding R; EURO IMPACT. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. J Pain Symptom Manage. 2014; 48(4): 660-677.

7. International Association for Hospice and Palliative Care (IAHPC) List of Essential Medicines for Palliative Care. Available from: https://hospice-care.com/about-iahpc/projects/palliative-care-essentials/iah-pc-essential-medicines-for-palliative-care/ Accessed: 14-July-2107.

8. Vranken MJ, Lisman JA, Mantel-Teeuwisse AK, Jünger S, Scholten W, Radbruch L, Payne S, Schutjens MH. Barriers to access to opioid medicines: a review of national legislation andregulations of 11 central and eastern European countries. Lancet Oncol. 2016;17(1):e13-22.

9. World Health Organization. Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. World Health Organization, 2011.

10

Recommendations for Patients and Patient Groups
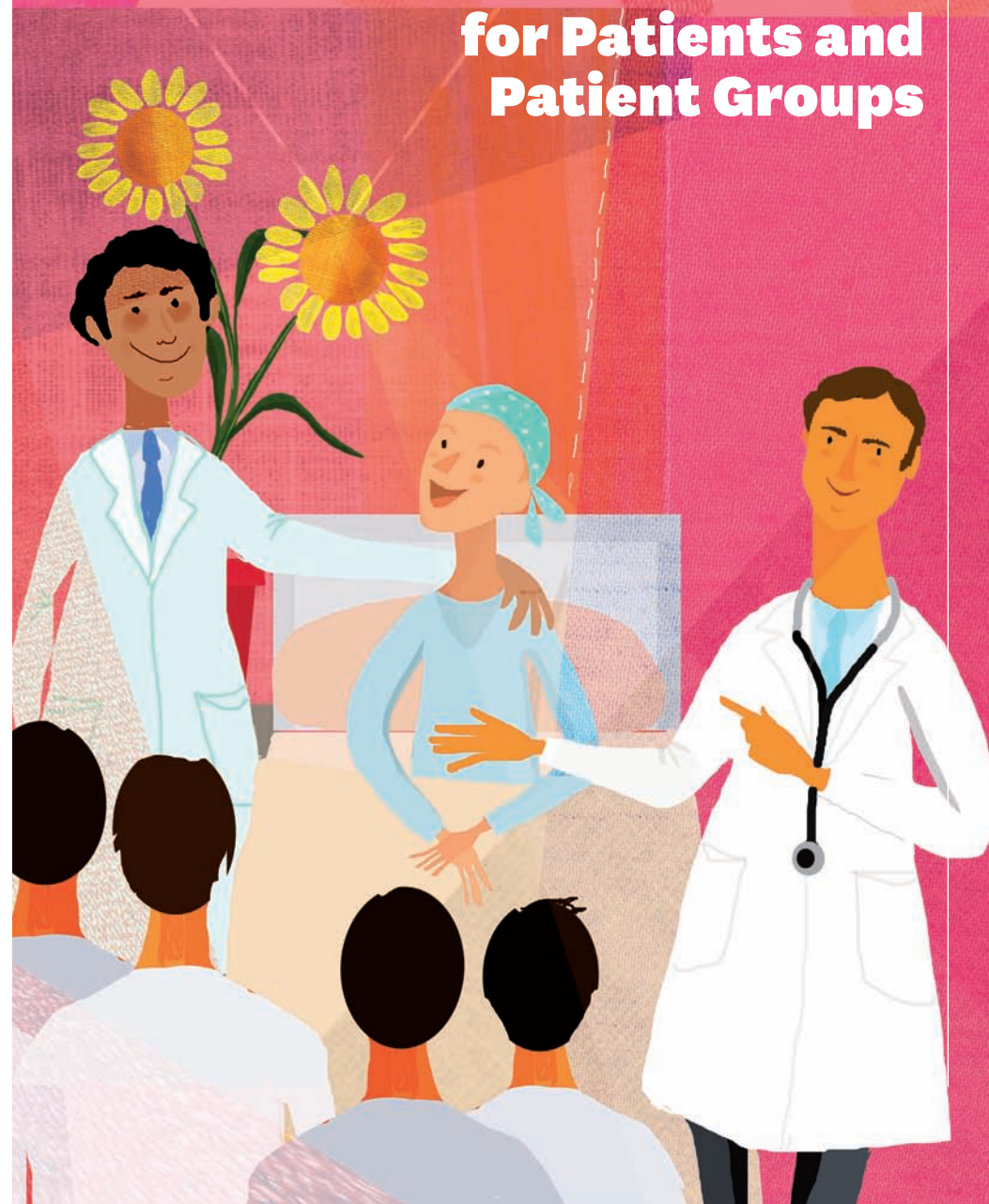
1st Recommendation

Patients and patients groups could be of great help in developing and demanding a health literacy campaign for all patients with PC needs and their families to increase the knowledge and understanding of PC and its role in the decision making process.

———

Rationale

Health illiteracy, even in countries where palliative care is well developed, is an obstacle for early integration of PC, which improves therapy (1). Mistakenly, some patients may percieve that alleviating symptoms is a way to hasten death (1). There is a significant health illiteracy and patients and families are not aware that PC can be given concurrently with active disease oriented therapies (1). Education targeted to these groups can help to dispel the myths about PC as hastening death or only a care approach for dying patients.

2nd Recommendation

Palliative Care patients and patients groups need the know how and tools to spread knowledge at a great variety of different levels (3) (4).

———

Rationale

Lack of knowledge, under- and overtreatment lead to futility (5), causes harm to patients and shortens their life instead of supporting their ability to resist and solve intermediate problems and symptoms. Information about PC supports society (6). Public availability provides keywords and shows how to find information. At the same time the necessary tools need to be implemented, to be prepared via internet for electronic use, printed versions, face to face or tutorials. People are unprepared but should know how to ask useful questions and need appropriate tools to find answers for shared decision-making and informed consent (7-8-9).

Bibliography

1. Temel JSS, Greer JAA, Muzikansky A et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010;363:733-742

2.Sitte T. Palliative Care instead of assisted suicide and euthanasia? About questionable needs of life-shortening behaviour. PALIATIA Journal of Palliative Care [Internet]. 2017; Available from: http://www.paliatia.eu/new/2017/03/palliative-care-instead-of-assisted-suicide-and-euthanasia-about-questionable-needs-of-life-shortening-behaviour/

3. Thompson G, Chochinov MH. Learning about dementia and care near end of life

4.Barcelona Declaration on Palliative Care, European Journal of Palliative Care 3 (1996), 15

5. Kasmann D. When is medical treatment futile? https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1492577/

6.Flessa S. Ultimate reliability as a resource. The value of palliative care for the economy. Z Palliativmed. 2014;15:78-83.

7.Budapest Commitment on Palliative Care http://www.eapcnet.eu/Themes/Policy/Budapestcommitments.aspx

8. National Strategy, charter caring severe ill and dying people in Germany [Internet]. Verfügbar unter: http://www.charta-zur-betreuung-sterbender.de

9.Cunningham T V, Scheunemann LP, Arnold RM, White D. How do clinicians prepare family members for the role of surrogate decision-mak-er? J Med Ethics [Internet]. 2017;medethics-2016-103808. Verfügbar unter: http://jme.bmj. de/lookup/doi/10.1136/medethics-2016-103808

Recommendations for Spiritual Care Professionals

1st Recommendation

Religious institutions and spiritual care groups should work to include spiritual care - including ongoing assessment of spiritual distress and spiritual well-being - integrated into guidelines of care and as a component of routine palliative care provision.

———

Rationale

The World Health Organization (WHO) has recognized spiritual care as a required element of PC. Spiritual distress (spiritual or existential suffering) needs to be addressed by all members of the team in order to provide the best quality care for patients and families and to help relieve suffering of patients and families. Several US and international consensus conferences have developed definitions and models for addressing spiritual distress in the clinical setting (1).

Religious leaders should advocate for the inclusion of inter-professional spiritual care in PC and advocate for appropriate training of all clinicians in providing spiritual care to patients and families, as well as developing, training, and helping to sustain adequate staffing of healthcare chaplains in all health settings (2-3).

2nd Recommendation

Rec. 2.1: To include inter-professional spiritual care as a required element of longitudinal palliative care in the curricula of all medical, nursing, social work, theological and other pre-professional education. Content will vary depending on the clinical role of each of these professionals.

Rec. 2.2: To include ongoing inter-professional educational training for all palliative care healthcare workers including chaplains and clergy involved in caring for palliative care patients.

Rec. 2.3: Spiritual care is a part of routine palliative care and integrated into policies for intake and the ongoing assessment of spiritual distress and spiritual well-being.

———

Rationale

In addition to the clinical aspects of spiritual care, there are ethical mandates for all health systems to honour the dignity of all people. Religious organizations in particular can lead efforts to ensure that all people are treated with dignity, that all people have a right to assessment and relief from suffering and that all people have access to interprofessional spiritual care (4). These models are based on the recognition that spirituality, broadly defined, is a critical element of palliative care. All clinicians provide generalist spiritual care; healthcare chaplains or spiritual care professionals are the experts in spiritual care provision.

Religious clergy and others, while not members of the healthcare team, do provide religious care in community settings and should also be trained in the clinical aspects of spiritual care. All healthcare and theology students and healthcare chaplains, in addition to pastoral care, should have a basic understanding of spiritual clinical care; more advanced content depending on the role of each profession in clinical settings

In addition to the clinical aspects of spiritual care, there are ethical mandates for all health systems to honour the dignity of all people. Religious organizations in particular can lead efforts to ensure that all people are treated with dignity, that all people have the right to assessment and to the relief from suffering and that all people have access to interprofessional spiritual care.

Bibliography

1. Yong J, Kim J, Park J, Seo I, Swinton J. Effects of a Spirituality Training Program on the Spiritual and Psychosocial Well-Being of Hospital Middle Manager Nurses in Korea [In-ternet]. Band 42, The Journal of Continuing Education in Nurs-ing. 2011. Verfügbar unter: http://www.slackinc.com/doi/resolver.asp?doi=10.3928/00220124-20101201-04

2. Vermandere M, De Lepeleire J, Van Mechelen W, Warmenhoven F, Thoonsen B, Aertgeerts B. Outcome Measures of Spiritual Care in Palliative Home Care: A Qualitative Study. Am J Hosp Palliat Med [Internet]. 2013;30(5):437-44. Verfügbar unter: http://www.ncbi.nlm.nih.gov/pubmed/22833554% 5Cn-http://ajh.sagepub.com/cgi/doi/10.1177/1049909112454563

3. Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. Gerontologist [Internet]. 2002;42 Spec No:24–33. Verfügbar unter: http://gerontologist.oxfordjournals.org/content/42/suppl_3/24.long

12

Recommendations for Non-PC Professional Associations and Societies

1st Recommendation

Non-palliative care professional associations and societies should encourage human rights organizations to consider existing declarations and to implement strategies whose aim is advancing palliative care development worldwide within a human rights framework.

_____

Rationale

Acknowledgement of pain relief and PC as a human right has been widely declared by many institutions and organizations (1-5).

2nd Recommendation

To encourage and collaborate with other professional organizations to develop guidelines for palliative care for specific diseases.

_____

Rationale

The WHO in its Global Atlas on Palliative Care, estimates 20 million patients each year —19 million adults and 1 million children— would benefit from palliative care at the end of life. The number increases to 40 million if we include the needs of seriously ill patients prior to their last year of life. Patients with cancer, HIV, and a wide range of non-communicable diseases are all candidates for palliative care. Disease specific specialists have recognized the need for palliative care and have developed palliative care guidelines in patients with TB, cardiac disease, HIV, cancer, renal, neurologic, and critical care (6-15).

Bibliography

1. Jagwe, Jack and AM. Uganda: delivering analgesia in rural Africa: opioid availability and nurse prescribing. J Pain Symptom Manage. 2007;33(5):547–51.

2. Worldwide hospice palliative care alliance. Universal Health Coverage and Palliative Care: Do not leave those suffering behind [Internet]. 2014. Available from: http://www.thewhpca.org/resources/item/uhc-and-palliativecare

3. Radbruck L, Foley K, De Lima L, Praill D, Fürst CJ. The Budapest commitments: Setting the goals a joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and help the hospices. Palliat Med [Internet]. 2007;21(4):269–71. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17656401

4. The PGA Handbook General Assembly [Internet]. New York: Permanent Mission of Switzerland to the United Nations; 2011. Available from: https://www.unitar.org/ny/sites/unitar.org.ny/files/UN_PGA_Handbook.pdf

5. World Health Assembly. WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course [Internet]. Sixty-seventh World Health Assembly. Geneva; 2014. Available from: http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf%5Cnhttp://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf

6. Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacsi P, et al. Palliative care in heart failure: A position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail. 2009;11(5):433–43.

7. HIV/AIDS Bureau Health Resources and Service Administration. A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa [Internet]. Joseph F. O'Neill PAS, editor. US Health Resources and Services Administration; 2006. 1-556 p. Available from: http://www.globalpartnersincare.org/clinical-guide-supportive-and-palliative-care-hivaids-sub-saharan-africa

8. Ferrell BR, Temel JS, Temin S, Alesi ER, Balboni TA, Basch EM, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. J Clin Oncol [Internet]. 2017;35(1):96–112. Available from: http://www.ncbi.nlm.nih.gov/pubmed/28034065

9. Schrijvers D, Cherny NI. ESMO clinical practice guidelines on palliative care: Advanced care planning. Ann Oncol. 2014;25(23):138–42.

10. Nelson MJE, Azoulay PE, Curtis JR, Mosenthal AC, Mulkerin CM, Puntillo K, et al. Palliative Care in the ICU. J Palliat Med. 2012;15(2):168–74.

11. Pediatrics AA of. Standards of Practice for Pediatric Palliative Care and Hospice. Pediatrics [Internet]. 2010;126(2):e488--e488. Available from: http://www.pediatrics.aappublications.org.

12. World Palliative Care Alliance. Global atlas of palliative care at the end of life [Internet]. World Health Organization (WHO), editor. London: Worldwide Hospice Palliative Care Alliance and World Health Organization; 2014. 111 p. Available from: http://www.who.int/cancer/publications/palliative-care-atlas/en/

13. Grubbs V, Moss AH, Cohen L et al. A palliative approach in Dialysis Care: A Patient-Centered Transition to the End. Clin J Am Soc Nephrol. 2014;9(12):2203–9.

14. Oliver D, Borasio GD, Caraceni A, de Visser M, Grisold W, Lorenzl S, et al. Palliative care in chronic and progressive neurological disease: Summary of a consensus review. Eur J Palliat Care [Internet]. 2016;23(5). Available from: http://www.eapcnet.eu

15. Hussainy SY, Box M, Scholes S. Piloting the role of a pharmacist in a community palliative care multidisciplinary team: an Australian experience. BMC Palliat Care [Internet]. 2011;10(16):16. Available from: http://www.ncbi.nlm.nih.gov/pubmed/22035160

16. International Association for Hospice and Palliative Care, Worldwide Palliative Care Alliance. Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights [Internet]. Vol. 22, Journal of Pain & Palliative Care Pharmacotherapy. 2008. p. 300–2. Available from: http://www.tandfonline.com/doi/

13

Recommendations for Pharmacists

1st Recommendation

Pharmacists should play an active role in palliative care teams by assessing the appropriateness of the medicines prescribed to patients, by ensuring timely dispensation, by educating the team members about pharmacological interactions and by ensuring that patients and caregivers understand the prescribed regimen to ensure adherence to treatment.

2nd Recommendation:

Pharmacists should work to provide efficient mechanisms for extemporaneous compounding of nonstandard dosage forms, and should find ways to make them available and accessible for the patient, especially when there are no generic/cheaper formulations available in the country.

3rd Recommendation:

Pharmacists should instruct the patients, families and clinicians on how to ensure safe and legal disposal of all medications after a patient's death, establishing and maintaining proficient communication with regulatory and licensing agencies to ensure safe dispensation and use, especially of controlled medications, such as opioid analgesics.

Rationale

PC patients often need to take multiple medications simultaneously and as a result, have an increased risk of drug interactions and drug-related problems of essential medicines for PC. Pharmacists have a greater knowledge of medications and their effects than any other member of the healthcare team and are, therefore, the best equipped to detect possible problems and make appropriate recommendations (1-2).

📖

Bibliography

1. Smith Y. The Pharmacist's Role in Palliative Care. News, Med Life Sci [Internet]. Available from: http://www.news-medical.net/health/The-Pharmaciste28099s-Role-in-Palliative-Care.aspx

2. Demler TL. Pharmacist involvement in hospice and palliative care. US Pharm [Internet]. 2016;41(3):HS2-HS5. Available from: http://www.embase.com/search/results?-subaction=viewrecord&from=export&id=L609154748

Epilogue
The contribution of Religions

From the beginning, the accompaniment of palliative care has included not only physical and mental symptom control, but also preparation for death, in the awareness that existential questions can never really be separated from a patient's experience of disease, especially when the disease is considered incurable and progression to death is inevitable. Thanks to palliative care, "death itself is introduced into a symbolic horizon within which it can stand out not so much as the end against which life halts and succumbs, but rather as the fulfillment of a freely received and lovingly shared existence"[1].

In achieving this goal, it is important that palliative care intensely meditate and reflect on the major anthropological issues and the enormous ethical challenges we face in relation to end-of-life issues and the needs of the person arising from the dynamic changes of the human spirit close to death. In addition to clinical experience, palliative care requires the contribution of the human sciences and the indispensable word of truth and meaning offered by religion to the human being's search for meaning and the mystery of self-discovery.

In reality, a close relationship links religions and palliative care. This relationship is based on the care that religions encourage in viewing the human person as a physical and spiritual whole, to help foster understanding that the meaning of life is not just attention to our individual selves, but that we are each interconnected with others, especially the weakest in society. The golden rule that says: 'Do not do to others what you do not want done to yourself', translated positively means, 'Be attentive to others as if they were yourself'. This is why love, care, and compassion are fundamental parts of the religious message, and it is this care of the other that must be extended, sustained, and deepened to all parts of the world in the expansion of the philosophy of palliative care.

Today, the scientific community of palliative care recognizes the important role of religions in giving concrete impulse to this form of care of the sick or dying person, given the ability of religions to reach the peripheries of humanity, those who, within a community, are most in need. Yet religions can do much more. Religions do not only promote achieving a greater pres-

ence of palliative care where needed, but they are the true force of palliative care. The integral attention to the person does not respond to any human logic, much less to the economic logic that governs our contemporary culture. The result of such logic can only lead to what Pope Francis calls the "culture of waste". Only a "religious" reading of human existence and of reality, whether confessed or not, allows us to see and affirm a good that goes beyond the visible and does not correspond to the measure of calculations. Only a "widened" rationality of the sacred makes it possible to affirm that there is an intangible preciousness in human life, even when it is fragile and apparently defeated by ill-

ness. Palliative care embodies a vision of the human being who is profoundly religious and precisely this vision is the true soul and the true force of palliative care.

"Religious faiths support the principles of palliative care in the relief of pain and suffering approaching a natural end of life".[2]

The hope is that all religions, in an active way, should support the palliative care movement, offering their precious contribution of wisdom to achieve a culture of accompaniment that is truly inclusive and respectful of the dignity proper to every human being.

📖

Bibliography

1. Vatican Radio. Pope Francis: We must not abandon the elderly. [Internet]. Vatican Radio; Available from: http://en.radio-vaticana.va/news/2015/03/05/pope_francis_we_must_not_abandon_the_elderly/1127144

1. Letter from the Cardinal Secretary of State to the President of the Pontifical Academy for Life on the occasion of the Palliative Care Convention organized by the PAV (Rome, 28 February - 1 March 2018).

2. Maruzza Foundation. Religions of the World Charter. Palliative Care for Older People. In http://www.fondazionemaruzza.org/wp/wp-content/uploads/2017/03/Charter.pdf (access 21 December 2018).

Palliative Care Definition

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

Palliative care:

—Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.

—Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.

—Is applicable throughout the course of an illness, according to the patient's needs.

—Is provided in conjunction with disease modifying therapies whenever needed.

—May positively influence the course of illness.

—Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.

—Provides support to the family and the caregivers during the patient's illness, and in their own bereavement.

—Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.

—Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).

—Can be provided by professionals with basic palliative care training.

—Requires specialist palliative care with a multiprofessional team for referral of complex cases.

To achieve palliative care integration, governments should:

1. Adopt adequate policies and norms that include palliative care in health laws, national health programs and national health budgets;

2. Ensure that insurance plans integrate palliative care as a component of programs;

3. Ensure access to essential medicines and technologies for pain relief and palliative care, including pediatric formulations;

4. Ensure that palliative care is part of all health services (from community health-based programs to hospitals), that everyone is assessed, and that all staff can provide basic palliative care with specialist teams available for referral and consultation;

5. Ensure access to adequate palliative care for vulnerable groups, including children and older persons;
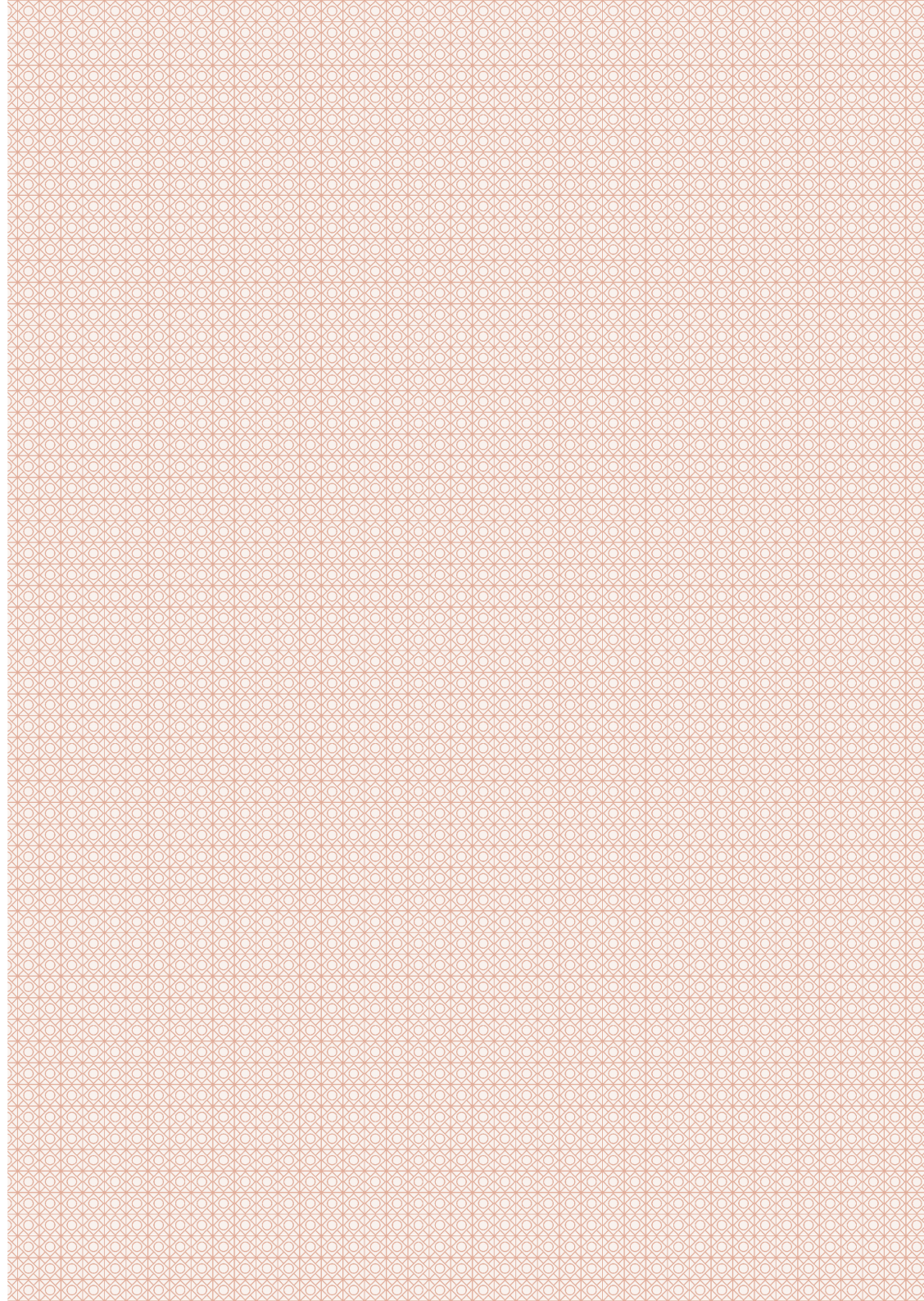
6. Engage with universities, academia and teaching hospitals to include palliative care research as well as palliative care training as an integral component of ongoing education, including basic, intermediate, specialist, and continuing education.

Full definition including also glossary terms and the text in other languages can be accessed here:
https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/