Palliative Care Palliative Chronic Conditions Chronic Disease
Advanced chronic care Integrated Care Comprehensive Compass
Empathy Suffering Frailty Pain Family Teamwork Services Prog
Public Health Community Emotional Spiritual Social Ethics
Research Education Quality People Care Families Illness
Communication Support Resource availability Interdisciplina
Patients Symptoms Management End-of-life Respect Sympa
Accessibility Health Cove
Advance Care Planning
Patient Per
Integrated Care Suppo
Interdisciplinary Pol
Decision-making Autono

Building Integrated Palliative Care Programs and Services

**Edited by Xavier Gómez-Batiste
& Stephen Connor**

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ALCP	Latin American Palliative Care Association
APCA	African Palliative Care Association
Dpment Salut	Catalan Department of Health
ICO	Catalan Institute of Oncology
CACP	Chair of Palliative Care. University of Vic
CSI	Cicley Saunders International Institute
EAPC	European Association of Palliative Care
HRW	Human Rights Watch
IAHPC	International Association for Hospice and Palliative Care (IAHPC)
ICPCN	International Children's Palliative Care Network
IPPCN	International Primary Palliative Care Network
King's College	King's College London (UK). WHO Collaborating Centre for Palliative Care, Policy and Rehabilitation
FBLC	"la Caixa" Banking Foundation (Spain)
PPAC	Chronic Care Program. Catalan Department of Health
UE	University of Edinburgh
UVIC	University of Vic - Central University of Catalonia
WHOCC-ICO	WHO Collaborating Centre Public Health Palliative Care Programmes. Catalan Institute of Oncology (Spain)
WHPCA	Worldwide Hospice Palliative Care Alliance

I am delighted to contribute to this initiative of the Technical Advisory Group of the WHO initiative for Palliative Care, which is a comprehensive approach and a practical tool for designing, implementing, and evaluating Palliative Care Programs and Services with a Public Health perspective. We are all facing the challenge of an enormous increase of prevalence, mortality, and complexity of people with advanced chronic conditions. This causes suffering in patients and their families, and impact in the organization and costs of the Health Care System.

Universal access to high quality Palliative Care is one of the main elements of human rights, and should be part of the mainstream of any Health Care System, available to all types of patients with advanced chronic conditions and limited life prognosis, timely in their evolution based in needs, responding to all dimensions, provided by all professionals, and in all settings of care.

In Catalonia, Palliative Care is considered as one of the best elements of our Health Care System since 1990, as a WHO Demonstration Project. A comprehensive network of palliative care services has been designed and developed since, which has achieved high coverage, effectiveness, efficiency, and high satisfaction of patients and families. Moreover, the experience has been regularly evaluated and internationally recognized as a model of Public Health Palliative Care Program.

The palliative approach has been recently expanded to people with all chronic conditions in all settings within the Chronic Care Program at the Department of Health, with emphasis in the community. The Program has been improved by the model of psychosocial and spiritual care through "la Caixa" Foundation Program, and the community and society are involved in the Program of compassive communities that started in the city of Vic last year.

We are proud of this experience and strongly committed to share this approach with other governments and institutions around the world to contribute to relieve suffering of people in need in all countries, with respect for their culture and values, and inserted in their Health Care Systems.

The WHO Collaborating Centre for Palliative Care Programmes at the Catalan Institute of Oncology and the Chair of Palliative Care at the University of Vic are good examples and ambassadors of our experience.

This Manual, *Building Integrated Palliative Care Programs and Services* is a good example of this commitment of improving the dignity of care at the end of life.

The Honorable Mr. Antoni Comín i Oliveres
Minister of Health
Government of Catalonia

In 2014 all members of the World Health Assembly (WHA) approved a resolution on "strengthening of palliative care as a component of comprehensive care throughout the life course." Uganda was one of the endorsers of this resolution and has made unique contributions to the global palliative care movement. This book is one of the important outcomes of this resolution in that it is designed specifically to assist governments and providers to build and strengthen palliative care in individual countries.

Building integrated palliative care uses the WHO public health model to ensure that policies are in place, essential medicines are available, and that comprehensive education on palliative care is delivered. All this is necessary so that palliative care services can be designed and embedded into existing health care systems and that specialist services are available for the sickest patients in our health care systems.

Readers of this manual will find specific guidance on how to assess need for palliative care, how to design and evaluate services in all settings, how to establish education and training programs, how to improve access to essential medicines for palliative care, how to design systems for financing palliative care, and what legislation, regulations, and policies are needed. Also included is a section on clinical palliative care that explains how to assess and identify palliative care needs, how to manage pain and other common symptoms, how to provide psychosocial and spiritual care, and how to address common clinical ethical issues.

This manual was designed and developed by members of WHO's Ad Hoc Technical Advisory Panel on Palliative Care that served as a resource to WHO in implementation of the palliative care resolution. Ministries of Health and those interested in palliative care development in their countries will find this an invaluable resource to ensure that all their citizens receive the services and dignity they need when faced with an advanced chronic and life limiting condition.

The Honorable Dr Jane Ruth Aceng
Minister of Health
Republic of Uganda

The philosophy and practice of palliative care has evolved much over the last few decades. Increasing expectancy of life and global transition of diseases have made palliative care more relevant today than ever.

World Health Assembly in 2014 had resolved to make 'mainstreaming' of palliative care a priority for health care systems. Kerala is proud to have initiated this process much before the World Health Organization initiative. The Government of Kerala declared a Palliative Care policy in 2008 incorporating community based palliative care in primary health care and has been actively involved in implementing it since then. As a result of these efforts, Kerala, with a population 3% of the national population accounts for more than 90% palliative home care services in the country. We have also been able to move towards a holistic approach with massive involvement of local community in the care of the incurably ill, chronically bedridden, elderly and dying people in the region. I am also happy to note that the two World Health Organization Collaborating Centers in the area of Palliative Care in low and middle income countries out of the of the six existing globally, are in Kerala. Kerala could show what a public health approach in palliative care can achieve.

This manual developed by an international team of experts offering guidance on development and establishment of all aspects of palliative care services can serve as a useful resource to policy makers all over the world. The additional section on clinical palliative care makes the book useful to clinical practitioners also. I am sure that the knowledge and information compiled will be widely disseminated and used for the benefit of millions of people all over the world.

Smt. K. K. Shailaja Teacher
Minister for Health and Social Justice
Government of Kerala, India

INTRODUCTION

THE TECHNICAL ADVISORY GROUP (TAG) SUPPORTING THE WHO PALLIATIVE CARE INITIATIVE

Xavier Gómez-Batiste, Stephen Connor, Emanuel Luyirika, Suresh Kumar, Eric Krakauer, Sara Ela and Kathy Foley on Behalf of the TAG

SUMMARY

An ad hoc technical advisory group (TAG) for palliative care was formed and is working with the WHO staff on plans for implementation with the mission to provide advice to WHO Secretariat for the implementation of the resolution on *Strengthening of palliative care as a component of comprehensive care throughout the life course*, adopted by the World Health Assembly, in May 2014 (WHA 67.19), the functions of identification of priority issues to be addressed for the implementation of the WHA Resolution, the definition of strategic directions and work plan including activities to be implemented in the main areas defined by the WHA Resolution, such as technical guidelines, monitoring and evaluation, capacity strengthening, global partnerships, the tool development including indicators for the monitoring and evaluation of quality palliative care programs and training tools and to knowledge sharing and analysis of palliative care models. The expected outputs include policy brief on strengthening of health palliative care services, throughout the life course and across disease groups, technical guidelines and monitoring tools for the strengthening and evaluation of palliative care programs, online training tools and educational programs for health care providers, including home care providers, dissemination of updated information on models of palliative care and identification of research priority issues. The TAG met in Barcelona in December 2015 to debate and define the conceptual framework and to elaborate the proposals.

AIMS OF THIS CHAPTER

To describe the background, principles, aims, and strategic plans proposed by the Technical Advisory Group (TAG) of the WHO initiative for Palliative Care between November 2014 and April 2015.

BACKGROUND

PALLIATIVE CARE AT THE WHO

The WHO has developed several initiatives on Palliative Care in different HQ clusters, regions, and country offices. The World Health Organization has a long history of contributions to the development of palliative care globally; initially the focal point for palliative care at WHO was the staff member responsible for cancer in the non-communicable disease cluster. Initially this was Dr Jan Stjernsward. The first publication from WHO on this topic was a booklet called *Cancer Pain Relief* (1986)[1]. This publication laid out the basic principles of palliative pain management that had been developed in the hospice movement and because it was a WHO publication had great influence in changing the way cancer pain management was taught and practiced. The book also introduced the WHO three-step analgesic ladders as a model for guiding prescribing practices based on the level of pain the patient was experiencing.

This publication was updated and released in 1996 under the title *Cancer Pain Relief*: 2*nd Edition with a Guide to Opioid Availability*[2]. Before this the WHO published National cancer control programs: policies and managerial guidelines, a handbook[3] to help give direction to the creation of national cancer control plans that should include a palliative care component.

WHO Pain Ladder

The WHO pain ladder was an important tool to help improve the quality of cancer care and pain relief. The ladder divides pain into three levels mild, moderate, and severe. Mild pain is treated with non-opioid analgesics with or without adjuvants. Moderate pain is treated with an opioid for mild to moderate pain with or without non-opioid analgesic and/or an adjuvant. There is ongoing discussion about whether to include a strong opioid like morphine at lower doses for those at step 2. For severe pain strong opioids were recommended, especially morphine with or without non-opioid analgesic and/or an adjuvant.

The WHO pain ladder has been a very effective teaching tool in low and middle-income countries where physicians are taught that opioids are dangerous and should only be used as a last resort.

1. World Health Organization. Cancer Pain Relief. Geneva: World Health Organization, 1986.
2. World Health Organization. Cancer Pain Relief. Second edition. With a guide to opioid availability. Geneva: World Health Organization, 1986.
3. Miller A, Stjernsward J. World Health Organization. National Cancer Control Programs: Policies And Managerial Guidelines. Geneva: World Health Organization, 1992.

WHO Definitions

The WHO published its first definition of palliative care in 1990 as part of a report of a technical expert committee on cancer pain relief and palliative care. Twelve years later in 2002 the definition was revised to reflect the changing nature of palliative care. Rather than focusing on cancer the definition broadened to all life threatening illnesses and rather than being limited to those unresponsive to curative treatment it called for palliative care to be provided concurrent with curative treatments.

While this redefinition was an important improvement there are still some ambiguities in the current definition that will be addressed in the future. There is a need to state that there should be no time or prognostic limitation on palliative care; that palliative care is needed for chronic as well as life threatening/limiting illness; that palliative care is needed in all levels of the health care system from primary to specialized care, and; that palliative care should be delivered in all settings.

The WHO Proposals for Person-centred Care, Universal Health Coverage, and Quality and Safety

Palliative care is one of the leading examples of person or people centred care and examples are included as such by WHO. The continuum of universal health coverage (UHC) includes prevention-promotion-treatment-rehabilitation-palliation. As such palliative care is recognized as an essential component of UHC and needs to be included in any national UHC scheme. Quality measurement of health care must include palliative care and include elements of safety measurement.

Other WHO HQ Departments

Other WHO HQ Departments (TB, HIV/AIDS, Ageing, and Essential Medicines) have introduced palliative care as an element of their programs.

- The WHO Global TB Program and Stop TB Partnership have recognized palliative care as an important component of the global response to TB, especially for drug-resistant TB. Clinical palliative care guidelines for TB and DR-TB have been drafted.
- UNAIDS and the WHO HIV department have included palliative care throughout their technical assistance publications for member states.
- The WHO Global Strategy and Action Plan on Ageing and Health[4] includes a section on palliative care.

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4. Available at: http://www.who.int/ageing/global-strategy/en/ Last accessed November 2016.

- The WHA resolution on strengthening palliative care as a component of integrated care throughout the life course includes multiple references to the need to improve access to essential controlled medicines, an important focus for the Department of Essential Medicines and Health Products at WHO.

Palliative care WHO Collaborating Centres

There are currently 5 active WHO Collaborating Centres specific to Palliative Care (info available at: http://apps.who.int/whocc/).

Their names are WHO Collaborating Centre for:

- Palliative Care. Churchill Hospital / Sobell House. Oxford, UK
- Palliative Care Public Health Programs. Catalan Institute of Oncology/ University of Vic. Barcelona, SPAIN
- Palliative care, policy and rehabilitation at King's College London (London, UK)
- Pain Policy and Palliative Care University of Wisconsin School of Medicine and Public Health. Madison, USA
- Training and Policy on Access to Pain Relief Trivandrum Institute of Palliative Sciences (TIPS). Trivandrum, INDIA

The WHO Demonstration Projects on Palliative Care

The concept and the practice of WHO Demonstration projects for palliative care were proposed by Jan Stjernsward in 1990 to promote a systematic approach in the implementation of National or regional Policies for Palliative Care. Initial proposals came from Catalonia (Spain) and Kerala (India), and some other programs were proposed (Alberta in Canada, Uganda, Jordan, and Mongolia, among others).

The WHO Euro Proposals

The WHO euro region has developed several initiatives to promote palliative care. Three technical reports have been elaborated (*Palliative care, the solid facts*, *Better Palliative care for Older people,* and *Better Palliative care for Older people: better practices*) in cooperation with the WHO Collaborating Centre for Policy and Rehabilitation at King's Fund and the support of various organizations. Additionally, a meeting of … countries "Building capacity for palliative care in Europe" has been organized jointly with the WHOCC Barcelona involving policymakers from the Ministries of Health.

The WHPCA/WHO Global Atlas of Palliative Care at the End of Life[5]

The Global Atlas is the first attempt to paint a comprehensive picture of palliative care worldwide.

Conceived as an advocacy tool the Atlas addresses the following questions:

- What is palliative care?
- Why is palliative care a human rights issue?
- What are the main diseases requiring palliative care?
- How many people need palliative care annually?
- What are the barriers to accessing palliative care?
- Where is palliative care currently available?
- What are some of the models for delivering palliative care worldwide?
- What resources are devoted to palliative care?
- What is the way forward for palliative care?

The definition of palliative care has been previously discussed, as has the argument for palliative care as a human right. WHO publications have addressed the need for palliative care for cancer and for HIV/AIDS but the Atlas for the first time broadens the diagnostic groups acknowledged by WHO that need palliative care to include cardiovascular disease, chronic obstructive pulmonary disease, liver and kidney failure, dementias, motor neuron diseases, diabetes mellitus, rheumatoid arthritis, drug resistant tuberculosis, and a host of paediatric diagnoses including congenital anomalies, neonatal, and many other conditions.

The number of people needing palliative care is difficult to determine. Several factors need to be considered including severity of illness, symptom burden, and goals for care. Taking a conservative approach that uses mortality data and pain as a surrogate for symptom burden the WHO estimates, in the *Atlas*, that at minimum over 20 million patients each year would benefit from palliative care at the end of life, including 19 million adults and over 1 million children for the diagnoses noted above. When considering the need for palliative care prior to the end of life the number doubles to 40 million per year. The barriers to palliative care delivery are discussed in the context of the WHO public health model for palliative care delivery including policy, medication availability, education, and implementation.

In order to measure where palliative care is currently available a mapping project was conducted that categorized countries into six levels of palliative care development. The levels ranged from 1 = no palliative care development or

5. Connor S, Sepulveda C. (eds.). Global Atlas of Palliative Care at the End-of-Life. Geneva/London: World Health Organization / Worldwide Palliative Care Alliance. 2014.

champions, 2= interest in developing palliative care but no service delivery, 3a= some palliative care delivery but isolated, 3b= more widespread provision of palliative care but not integrated into existing system, 4a= beginning integration into the formal health care system, and 4b= integration into the health care system. The specific criteria for these six levels can be found in Appendix 2 of the *Atlas*. Only 20 (8.6%) countries were at level 4b at the time of this analysis.

Seven case studies are given showing how palliative care has developed models of operation in different resource settings. Integration into the community and incorporation into existing health care facilities is key to global palliative care development and sustainability. Examples are given from India, Tanzania, Vietnam, UK, Argentina, Romania, and the USA.

Resourcing palliative care globally continues to be a limiting factor. While community support has compensated to some degree for lack of government resources it is essential that the mainstream health care system include palliative care as part of the continuum of care and budget and reallocate for palliative care services, particularly in the home setting. The *Atlas* includes a short summary of the literature on the cost impact of palliative care, which generally demonstrates that palliative care reduces unnecessary use of health care resources. Other resources include research centres, journals, graduate education programs, literature, and philanthropic support for palliative care.

Finally, the way forward is discussed. The *Atlas* is essentially an advocacy document that begins a global baseline on palliative care that can be measured over time. There is discussion on reviewing and improving the evidence base, an analysis of available guidance is needed, a call for scale up, leadership and accountability is needed, and specific recommendations for technical agencies and national governments is given. All of these recommendations have been included in the recent World Health Assembly resolution on "Strengthening Palliative Care as a Component of Comprehensive Care throughout the Life Course."[6]

The World Health Assembly Palliative Care Resolution

For the first time in its history the World Health Assembly (WHO's governing body) passed a stand-alone resolution on palliative care at its 67th meeting May 24th of 2014. The resolution titled "Strengthening of palliative care as a component of comprehensive care throughout the life course" was informed by the findings of the Atlas and addressed all the most important advocacy goals of the global palliative care community. The recommendations were divided into those for member states and those directed towards the WHO itself.

6. World Health Assembly Resolution WHA 67.19. Strengthening palliative care as a component of comprehensive care throughout the life course. Available at: http://apps.who.int/medicinedocs/en/d/Js21454en/

Those for member states included:

- Develop policies to integrate palliative care (PC) into health systems
- Ensure adequate domestic funding for PC
- Integrate PC training into health professional curricula at all levels
- Assess domestic palliative care needs
- Review and revise drug control legislation and add PC meds to all essential medicine lists

Those calling for action at the WHO included:

- Ensure PC is integrated into health system plans
- Update or develop clinical guidelines on palliation
- Reviewing and improving drug legislation to remove barriers
- Work with INCB to support accurate estimates of the need for opioids
- Collaborate with UNICEF to promote paediatric palliative care
- Monitor the global situation of palliative care
- Encourage research on palliative care models
- Report back in 2016 on implementation of the resolution

This resolution becomes a major turning point for palliative care globally if it is implemented effectively. The WHO has moved forward in hiring a full time technical officer for palliative care in the Non-Communicable Disease and Mental Health cluster and in the Health Systems Innovation cluster appointed a part time staff member for palliative care along with a temporary Medical Officer for Palliative Care on a six-month basis to initiate planning for palliative care resolution implementation and now is hiring a full time medical officer for palliative care. A palliative care expert from the Worldwide Hospice Palliative Care Alliance has also been made available to support staff through its NGO in official relations plan with the WHO.

Palliative Care for Children

Children's palliative care (CPC) is a distinct area of palliative care specialization. In contrast to adult palliative care there are a number of important differences that need to be noted. Children are not little adults. The WHO definition of palliative care includes a separate section that emphasizes the active total care of children who may have are a wide variety of childhood conditions causing death before adulthood, many of which are rare. Many of these illnesses are familiar and may affect more than one child in the family.

The timespan of a child's illness is often different from an adult's and may extend over many years. Children continue to develop physically, emotionally, and cognitively, which affects their medical and social needs and their understanding of disease and death. Children need to be cared for in a child-centred environment. Families are the prime carers and home should be the centre of care. Children are cared for by a wide range of service providers across the health and voluntary sector, which requires effective coordination. Children have an entitlement to education, which adds to the complexity of care provision. Professionals with expertise in paediatrics often lack knowledge of palliative care and palliative care professionals often lack knowledge in paediatrics. Both need cross-training to ensure optimal care for children.

Essential Medicine Availability Initiatives

The WHO Essential Medicines and Health Products department has been actively working to improve access to essential palliative medicines. In 2013 the WHO list of essential medicines for the first time included a section on medicines for palliative care[7]. The problem of access to essential medicines for palliative care is complex and has been resistant to change. The INCB reports that 75% or 5.5 billion people lack adequate access to opioids for pain relief and 92% of morphine is used by 17% of the world's population.

A number of initiatives have been implemented to attempt to address this problem. The WHO Department of Essential Medicines and Health Products has produced a number of important publications aimed at addressing the problem. In 2011 *Ensuring Balance in National Policies on Controlled Substances* was published in an effort to give guidance to countries on how to maintain controls on illicit use without interfering with medical and scientific use[8]. In addition to the publication of a palliative care section in the *Model List of Essential Medicines*, guidelines for the treatment of persisting pain in children with medical illnesses were recently published.

Other significant non-WHO efforts to address the problem of lack of access to essential palliative care medicines include:

- The ATOME (Access to Opioid Medication in Europe) http://www.atome-project.eu/The ATOME project aims to improve access to opioids across Europe. A consortium of academic institutions and public health organizations is working to help governments, particularly in Eastern

7. World Health Organization. WHO Model Lists of Essential Medicines. Accessed 03/10/15 at: http://www.who.int/medicines/publications/essentialmedicines/en/
8. World Health Organization. WHO Policy Guidelines for Controlled Substances. Available at http://www.who.int/medicines/areas/quality_safety/guide_nocp_sanend/en/

Europe, identify and remove barriers that prevent people from accessing medicines that could improve end of life care, alleviate debilitating pain and treat heroin dependence.

- Global Access to Pain Relief Initiative (GAPRI) http://www.uicc.org/programmes/gapri The Global Access to Pain Relief Initiative (GAPRI) is a program of the Union for International Cancer Control (UICC) to address target 8 of the World Cancer Declaration to make essential pain medicines universally available by 2020.
- IAHPC List of Essential Medicines for Palliative Care http://hospicecare.com/resources/palliative-care-essentials/iahpc-essential-medicines-for-palliative-care/ In response to a request from the World Health Organization (WHO), the International Association for Hospice and Palliative Care (IAHPC) developed a List of Essential Medicines for Palliative Care based on the consensus of palliative care workers from around the world.

The Public Health Approach and its Implementation in Palliative Care Public Health National or Regional Programs (PCPHPs)

The Public Health perspective for palliative care has been developed and practiced in national or regional experiences. It comprises four main dimensions: national Policy, essential medicines' availability, education, and implementation (of resources, structures, and services). The reasons for developing PCPs are based on the increasing needs and the presence of persons with advanced chronic conditions in all settings of health care systems. The principles and values of PCPs are based on the consideration of quality palliative and End of Life Care (EOLC) as a Human Right, and include:

- Support to persons suffering in vulnerable conditions, with respect for their values and preferences
- Universal coverage, equity, access and quality to every patient in need of it
- Population-based, community oriented, integrated into the health care system and into the culture
- Model of care: based on patients and families' needs and demands, respectful, patient and family-centred
- Model of organisation: based on competent interdisciplinary teams, with clinical ethics, integrated care, case management, and advance care planning
- Quality: effectiveness, efficiency, satisfaction, continuity, sustainability
- Evidence-based, systematic evaluation of results, accountability
- Social interaction and involvement
- Innovation in the organization of the Health Care System

The WHO Initiative for Palliative Care
Aims:

In the context of WHO priority for Universal Health Coverage, the Service Delivery and Safety (SDS) Department is working to strengthen health service delivery systems that are safe, high quality, people-centred and integrated.

The WHO principles related to palliative care are:
- Strengthening of integrated palliative care services in the continuum of care in countries, with an emphasis universal coverage schemes and person-centred-ness
- Strengthening of global partnerships for sustainable palliative care programs
- Key aspects of person-centred, safe and respectful care for the elderly

Proposed mission, vision, principles and values of a Palliative Care Initiative:
- Mission
  To insert Palliative Care in WHO and State Members Health Care agenda
- Vision
  WHO and Member States have integrated Palliative care and essential drugs availability in their National Health Care systems with universal coverage, equity, access and quality
- Principles
  Patient-centred, respectful, and comprehensive care; early, for persons with all conditions, in all settings of care; based in suffering, needs, and complexity; considered a Human right; integrated care across all settings; public health; population-based; universal coverage; community-oriented; effective, efficient, and sustainable and evaluable
- Values
  Active, competent and compassionate care for persons and their families with suffering by complex and/or advanced progressive chronic conditions with a limited life prognosis or at the end of life
  Multidimensional approach, including physical, emotional, social, ethical, and spiritual components of needs
- Concepts
  Multidimensional care, Patient centred, respectful,
  Integrated care across settings
  Early, All settings, All conditions

THE TECHNICAL ADVISORY GROUP FOR PALLIATIVE CARE (TAG)

In agreement with the different Headquarters (HQ) departments involved in the strengthening of PC, it was decided to establish an Ad-hoc Technical Advisory Group (TAG) constituted by experts from the different WHO regions and representatives of other international organizations, government agencies and ministries, professional medical associations, academic and research institutions, as well as staff of various WHO departments and regional offices involved in the field of PC (see full list of members in annex 1).

Expected Outcomes and Main Issues to Be Addressed by the TAG

They were defined to establish priorities, objectives, and actions at short and mid-term:

- Involvement of Ministries of Health and all WHO levels of organization
  – Inserting Palliative Care in all agendas
  – Involving and Empowering WHO structures and policymakers
- Policies for low-middle income countries and countries with no implementation
  – Specially with no prior implementation of palliative care policies
  – Essential drugs accessibility in all settings of care
  – Institutional consensus with agencies
  – Training of WHO offices and Policymakers
- Model of care and ethics
  – Person-centred, respectful care
  – Inserting the spiritual component of care
  – Adapting the ethical decision-making to an early palliative care intervention
- Palliative care approach for persons with complex and advanced progressive chronic conditions
  – Interaction between palliative and long-term/chronic care
  – Integrated models of organization
  – Palliative care in long-term settings
- Primary and community perspective
  – Developing early identification and care
  – Empowering primary care resources
- Leadership empowerment
  – Palliative care leaders adopting a population and public health perspective
  – Policymakers adopting palliative care as a priority

The Consensus Meeting

The first meeting of this group was held on 10-11 December 2014 in Barcelona (Spain). The objectives of the meeting included:

- To agree on the principles and aims of the WHO initiative for the strengthening of PC as a component of comprehensive care throughout the life course
- To adopt the terms of reference of the TAG, define strategic directions and elaborate an action plan for the implementation of the WHA resolution
- To establish working groups which will provide advice on specific issues to be addressed

The methodology was structured around working sessions in smaller groups and plenary presentations, debates and report of group conclusions.

Prior to the meeting, members were asked to answer a survey on the strategic components and action plan for the implementation of PC programs. Contributors were asked to comment on a list of 20 dimensions, prioritizing on those related to their area of expertise. The list of dimensions included:

1. Foundation measures
2. Population targets
3. Population needs assessment
4. Models of organization
5. Leadership and consensus with stakeholders
6. Capacity building
7. Model of care and intervention
8. Clinical care
9. Essential medicines availability
10. Policy
11. Legislation
12. Education and training
13. Research
14. Ethical aspects
15. Financing systems
16. Fundraising & advocacy
17. Action plan development
18. Deliverables that will accompany the initiative
19. Program of results evaluation
20. Dissemination

For each dimension or topic, the experts were requested to:

- State the current state of art, the existing knowledge and evidence
- Identify the most relevant barriers, weaknesses or challenges to overcome or improve
- Suggest some feasible actions for quality improvement at short-term

Participants were asked to review and comment each statement cited as conceptual transition. The most cited concepts were that palliative care is activated by suffering, with a flexible shared model of intervention (table 1).

Table 1. Proposals of conceptual transitions: Comments of the TAG

	FROM	Change TO / AND	Comments TAG Survey: Combine advanced and terminal
Concepts	Terminal disease	Advanced progressive chronic disease	The degree of suffering is the criteria for palliative care
	Death weeks or months	Limited life prognosis	Based on needs
	Cancer	All chronic progressive diseases and conditions	Limited life prognosis much easier understanding by general population
	Disease	Condition (multi-pathology, frailty, dependency, .)	Chronic diseases and conditions
	Mortality	Prevalence	Prevalence, burden, and mortality included
Model of care and organization	Dichotomy curative - palliative	Synchronic, shared, combined care	Shared and combined care
	Specific OR palliative treatment	Specific AND palliative treatment needed	PC intervention has to be always flexible
	Prognosis as criteria intervention	Complexity as criteria	Suffering as a criteria of intervention
	Late identification in specialist services	Early identification in all settings	Both specialized and all settings have to be combined
	Rigid one-directional intervention	Flexible intervention	Patient involvement
	Passive role of patients	Autonomy / Advanced care planning	Prevention and treatment of crisis
	Reactive to crisis	Preventive of crisis / Case management	Integrated care as a crucial issue
	Fragmented care	Integrated care	
Perspective for planning	Palliative care services	+ Palliative care approach everywhere	Palliative approach in all settings - with specialist palliative care services for complex cases
	Specialist services	+ Actions in all settings	
	Institutional approach	+ Community approach	Inclusive of all levels of care with emphasis on community approach
	Services' approach	+ Population & District	
	Individual service	+ District approach	A global population vision is needed

Additionally, TAG Members were asked to give their opinion on a list of terms and propose new taxonomic approaches. The most cited proposals were Palliative Care, Palliative Approach, and Advanced chronic conditions in some combination (figure 1). A possible agreed definition might be "Comprehensive person-centred and integrated palliative approach and care for people with advanced and terminal chronic conditions".

Main Results from the Survey

The survey on the strategic components and action plan for the implementation of PC programmes meant at helping the TAG members in their mission of providing advice to the WHO in the implementation of the WHA 67/19 Resolution. The responses at the survey provided relevant inputs regarding the main components of PC and brought preliminary proposals on the actions to be implemented by the WHO Headquarters. The main conclusions are listed as follows:

Figure 1. Proposals of conceptual definitions: Responses of the TAG
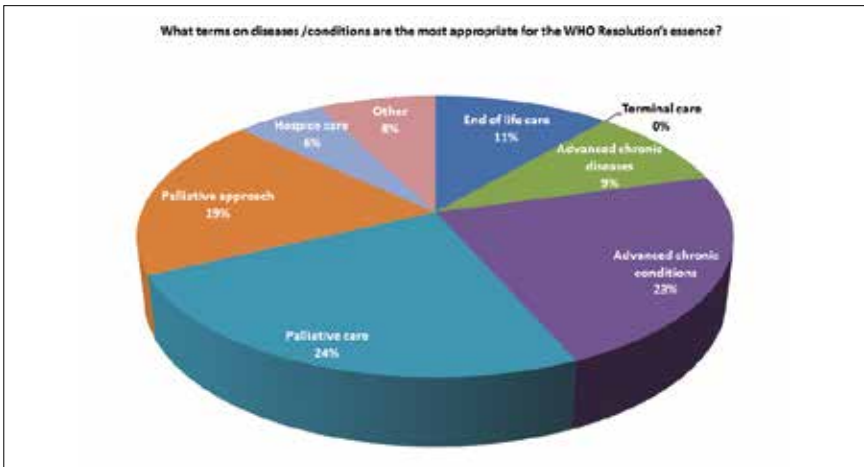
Foundation Measures

In view of the analysis of their comments, there was broad consensus with regards to the availability of established models and national strategies for PC – though the need of assessment strategies is also largely recognized – and to the progress made in regards to development of evidence-based clinical guidelines and the existence of consistent programs for teaching PC. The feasibility of measuring the state of the art in PC globally is considered. The need for including PC within national plans in order to reach universal coverage is

identified, which coincides with a current increasing recognition of PC and the importance of quality at the end of life in professional, social and media contexts.

Lack or inadequate use of resources, frequent and widespread misinformation on what PC is and what its goals are, capacity building, availability of opioids and political commitment are identified as barriers/challenges for the development of PC. The need for establishing solid approaches regarding research and assessment strategies is emphasized.

With the main goal of generating evidence and dissemination strategies, the revision of current strategies and the establishment of common evaluation and assessment policies are identified as key actions, altogether with establishing measures to strengthen policy plans and governments' commitment for the development of PC programs.

Models of Organization

Comments insist on the availability and variability of models for PC provision. However, the identification of best practices is not clearly established and the need for integration of PC into health care systems – primary and secondary level – outpacing the specialization model and placing the specialists providers at the third level of care is clearly identified.

Again, lack of resources is identified as a barrier/challenge, as well as the non-integration of PC into service sectors and care services and the difficulties around the expansion of PC provision to diseases other than cancer, in concordance with the description of the identified situation.

Proposals on short-term actions emphasize the need for adopting measures to impulse the identification of models of success and for the integration of PC into health and social care systems.

Capacity Building

The importance of increasing the skills of health care professionals and the significance of leadership are highlighted. In this sense, the current scenario presents major gaps and difficulties, mainly related to the lack of training and competence of health care providers.

For a third time, lack of resources as well as lack of political commitment and, for the moment, low visibility and/or recognition of PC are identified as barriers/challenges.

Reviewing and adapting, when necessary, current existing and successful toolkits for capacity building purposes, adopting solid assessment and evaluation plans and investment in leadership are proposed as the main short-term actions.

Essential Medicines Availability

The existence of tools and organizations devoted to update information on opioid availability and legislation globally is underlined. Nevertheless, difficulties for opioid availability and prescription describe the current picture for essential medicines accessibility and availability.

Legislation barriers, medicines costs and education and training gaps with regards to PC essential medicines prescription are the main barriers/challenges identified.

With the aim of developing further stronger systems globally, adopting measures to ensure accessibility to essential medicines, including policy and regulations procedures, as well as implementing educational strategies are suggested as main short-term actions to be implemented.

Policy

The existence of national strategies for PC in many countries and the inclusion of PC within health care systems are recognized once more. The accent is put on the need for implementing global policy measures, considering the inclusion of PC in chronicity/non-cancer programs.

The long processes for policy changes and development and the difficulties involved in the execution of PC plans - lack of political commitment and inadequate dissemination of PC goals, lack of PC leaders who can influence on policy implementation and insufficient resources- are acknowledged as main barriers/challenges in regards to policy.

Identification of current models of success and its adaption or replication in other regions, as well as creating a global model for PC policy and strategic plan are suggested as short-term actions. The inclusion of PC in national policies, achieving political and institutional commitment so as to develop models of success, is also proposed.

Conclusions of the Meeting

There was broad consensus among the meeting participants that, due to the short time frame and wealth of existing resources, creating and studying new models of PC is not necessary or realistic. The discussions brought into sharp focus the necessity to review and update already existing models, documents and ongoing projects.

The participants concluded the WHA Resolution has become a great opportunity to strengthen the task already done and to promote PC. The group noted the importance of raising awareness of the process among the global health, medical, nursing, public health, and scientific communities. This is why they made suggestions to the WHO on how to disseminate the resolution and

spread it out in the already ongoing activities (seminars, congresses, conferences, etc.) as a mobilization measure for policy purposes. The outcomes of the advisory board should also be published in the WHO bulletin or other scientific journals.

The strategic objectives proposed by the TAG were:

- The definition of strategic directions for palliative care across disease groups (non-communicable diseases and infectious diseases)
- The development of a work plan, including activities to be implemented in the main areas defined by WHA resolution on Palliative Care
- The development of indicators, guidance documents, and training tools for the monitoring and improvement of quality palliative care
- The development of national regulations and policies on palliation

The proposed operational objectives to start 2015-2016 included:

1. Organizing Palliative care at WHO HQ and regions with all clusters
2. Information sent & training offered to Focal points, WHO CRs, Ministries
3. Consensus WHO – Drug control agencies
4. Consensus main stakeholders: professional leaders and organizations, NGOs, partners
5. Build and disseminate the knowledge for capacity building: guidelines, manuals and tools
6. Build and implement the methods for training
7. Start implementation in country' support initiatives and demonstration projects
8. Define evaluation plan: methodology and indicators (globally and at a national level)
9. Funding, Marketing, and Dissemination of the WHO initiative

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SECTION 1
PRINCIPLES, DEFINITIONS AND CONCEPTS

1
PRINCIPLES, DEFINITIONS AND CONCEPTS

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KEY POINTS

- Palliative care is the *comprehensive* and *integrated care* of *persons with advanced chronic conditions and limited life prognosis and their families.*
- The target patients for a palliative care approach can be defined in terms of a cluster of symptoms or factors, including the presence of a chronic advanced disease or condition, a limited life prognosis, multidimensional needs, and the need for a comprehensive and integrated care.
- Palliative care is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with serious chronic, complex, or life-limiting health problems.
- It is a person-centered accompanying of patients and their families throughout the illness course, including at the end of life that optimizes quality of life, promotes human development and well-being, and maximizes dignity.
- Palliative care is a basic human right and an essential component of comprehensive and integrated care.
- It should be practiced by health and social care providers of many kinds as well as by palliative care specialists and should be provided in any health care setting, including patients' homes.

AIMS OF THIS CHAPTER

This section aims to define the concepts, definitions, principles, and models of palliative care as agreed by the editors.

Box 1. Summary of key concepts

Targets and time
■ Palliative care is needed by persons suffering from all types of serious complex / chronic or progressive conditions in all settings
■ It is applicable early and timely in the course of serious chronic, complex or life-limiting health conditions/illness in conjunction with disease-modifying or potentially curative therapies, for people living with long-term sequelae of diseases or treatments, and to neonates and children with serious congenital or acquired health problems

Model of care
■ Palliative care starts with a multidimensional assessment of physical, emotional, social, spiritual needs, values and preferences of patients and their families followed by a systematic approach to care
■ It focuses on the essential needs of patients and their families such as spirituality, dignity, autonomy, hope, growth and well-being, and key relationships
■ It uses ethical principles and advance care planning to identify patients' priorities and goals, in the case of children, the developmental stage, for care at the end of life, and shared decision-making along the process
■ It never hastens death intentionally
■ It provides family care and personalized bereavement support for adults and children as needed
■ It should be integrated into standard responses to humanitarian disasters

Model of organization
■ Palliative care should be integrated into every setting of the health care system and accessible by anyone in need
■ It should be a standard part of training for medical and nursing students, primary care providers, and health care workers
■ It should be practiced by doctors, nurses, social workers, spiritual supporters, community health workers, therapists, volunteers, and other allied health professionals and carergivers, with adequate training
■ It should use a three-level structure: palliative care approach in all settings, general basic palliative care and specialist palliative care with adequate skills to each level
■ It is best practised by a competent interdisciplinary team
■ It uses care management principles to prevent crises and assure integration and continuity of care along the different settings
■ It encourages active involvement by family members, communities and community members;
■ It has proven its effectiveness in addressing patients and families' needs, and efficiency in the provision of care
■ Much avoidable pain and suffering continues to exist at the end of life. In both resource-rich and resource-poor countries, fewer than 14% of people currently access any end-of-life palliative care. The only way that palliative or end-of-life care can reach the vast majority of people who need it any country is by integrating its availability in all settings for care: hospitals, care homes, and the community

SHORT HISTORY OF MODERN PALLIATIVE CARE

Modern palliative care was initiated at St Christopher's hospice in 1967[1] by Cicely Saunders, who created a conceptual frame to identify the multidimensional needs of patients and their families and the concept of treating "total pain", defined as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles. A new model of care was proposed to respond to those multidimensional needs with symptom control, emotional support, and communication as the main elements, the patient and family as the unit of care, and promoting quality of life as the main purpose of care. To provide this approach, the practice of a competent interdisciplinary team was developed with contributions from all disciplines. This concept was initially provided in English inpatient hospices, with strong commitment and community and social support, with great success focused mainly on the care of patients with terminal cancer and very limited prognosis in hospice units across the UK.

Gradually by the 1970s, this model of care developed different types of organizations, such as home care services (St Christopher's), outpatient clinics and day care (St Luke's), and support teams (Thelma Bates). Palliative care was also extended into other settings such as acute bed hospitals (Royal Victoria Montreal), cancer institutes (Royal Marsden), support teams (St Thomas'), and comprehensive networks, and to look after other types of patients (AIDS, motor neuron disease, organ failure, etc.). From the mid-1970s to the late 1980s, palliative care services were disseminated into many other countries (North America, Australia, Europe, and some low and middle-income countries), adapting gradually to their health care systems and cultures. In the 1990s, the concept of palliative care as a public health topic was developed at the WHO, and several regions and countries (Catalonia, Spain; Alberta, Canada; Kerala, India; and others) developed palliative care programs with systematic planning and aims of coverage and equity.

During the 1990s, theory, education and research were extended in many countries, academic positions were established, pre-graduate and postgraduate medical and nursing training developed, training for other members of teams created, and the specialty of palliative medicine established. It is now a recognized specialization in at least 30 countries. Experience, evidence, organizational indicators and standards, and many clinical procedures were developed during this period and added to textbooks and specialized journals.

1. The term palliative care was first used by Dr. Balfour Mount at the Royal Victoria Hospital in Montreal Canada in 1974. The English word hospice translates in French speaking Canada as poor house.

More recently, and related to the increased prevalence and mortality of people with all chronic conditions, the concept of a *palliative approach* has been developed, alongside the need for timely identification of people with all types of advanced chronic conditions in all settings of care, using community and population perspectives. In May 2014 the World Health Assembly approved the Resolution on Palliative Care, "Strengthening of palliative care as a component of comprehensive care throughout the life course,"[2] to promote the concepts of palliative care for all people in need, from the time of diagnosis, in all settings of care. Tools to identify patients at these so-called "first transitions" have been developed, and the concept of palliative approach in all settings is currently being extended, with public health policies implemented to develop these approaches.

TRANSITIONS OF PALLIATIVE CARE IN THE 21ST CENTURY

Palliative care has been adapted to growing needs, extending from the focus on the care of patients with terminal cancer in institutions and interventions based in prognosis towards a wider perspective that includes the concept of "life-limiting" illness and early intervention, the care of persons with all types of chronic diseases and conditions, not just cancer, and planning based on prevalence, rather than mortality (table 1).

This change in perspective has radically altered the scope of palliative care and its provision, towards a public health, global, population, and community perspective, introducing the concepts of the palliative approach in all settings, in combination with the initial concept based on specialist services, in the context of universal health care coverage and access.

PRINCIPLES

The **key principles of palliative care provision** include the concepts of:

- **Comprehensive care** (responding to all multidimensional needs of patients and families),
- **Integrated care** (into all services and settings and with coordination of care),

2. World Health Assembly. Resolution 69.

- **Quality** (to respond with effectiveness and efficiency),
- **Universal access** (equity, coverage, insertion into all systems),
- **Values** of compassion and commitment needed to care for persons in a frail and vulnerable situation.

Table 1. Conceptual transitions in palliative care in the 21st Century

	Change FROM	Change TO
CONCEPTS	Terminal disease	Advanced progressive chronic disease
	Prognosis of weeks or months	Limited life prognosis
	Cancer	All chronic progressive illnesses and conditions
	Progressive course	Progressive course with frequent crises of needs and demands
	Mortality	Prevalence
MODEL OF CARE AND ORGANISATION	Dichotomy curative or palliative	Synchronised, shared, combined care
	Specific OR palliative treatment	Specific AND palliative treatment as needed
	Prognosis as criteria for intervention of specialist services	Complexity/severity as criteria
	Late identification in specialist services	Early identification in community and all settings
	Rigid one-directional intervention	Flexible intervention
	Passive role of patients	Advance care planning
	Fragmented care	Integrated care
PERSPECTIVE FOR PLANNING	Palliative care services	Palliative care approach everywhere
	Specialist services	Actions in all settings of health care
	Institutional approach	Community approach
	Services approach	Population approach
	Individual service	Systems approach

The main reasons for this conceptual framework are its response to the multidimensional needs of patients and families who suffer from advanced-progressive illnesses and conditions and limited life prognosis, with frequent crises and demands throughout the course of their care, and with physical, psychosocial, spiritual and emotional impact.

THE WHO DEFINITIONS

The World Health Organization defines palliative care[3] as follows:

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

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may positively influence the course of illness;
- Applies early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO OF PALLIATIVE CARE FOR CHILDREN

Palliative care for children represents a special, albeit closely related, field to adult palliative care. The WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.

3. World Health Organization. Definition of palliative care. Available at: http://www.who.int/cancer/palliative/definition/en/ Accessed 20 August 2016.

- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

AN UPDATED FRAMEWORK FOR DEFINING PALLIATIVE CARE

Additional work in the context of the WHO Ad Hoc Technical Advisory Group on Palliative and Long Term Care (TAG) has been done to help clarify a conceptual framework for palliative care as follows:

Box 2. Updated key words and short updated definition of palliative care according to the TAG

Key words

Palliative care is the comprehensive and integrated care of persons with advanced chronic conditions and limited life prognosis and their families.

Short version

Palliative care is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with serious, chronic, complex, and life-limiting health problems and the promotion of dignity, best quality of life, and adjustment to progressive illnesses, using best available evidence. It is a person-centred accompanying of patients and their families throughout the illness, including at the end of life that optimizes quality of life, promotes human development and well-being, and maximizes dignity.

Palliative care is a basic human right and an essential component of comprehensive and integrated care for persons with serious chronic, complex, and life-limiting health problems that should be practised by health and social care providers of many disciplines, as well as palliative care specialists, and should be provided in any health care setting, including patients' homes.

FULL VERSION

Palliative care is the prevention and relief of suffering and the promotion of dignity, best quality of life, and adjustment to progressive illnesses for adults and children living with serious chronic, complex, or life-limiting health problems and their families. Because the most common and severe types of suffering may vary by location and culture and over time, the concept definitions and the populations served by palliative care may also vary.

Palliative care is a basic human right and an essential component of comprehensive and integrated care throughout the course of life, including at the end of life; it should be provided in any health care setting including hospitals, long-term care facilities, community health centres, and in patients' homes; and should be practised by health and social care providers of many kinds as well as by palliative care specialists.

TAXONOMY

The TAG members were asked to propose the most appropriate denomination for the WHO initiative prior to the TAG meeting done in December 2014 in Barcelona. The most cited terms proposed were: "care of " "advanced chronic conditions" (24%), or "palliative care" (23%), or "palliative approach" (21%). Other suggested denominations were "end of life care" (11%), "advanced chronic diseases" (9%), hospice care (6%) and others (6%). Terminal care was not mentioned.

THE GOALS OF PALLIATIVE CARE

- To accompany and comfort adult and paediatric patients throughout the course of serious chronic, complex, or life-limiting conditions by continually assessing, preventing, and relieving pain and suffering of any kind – physical, psychological, social, or spiritual – using best available evidence;
- To thereby provide person-centred and family care that optimizes quality of life and maximizes the dignity of patients and their families;
- To integrate with and complement prevention, early diagnosis, and treatment of serious chronic, complex, or life-limiting health problems at all levels of any health system and thereby to improve continuity of care, strengthen health systems, and promote universal health coverage.

DEFINING TARGET PATIENTS[4]

People in need of a palliative care approach to care can be defined in terms of a cluster of symptoms or factors:

- Chronic serious, complex, and/or advanced and/or progressive and/or life-threatening disease or condition of varied causes. The most prevalent in high-income countries are multi-morbidity, frailty, and dementia, followed by specific organ failures and cancer, whereas HIV/AIDS, malaria, and drug-resistant tuberculosis are very frequent in Africa, as is cancer in Latin America;
- Multidimensional needs (physical, emotional, spiritual, family, social, ethical, legal, financial, other);
- Need for palliative interventions of various complexity;
- Limited life prognosis (weeks, months, and some years, from the so-called "first transition" to the terminal situation). The median survival of patients identified with the NECPAL tool (Necesidades Paliativas in Spanish [Palliative Needs]) is 2 years (Gómez-Batiste et al, unpublished observations, 2016);
- In any setting of health and/or social care.

Figure 1. Factors to define target patients
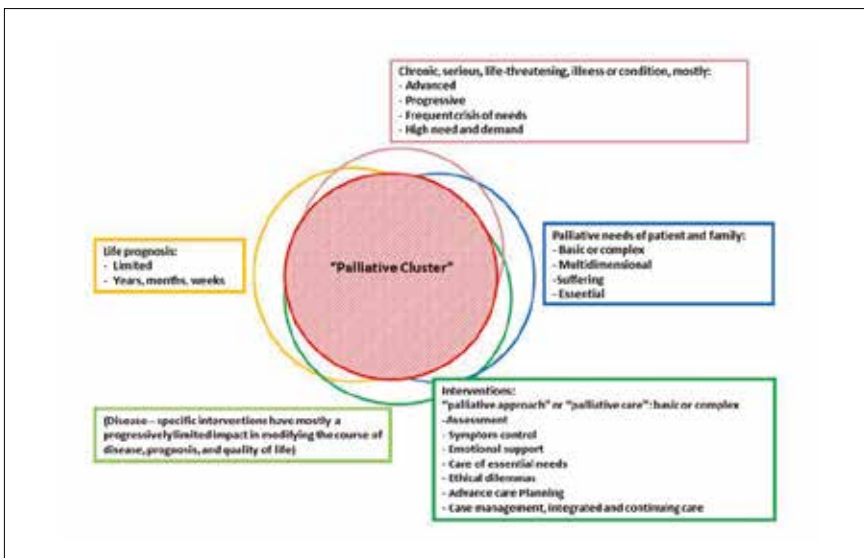
4. There are several definitions of the target patients and terminology to describe them. In this manual, we will use all these terms, using the concept of "Palliative cluster" with the combination of several dimensions (Figure 1).

Additionally, there are several aspects that can be considered:

- Palliative care is given in conjunction with disease-modifying or potentially curative therapies;
- Patients with long-term complex, chronic conditions will frequently need most of the elements of good comprehensive and integrated palliative care;
- These patients have a progressive course, with frequent crises of needs, high need for care, and need to use all types of resources;
- The disease-specific treatments have a progressively limited impact in modifying the course of disease, prognosis, and quality of life.

WIDE SCOPE OF PALLIATIVE CARE

The potential scope of integrated palliative care – who can benefit, when it should start, what aspects of care should be covered, where can care be given, and by whom - is detailed in box 3.

Box 3. By operating as an approach, palliative care can be provided to/in

1. To all patients with progressive life-threatening illnesses.
2. At all times. Be introduced at diagnosis of a life-threatening illness, not just in the last weeks or days.
3. In all dimensions. Help integrate physical, social, psychological and spiritual, not just the physical.
4. In all settings. Extending its reach to people in hospitals, care homes and most strategically in the community.
5. In all regions of the world not just in economically developed countries.
6. To all family members. Support family care-givers, at all stages (before, at the time of death, and after).
7. All ages: applied to children with life-threatening illnesses as much as adults.
8. All society: Promote a public discourse about living in the face of dying and maximizing individual and community assets to promote individual and community growth.

CARING FOR PEOPLE WITH ALL LIFE-THREATENING ILLNESSES OR CONDITIONS

Provision of palliative care should be equitable according to need, rather than favouring people with particular diagnoses. There are several trajectories according to the causes (Figure 2).

Figure 2. Trajectories of illnesses and GPs workload (*Modified from Murray SA et al*)[5]
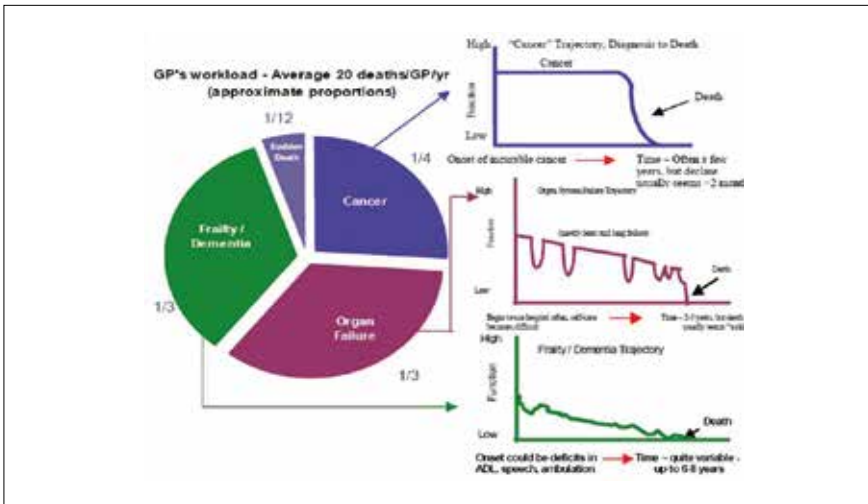
People dying of cancer generally have a predicable course with a short terminal decline. Hospice inpatient and home care is currently configured to meet their needs well. In contrast, patients with heart, lung, liver, or kidney failure may have a fluctuating decline over 1-5 years and rarely access palliative care, even in economically developed countries. People with frailty, dementia, or multi-morbidity need integrated clinical and social care at home, and support for their family careers, again usually absent worldwide. Figure3 illustrates how integrated palliative care can reach all illnesses early in their course, as soon as the illness is life-threatening, and can deal with all dimensions of need in all settings.

To reliably meet the end-of-life needs of all patients, we must seek to identify and care for patients in all settings.

CARING FOR PEOPLE FROM DIAGNOSIS OF A LIFE-THREATENING ILLNESS

Starting a palliative approach to care as soon as the health problem is serious and life-threatening is important, while disease-modifying care may continue. This concept is relevant to all and sometimes multiple conditions. As curative options decrease, the focus turns more to quality of life (palliative) care.

The difficulty of identifying when a palliative approach might be triggered or escalated has prevented this concept from being fully operational. However, there

5. Murray SA, Kendall M, Boyd K, et al. Illness trajectories and palliative care. BMJ 2005; 330: 1007–1011.

Figure 3. Integrated model of palliative care along disease evolution
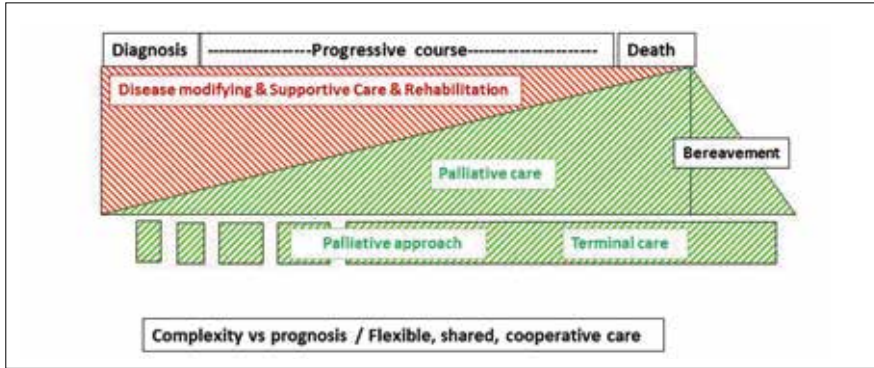
are ways to make early identification a feature of all health conditions with available validated clinical tools. Some clinical indicators such as breathlessness at rest or functional decline might trigger this approach, or even the "surprise question", where a physician asks himself or herself: "Would I be surprised if this patient were to die in the next year?" If the answer is no, a conversation may be worth having with the patient and family to seek to maximize the quality of life, "just in case".

CARING FOR ALL DIMENSIONS OF NEED - PHYSICAL, PSYCHOLOGICAL, SOCIAL AND SPIRITUAL

It is now recognized that everyone has spiritual needs when faced with serious, life-threatening illness. Such spiritual needs relate to the meaning and purpose of life. People may or may not use religious vocabulary to express such needs. If the spiritual issue or need causes the person distress, it becomes "spiritual distress". If such distress is upsetting the person, then this should be identified and addressed by someone, because such distress also impinges on other areas. It makes pain more painful and anxiety less bearable and it leads to increasing health service utilization.

CARING FOR PEOPLE IN ALL HEALTH CARE SETTINGS

Palliative care should not only be available in hospices, but in all settings: hospitals, health centres, care homes, and patients' own homes. In many economically developed countries, typically only 20% of people die at home, although many more would prefer to die at home, if possible. This is because resources to help people die well at home may not be available, for example, strong pain relievers and access to caregivers. Although the actual place of death may commonly be in hospital, most care is still given in the community and resources should follow needs.

INTEGRATION OF PALLIATIVE CARE ALONG THE COURSE OF DISEASE AND ACROSS ALL SETTINGS OF CARE

In the evolution of progressive illnesses or conditions with a limited life prognosis, there are several phases, from the initial complex condition, followed by the so-called first transition – when the disease progresses and there is a limit in life prognosis – and the end of life or terminal phase.

Each of these situations has specific characteristics, and there is a need to adapt the clinical, ethical, and organizational goals to their needs and demands, from care more focused on disease-modifying, supportive, rehabilitation, and curative approaches, with active interventions of specialist services, towards the gradual increase in the palliative approach and palliative care from the beginning, with interaction between palliative care and primary care services (Figure 4).

Figure 4. Adapting the clinical, ethical & organizational perspectives of palliative approach & palliative care to phases in the evolution of persons with advanced chronic conditions and limited life prognosis
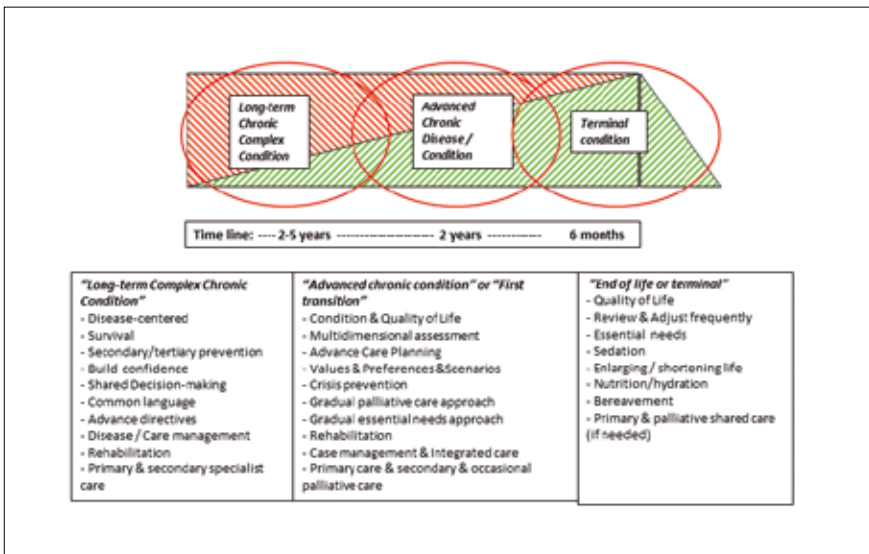
The model of identification and intervention needs to change from a late (last 2-3 months of life), institutional (based on specialist services), reactive to crisis, based on hospitals and emergencies, and fragmented approach towards a model of timely, planned and preventive, community-based care, based on advance care planning and case management, and integrated in all settings with pathways (Figure 5).

Figure 5. Models of palliative interventions in chronic advanced palliative care

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OTHER AVAILABLE RESOURCES

African Palliative Care Association: www.africanpalliativecare.org

Asia Pacific Hospice Palliative Care Network: www.aphn.org

Australian standards: http://palliativecare.org.au/the-national-standards/

Canadian Standards http://www.chpca.net/professionals/norms.aspx

CAPC Quality standards and guidelines www.capc.org/topics/palliative-care-guidelines-quality-standards/

European Association for Palliative Care: www.eapcnet.eu

Hospice UK: www.hospiceUK.org

International Primary Palliative Care Network. http://www.ippcn.org/

International Association for Hospice and Palliative Care: www.hospicecare.com

International Children's Palliative Care Network: www.icpcn.org

Latin American Palliative Care Association: www.cuidadospaliativos.org/

National Hospice and Palliative Care Organization: www.nhpco.org

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White Paper on standards and norms for hospice and palliative care in Europe: part 1&2. Recommendations from the European Association for Palliative Care http://www.eapcnet.eu/

Worldwide Hospice Palliative Care Alliance: www.thewhpca.org

SECTION 2

PALLIATIVE CARE PROGRAMS AND SERVICES

1
THE FOUNDATIONS OF PALLIATIVE CARE PUBLIC HEALTH PROGRAMS

Xavier Gómez-Batiste, Stephen Connor, Kathy Foley,
Mary Callaway, Suresh Kumar, Emmanuel Luyirika

KEY POINTS

- The World Health Assembly resolution, "Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course" (WHA67.19) of May 2014 has been a milestone in WHO involvement in palliative care, asking all governments to design and implement palliative care programs throughout the health care system.
- We **define** palliative care public health programs (PCPHP) as the systematic (comprehensive, combined, multi-level, stepwise) measures taken to improve quality of care for defined target patients and their families, within a defined, population-based context (national, regional, or district level).
- The **vision** for a PCPHP is to develop comprehensive health systems that look after patients with advanced life-threatening illnesses and terminal conditions in order to promote their quality of life throughout the life course, in a context of universal coverage and promoting integrated people-centred health care services.
- The conventional components of PCPHP are defined.
- PCPHPs need a systematic, multilevel, stepwise, and strategic approach.
- Recommendations to implement the foundation actions of programs, include the actions, actors, and key implementation processes.
- PCPHPs must be reviewed and evaluated systematically with quantitative and qualitative methodology.

AIMS OF THIS CHAPTER

To describe the principles, aims, basis, and initial foundation actions of Public Health Palliative Care Programs.

BACKGROUND

Palliative care has developed in many countries since modern palliative/hospice care started in the British hospices in the 1960s. The most relevant achievements have been:

- Development and consolidation of models of palliative care provision in all settings in most countries;
- Extension to specific needs (paediatric, prisoners);
- Extension to other health care disciplines;
- Increasing evidence of effectiveness in all dimensions of care: control of pain and other symptoms, emotional/psychological support, bereavement, and gradual development of care for essential needs such as spirituality and dignity;
- Increased evidence for costing, efficiency and satisfaction;
- Gradual insertion in countries as a component of national health policies;
- Palliative care considered as a public health topic;
- Consolidated education, research, and quality improvement models;
- Increased public awareness and support.

More recently (table 1), palliative care has incorporated:

- Gradual extension into earlier, more flexible intervention;
- Gradual extension to all types of diseases and conditions;
- Development of the palliative approach concept in all settings of care;
- Palliative care considered a human right;
- Chairs of palliative care;
- Textbooks, materials, training methods at all levels.

THE PUBLIC HEALTH PERSPECTIVE FOR PALLIATIVE CARE

- The public health perspective for palliative care has been progressively developed, with palliative care proposed as a key component of every health care system. Many successful initiatives are applying this approach.
- The World Health Assembly resolution, "Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course" (WHA67.19) of May 2014, was a milestone in WHO's involvement, calling on all governments to design and implement palliative care programs.

Table 1. Conceptual transitions in palliative care in the 21st Century

	Change FROM	Change TO
CONCEPTS	Terminal disease	Advanced progressive chronic disease
	Prognosis of weeks or months	Limited life prognosis
	Cancer	All chronic progressive illnesses and conditions
	Progressive course	Progressive course with frequent crises of needs and demands
	Mortality	Prevalence
MODEL OF CARE AND ORGANISATION	Dichotomy curative or palliative	Synchronised, shared, combined care
	Specific OR palliative treatment	Specific AND palliative treatment as needed
	Prognosis as criteria for intervention of specialist services	Complexity/severity as criteria
	Late identification in specialist services	Early identification in community and all settings
	Rigid one-directional intervention	Flexible intervention
	Passive role of patients	Advance care planning
	Fragmented care	Integrated care
PERSPECTIVE FOR PLANNING	Palliative care services	Palliative care approach everywhere
	Specialist services	Actions in all settings of health care
	Institutional approach	Community approach
	Services approach	Population approach
	Individual service	Systems approach

MISSION, VISION, PRINCIPLES, VALUES, AND AIMS OF INTEGRATED PALLIATIVE CARE PUBLIC HEALTH PROGRAMS

The *mission* of PCPHPs is to achieve a palliative care network inserted into the national health care system with the principles of universal coverage, access, equity, and quality.

The *vision* consists of developing comprehensive health systems to look after patients with advanced life-threatening illnesses and life-limiting conditions in order to promote their care and quality of life throughout the life course, in a

context of universal coverage and promoting integrated people-centered health care services.

The ***principles and values*** of PCPHPs are based on the consideration of quality palliative and end-of-life care (EOLC) as a human right:

- Support to persons suffering and in vulnerable conditions, with respect for their values and preferences;
- Universal coverage, equity, access, and quality to every patient in need;
- Population-based, community-oriented, integrated into the health care system, and into the culture;
- Model of care: based on patients' and families' needs, goals, and demands, respectful, patient- and family-centred;
- Model of organization: based on competent interdisciplinary teams, with clinical ethics, integrated care, case management, and advance care planning;
- Quality: effectiveness, efficiency, satisfaction, continuity, sustainability;
- Evidence-based, systematic evaluation of results, accountability;
- Social interaction and involvement;
- Innovation in the organization of the health care cystem.

Definitions and terms should be clarified from the beginning. Some existing sources include previous WHO definitions of palliative care, the working definition currently elaborated, and the existing definitions available. But it is necessary to adapt these definitions and concepts to the culture and wording of every country. A syllabus is a recommended option.

The ***aim*** is the development of a system of care inserted as a component integrated within the health care system in the context of universal coverage. Aims need to be defined globally and for every dimension at short, mid, and long term.

The **methodology** of implementation needs to be a **multi-level approach** combining all types of actions.

Components of PC programs

Consider all of the following components in the design of a comprehensive program, and implement them with a strategic plan, identifying the aims and actions at short, mid, and long term:

- Foundation measures
- Leadership
- Mission, vision, definitions, and values
- Defining target patients / population
- Model of care and intervention

- Models of organisation: levels, settings, scenarios, integrated models adapted to the culture and health care system
- Specialist services implementation
- Palliative care approach in conventional services
- Essential medicines availability and accessibility
- Legislation
- Indicators, standards, and quality improvement
- Budgeting, financing and purchasing services models
- Training: clinical, organisational, leadership
- Research
- Advocacy and human rights
- Indicators for follow-up
- Strategic roadmap of implementation

The main actors involved in design, implementation, and evaluation include: the WHO, Ministries of Health, health care and allied professionals, organizational leaders/managers, academics , human rights and legal practitioners, patients advocacy groups, society, NGOs, private sector, funders, and so forth.

KEY IMPLEMENTATION ISSUES: FOUNDATION MEASURES

KEY FOUNDATIONAL ACTIONS

- Support of leadership at the Ministry of Health / Officers in charge;
- Assessing needs (and basal situation);
- Identifying leaders (pioneers, champions) and settings in which to start services;
- Identifying the main barriers and actions to promote access to essential medicines and to prepare legislation and regulation (and mechanisms to facilitate early access if legislation will be approved later);
- Elaborating the national strategic plan for implementation;
- Creating the government sanctioned national stakeholders and experts board;
- Organising the foundational meeting;
- Advocacy of the main policymakers and stakeholders.

The foundational actions can start with the **combination (multi-level approach) of several actions**, such as identifying leaders/champions or feasible projects, advocacy to policymakers, context/needs analysis, leadership at the

MoH, or involvement of WHO Country/Regional offices, depending on the sources of the demand. Other institutions as development agencies have been providing support.

Needs Assessment and Basal Description

Needs assessment consists of estimating or measuring the needs of people with advanced chronic conditions requiring palliative care, either in the general population or in the different settings). If local data are not available, some estimations based on WHO or organizations such as CDC, World Bank in similar countries could be helpful. From these estimations, proposals of service needs could be elaborated.

Description of the basal situation consists of an evaluation of the current situation of development of palliative care in the country. Some quantitative data can describe the specialist services available (if any), and the related services (oncology, geriatrics, primary care) palliative care approach, the palliative care training offers, the accessibility of opioids, and other components of a palliative care public health program. It is recommendable to combine this description with a qualitative analysis of the situation, performed with a national committee of experts. A SWOT analysis of the main dimensions might be very useful to identify the strengths, weaknesses, barriers and opportunities, and to use this information to build the national plan.

A **Foundational Meeting** (table 2) can be an excellent way to formalize the initiation of the program, bringing together the main stakeholders to achieve consensus on the principles, aims and agenda. The group (around 40 people) should be interdisciplinary (including senior MoH official who will have responsibility for palliative care, doctors (representing different populations and diseases, e.g. geriatricians, paediatricians, cancer, infection, disease), nurses, psychologists, social workers, chaplains, legal providers, physiotherapists, occupational therapists, pharmacists, nutritionists, advocacy group representation, competent narcotic authorities, also international donors to educate and inform them and to get their buy-in, etc.). Additionally, the group should represent different settings: hospitals, primary care/long-term care, rural/urban, home-based and community, etc.

CRITERIA FOR SUCCESS

- Clear leadership (local and international, policymakers, clinical and organizational)

Table 2. Foundational Meeting Plan

Expected aims and outcomes
1. To present the national needs assessment 2. To build the basis and principles of a national plan and/or review an existing plan
3. To generate agreement and consensus
4. To create or consolidate a National PC TWG Committee; with sub committees specifically charged with 1) education/training, 2) policy, 3) drug availability, 4) implementation
5. To build up an action plan and a follow-up agenda 6. To identify the leader of the PC TWC
Actions at short-term should be oriented, focused, and prioritized to
■ Design and start the national plan
■ Create the National Advisory Board or country palliative care team
■ Create a core group of leaders/pioneers/champions
■ Create a core nucleus of experiences: specialist services, palliative approach in conventional services, different types of patients, demographic references (rural, urban, etc.)
■ Achieve availability, affordability, and accessability of essential drugs, including strong opioids, and inclusion in the national essential medicines list
■ Create a centre of excellence to support the process
■ Generate consensus
■ Assure commitment and continuity
Attendees
1. Policymakers and health care regulators (policy and drugs)
2. Palliative care professionals and organisations (scientific, clinical, NGOs)
3. Other specialists directly involved: primary care, geriatrics, family medicine, oncology, internal medicine, paediatrics, etc.
4. Managers and directors from different health care settings
5. Funders
6. Academics (medical, nursing, and social science deans)

There are several components, methods, and aims to consolidate leadership through capacity building:

- Clinical training of key leaders to develop examples of good practices;
- Organisational and leadership training to develop examples of good services;
- Leadership capacity;
- Tutorships, mentorships, visits to centres of excellence;
- Policy development;
- Clear principles;

- Involvement and commitment of all levels (depending on the country this may include the Ministry of Health, Ministry of Internal Affairs or Ministry of Social Affairs, WHO country offices, WHO regions, other development agencies, e.g. DFID, USAID, religious community);
- Identification and plan for dealing with competition and conflicts;
- Combination of top-down & bottom up approaches;
- Systematic approach;
- Multimodal, multi-level coordinated interventions;
- Good training and support methodology and competent faculty;
- Good solid local references of projects and services; must include model services to educate policy makers;
- Continuity, tutorship and mentorship of initial projects;
- Benchmark is established;
- Evaluation is conducted.

KEY INITIAL IMPLEMENTATION PROCESSES

It is recommended to combine several processes added to the listed activities. **Catalytic actions** can be promoted as easy measures that can facilitate starting the implementation. For instance, hiring or assigning a trained, funded, dedicated nurse or medical doctor could be the first action to be taken in a hospital or in the community to start palliative care. Or the patients with advanced illness could be brought together in a hospital area, specific times in an outpatient clinic could be dedicated to palliative care. Although it does not accomplish the criteria of a specialist team, it will generate experience about the benefits and facilitate the implementation of a complete service. Every dimension needs to be implemented in a stepwise way, with short-, mid- and long-term aims (table 3).

In many settings, a substantial source of resources is the reallocation of existing human capital, and financial resources. A good example consists of reallocating existing beds into palliative care beds.

ADAPTING TO SCENARIOS: CARE AND DEMOGRAPHIC SETTINGS

Mapping the existing settings and scenarios, defining their models of palliative care and approach, and identifying settings where implementation will be more effective and feasible are recommended in order to generate complementary experiences that can be reproduced in similar contexts.

Table 3. Timelines for Palliative Care Development

TIME DIMENSION	0-2 years: foundation and initial references	2-5 years: consolidation of solid references	+ 5 years: spread	+ 10 years: coverage
GENERAL AIMS	Foundation	Extension Other settings All types of patients	Coverage Inserted in mainstream	Total coverage
REASONABLE GENERAL OUTCOMES	Advocacy done National Plan approved Officer at DoH Leaders identified National Board Foundation meeting Initial legislation or ways to access essential medicines	Coverage 25-50% Legislation approved Gradual insertion into all the health plans	Coverage 50% of needs	Total coverage for all patients, all settings
SPECIALIST AND PRIMARY SERVICES	Create and consolidate 5-10 specialist services in different settings (home, hospital, other) Standards Directory of services Feasibility as main criteria	Develop 5-10 services Different models: settings, districts, systems Benchmarking processes	Replication and spread of models in all settings	Consolidation
INTEGRATION IN ALL SETTINGS	4-5 references of conventional services adopting palliative approach 4-5 references of integrated palliative care systems in rural / urban	25-50% of primary care services adopting palliative approach		+ 75% of conventional services adopting palliative care approach

TIME / DIMENSION	0-2 years: foundation and initial references	2-5 years: consolidation of solid references	+ 5 years: spread	+ 10 years: coverage
EDUCATION AND TRAINING	Focused on policymakers, leaders and specialist teams Training and support to leaders/ pioneers in clinical/ managerial/ training the trainers Managers and stakeholders Public awareness and education	Extension to other specialities Tutorships/ mentor-ships Medical and nursing speciality or sub-speciality Starting pre-graduate	Gradual extension to all levels of training (pre-post graduate, specialist) of all professionals	Total coverage of all levels of training
ACCESS TO ESSENTIAL MEDICINES	Initial actions focused on starting services Access in specific places	Legislation approved Gradual access in all settings	+ 75% population of all settings with access Funding access	Total access
INDICATORS & EVALUATION OF THE PROGRAM	Structure: team at MoH, services, legislation, Process: According to the actions for 2 years Outcomes: number of patients, services, trained professionals, essential medicines, prescriptions, etc.	According to the aims x dimensions Start outcomes evaluation: effectiveness, efficiency, satisfaction Start qualitative assessments to identify areas of improvement	According to the aims x dimensions Regular assessment of outcomes Qualitative assessments to identify areas of improvement	According to the aims x dimensions Qualitative assessments to identify areas of improvement

For instance, models in rural/urban areas, community/hospital/nursing homes, different specialities, cancer institutes, or comprehensive/integrated systems in districts.

INSERTING INTO THE EXISTING RELATED NATIONAL PROGRAMS

Most countries have national health care plans, and also plans to address NCDs, cancer, ageing/geriatrics, dementia, AIDS, TB, cardiovascular, or any individual or specific conditions. Palliative care must be inserted in all of these plans as an essential component added to the other (prevention, early detection, care).

DESIGNING EVALUATION AND FOLLOW UP

From the beginning, a set of indicators and a follow-up plan must be elaborated. There are frequent questions and dilemmas that can be resolved with common sense (table 4).

Table 4. Common dilemmas and challenges

Question	Recommendation
Where to place the services?	In the initial phases, the criteria for implementing services are based on feasibility, available leadership, and the impact of the referral service. More generally, the initial aim would be to begin with different models of services in different settings (hospital, home, intermediate-care in rural and urban settings).
	Integration into existing services by developing palliative care teams of a doctor and/or clinical officer, nurse, social worker in each unit.
Who are the target patients in the initial phases?	In some countries, palliative care (PC) starts to be provided for advanced cancer patients and, subsequently, gets extended to cover other patients with life limiting conditions. In Africa the majority of palliative care patients are HIV and cancer patients.
	There are experiences starting with all types of patients.
How many specialist services are needed?	This can be variable. A good criterion for the long-term aim is to have at least one service available in every district, and for complex patients from every setting to have access to some specialist services. A palliative care consultation team can be used to provide consultations to primary and secondary providers.
How many specialist beds are needed?	The need for PC beds is variable and depends on patient needs and on the capacity of existing services. In European countries the estimate is for between 80 and 100 beds per million inhabitants. These beds can be located in acute hospitals, intermediate care, or nursing home settings, in various proportions. These should be minimal, especially in LMICS, because of costs and the importance of delivering home care services to patients and families.
Do we need extra beds for implementing specialist PC units?	Not necessarily. In most countries the PC specialist units result from the re-allocation of pre-existing beds, or even re-assignment within the context of bed number reduction.
Which is the best model of service?	Create a set of different services in different settings.
	Hospice initiatives and nursing could be the first service-of-choice since they are supported by charitable organizations and NGOs, which play a significant role in countries such as the United Kingdom. Outpatient, home-based services linked to a health unit are less costly and easier to implement in some LMICS.

How should specialist services be implemented?	In the initial phase, it is recommended to start with palliative care support teams (at home or at hospital), since these are the most feasible.
	In some settings, the so-called general and/or transitional measures are good ways to start (i.e.: specialist nurses, dedicated doctors or other professionals, etc.).
	Define the minimum HR requirements and minimum service delivery package linked to an essential medicines list including the three step WHO pain ladder approach, within the health system and required finances
Where should specialist services be implemented?	In the initial phases of development, the most relevant criteria for choosing locations is feasibility, based on the existence of good leadership, with institutional commitment. In many countries initial phases are planned in tertiary hospitals, where cancer and aids services are based.
Do specialist palliative care services need to be attending-only, specific-disease patients?	It depends on the setting and the level of development: – Setting examples: specific in a cancer institute, or paediatric, and mixed in the community or in a general hospital; – Some patients need specific measures (ambient, preventive, etc.): HIV, MDR TB, dementia, Ebola, paediatrics; – Time examples: starting with cancer, and extending after to non-cancer.
Common barriers and/or resistances	
General resistances	Start with solid experiences/visit model programs.
	Select easy/feasible/short-term results.
	Elaborate and disseminate results of services.
"We don't need palliative care services, we are already doing them"	Identify areas of improvement in the care of patients.
	Use quality evaluation and improvement processes to improve the quality of palliative care.
	For evidence of the results of initial implemented services, choose simple measures of effectiveness, efficiency, and satisfaction.
	Have improved palliative care standards.
"We don't have so many patients"	A good response is to conduct a prevalence study in the different settings (using existing tools to identify patients in need).
	Wherever there are people there a need for palliative care. The difference is size of the problem and level of need.
Access to essential medicines	If there is resistance to implementation, initially, a wide access policy of a national regulation, it is recommended to find transitional mechanisms to provide essential medicines to specialist services in their initial phases. Strong barriers to access are active in the professional, society, and culture, and need to be addressed.

Controversies over the leadership	The "administrative" leadership and services depend in most instances on the managerial criteria.
	Need for sensitization as part of the program for policy makers, managers, health workers and patients and their families.
Controversies over the scope of palliative care and interaction, palliative care for end- of-life patients, and/or for persons with chronic advanced conditions	Describe the existing knowledge of epidemiology.
	Emphasize the population-based perspective.
	Create and evaluate models of chronic / palliative care in the community and other settings.

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2
ASSESSING THE NEED FOR PALLIATIVE CARE IN POPULATIONS AND CONTEXTS

Stephen Connor, Xavier Gómez-Batiste

KEY POINTS

- Needs assessment is a key first step in country-level palliative care development.
- All cancer and non-cancer diagnostic groups should be included for both adults and children.
- Both quantitative and qualitative methods should be used in assessing need for palliative care.
- Health workforce needs should be included as well as inpatient need in context.
- Recommendations for needed policy work, essential medicine availability, educational development and implementation of services should also be included.

AIMS OF THIS CHAPTER

The purpose of this chapter is to provide researchers, organizational leaders and policymakers with the tools necessary to understand and map out the need for palliative care in a given country or region.

BACKGROUND

Assessment of the context and the need for palliative care is necessary in order to plan for the establishment and growth of services and to measure the extent to which the need is being met. Estimation of need begins with determining all diagnostic groups requiring palliative care. Mortality data are usually used to calculate need; however, this will normally underestimate the need as there are many patients with palliative care needs before to their last year of life.

Mortality data can be combined with population-based or setting-based prevalence data, once systems have been described to identify patients in need of palliative care in all settings.

A population-based approach can also be used to estimate the need. This approach can be more inclusive, although it is important to distinguish those who will benefit from a palliative care approach by their primary health caregivers from those who need more specialized palliative care services. We will illustrate both approaches in this chapter.

AIMS AND TARGET AUDIENCE

The purpose of this chapter is to provide researchers, organizational leaders and policymakers with the tools necessary to understand and map out the need for palliative care in a given country or region. Every country has unique needs and resources, so it is important that assessment is not simply a numeric exercise but includes a qualitative understanding of the context in which this need exists. A thorough understanding of the existing health care system is also necessary to find the best approaches to incorporating palliative care.

Integrating palliative care into the fabric of the existing health care system is generally better than creating palliative care as a separate, parallel system that lacks integration with those who are already caring for the patient and family. This will require changes to the way health care providers organize and deliver care. It also requires changes to the way health professionals are trained.

DIAGNOSTIC AND CONDITION GROUPS

Historically, most palliative care providers initially targeted cancer patients; however, this is not the main diagnostic group needing palliative care. The WHO definition of palliative care[1] refers to all patients with life-threatening illnesses from the point of diagnosis to death and bereavement. We expand this approach to include those with serious chronic illness including multi-morbidity, the very frail elderly, and children as well as patients at the end of life.

1. World Health Organization. WHO definition of palliative care. Available at: www.who.int/cancer/palliative/definition/en/. Accessed 23 March 2015.

The WHO and the Worldwide Hospice Palliative Care Alliance recently published a *Global Atlas of Palliative Care at the End of Life*[2] that provides a listing of diagnostic conditions appropriate for palliative care. This list and the approximate percentages of need at the end of life are as follows:

- Cardiovascular Disease   38.47%
- Cancer   34.01%
- Chronic Obstructive Pulmonary Disease   10.26%
- HIV/AIDS   5.71%
- Diabetes Mellitus   4.59%
- Kidney Disease   2.02%
- Cirrhosis of the Liver   1.70%
- Alzheimer's and Other Dementias   1.65%
- Drug Resistant Tuberculosis   0.80%
- Parkinson Disease   0.48%
- Rheumatoid Arthritis   0.27%
- Multiple Sclerosis   0.04%

Additionally, other methods have been described to estimate needs based on mortality[3], applied for high-income countries. Recently, the development of methods of early identification[4] has permitted us to explore the prevalence of persons in need, which could be as high as 1% of the population in high income countries, mostly due to the ageing population and high prevalence of advanced frailty, multi-morbidity and allied conditions[5]. For children and adolescents, the list is somewhat different:

- Congenital Anomalies   25.06%
- Neonatal Conditions   14.64%
- Protein Energy Malnutrition   14.12%
- Meningitis   12.62%

2. Connor S, Sepulveda C. (eds.). Global Atlas of Palliative Care at the End of Life. 2014. London UK/Geneva CH: Worldwide Palliative Care Alliance/World Health Organization.
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- HIV/AIDS   10.23%
- Cardiovascular Disease   6.18%
- Endocrine, Blood, & Immune Disorders   5.85%
- Cancer   5.69%
- Neurological Conditions   2.31%
- Kidney Disease   2.25%
- Cirrhosis of the Liver   1.06%

WHAT TO INCLUDE IN A NEEDS ASSESSMENT?

The needs assessment survey has to be adapted to the different existing levels of information available in countries, ranging from very basic to complete, and from estimations to accurate data.

The following outline is a suggested listing of the content that can be included in a national needs assessment, along with explanatory text. Further details on the methodology of calculating need follow this section.

- Introduction: Aims, purpose, target audience;
- Methods: Including data sources, palliative care definitions;
- Country description: History, geography, people, economy;
- Profile of the country's health and illness:
    – Including breakdown of incidence, prevalence, and mortality for major illnesses in the population or in settings of care;
    – Description of the current health care system's resources – including health professionals and health facilities;
    – Profile of non-governmental organizations involved in health and palliative care;
- The public health situation regarding palliative care:
    – Policy;
    – Availability of essential palliative care medications;
    – Education;
    – Implementation of palliative care services;
- Interviews conducted for qualitative assessment: several methodologies;
- The country's need for palliative care:
    – Calculation or estimation of numbers of patients needing generalist and specialized palliative care annually and by diagnosis and region;
    – Estimation of the health workforce and services, and needed to serve need;
    – Plan for founding, scaling up and integrating palliative care into existing health care system (see Chapter 1 and other related chapters);

- Recommendations;
- References;
- Appendices;
  – Geography and population demographics;
  – Government and economy;
  – Methodologies for calculation of need.

INTRODUCTION

Summarize the reason for conducting the needs assessment, what the primary aims and goals are for the document, who the target audience is and what plans are for follow up.

METHODS

Data sources can include within country disease registration data, Ministry of Health reports, external data from WHO, UNAIDS, World Bank, UN Population Bureau, CIA World Fact Book, Institute for Health Metrics and Evaluation, and so forth. All data and methods used should be accurately referenced. Include latest WHO or national definitions of palliative care and major terms used.

COUNTRY DESCRIPTION

Include a general description of the country including history, geography, demographics of its population, and economic indicators. Include as little or as much information as necessary.

PROFILE OF COUNTRY HEALTH AND ILLNESS

Begin by listing all the major causes of death, using either WHO's Global Health Estimates Mortality File[6] and/or country-level data. If incidence and prevalence data are available, include this information. Summarize all the available health care system resources including numbers of health professionals (working physicians, nurses, pharmacists, dentists, allied health professionals) and public and private health facilities (hospitals all types, primary health care facilities and clinics, long-term care facilities including nursing homes and assisted living, home-based care services) by category. Summarize health expen-

6. World Health Organization. Disease and injury country mortality estimates, 2000-2012. Available at: http://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html. Accessed 1 April 2015.

ditures by category (per capita, % of GDP, public/private %, out-of-pocket). Profile the major non-governmental organizations involved in health. Include any palliative care NGO's that exist.

THE PUBLIC HEALTH SITUATION RELATED TO PALLIATIVE CARE

Policy

What is the situation regarding efforts to date to establish palliative care in the country? Has palliative care been included in any major health policy documents including:

- Legislation on health
- The national health strategy
- National cancer control plan
- National NCD plan
- HIV plans and strategies
- TB plans and strategies
- Recognition as a health specialization
- Other health planning efforts

Medication Availability

Are all the essential palliative care medications defined by the WHO[7] available in the country? Pay special attention to the availability and affordability of opioids for pain relief. Are oral medicines including immediate and slow release morphine tablets or liquid registered and in-stock in pharmacies? What restrictions are placed on access to controlled substances? Do these restrictions interfere with medical practice in such a way that they impede access for pain relief and medical use?

QUALITATIVE ASSESSMENT

There are several methods than can be used[8], including interviews. Interviewing patients who need palliative care and their families is very important to highlight the unmet needs for care, strengths, weaknesses and barriers, as well as making the case for palliative care more clear and meaningful. This can be done in addition to interviewing government officials, key persons, and stakeholders.

7. World Health Organization. Model list of essential medicines. Available at: http://www.who.int/medicines/publications/essentialmedicines/en/. Accessed 1 April 2015.
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A structured interview is best, with ample opportunity for comments by the interviewee. A SWOT analysis can be useful to identify specific challenges. It is particularly relevant to assess the capacity of key related services (primary care, geriatrics, oncology, AIDS, etc.) to provide palliative care and identify settings for implementing actions.

THE COUNTRY'S NEED FOR PALLIATIVE CARE

Several approaches to determining the number of persons needing palliative care can be used depending on the country's priorities. While it is essential to know the full need for palliative care, it is not uncommon for it to take decades to achieve full coverage for palliative care. It is also necessary for planning purposes to estimate the health care workforce needed to meet the need and the number of inpatient beds/services needed-tailored according to each country's organization.

USEFUL METHODS FOR CALCULATING THE NEED FOR PALLIATIVE CARE

Several published sources can be used to estimate the need for palliative care, either using mortality data or prevalence or the combination of both.

POPULATION AND SETTING-LEVEL PALLIATIVE CARE NEED ESTIMATION

Once we can identify patients in need with available simple tools, the use of prevalence studies is recommended, either in the general population or in specific settings. This approach could also be potentially useful for advocacy purposes. Surveys utilized in high income countries have identified that around 1-1.4% of the population, near 40% in acute bed hospitals and 40-65% in nursing homes could be persons with advanced chronic conditions and limited life prognosis with palliative care needs[9]. In LMICs, similar approaches have been used.

9. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, Espaulella J, Espinosa J, Constante C, Mitchell GK. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: a cross-sectional study. Palliat Med 2014; 28(4):302-311.

GLOBAL ATLAS OF PALLIATIVE CARE AT THE END OF LIFE[2]

To calculate the need for palliative care only at the end of life, the method published in the *Atlas* can be used. Estimates can be calculated for cancer, HIV/AIDS, and ten other progressive non-malignant diseases. The need for palliative care at the end of life should be doubled to account for patients needing palliative care prior to the last year of life. (See Appendix A for instructions on how to calculate need using the *Atlas* method.)

ESTIMATIONS BASED IN MORTALITY

Murtagh[3] identified three different methods using death registration data using both underlying and contributory causes, which can give reliable estimates of the population-based need for palliative care without needing symptom or hospital activity data. In high-income countries, 69%–82% of those who die need palliative care.

AVERAGE DAILY CENSUS

The number of people annually that need palliative care can be converted to an average daily census (ADC) to estimate the number of people at any given time that need specialized palliative care services. To calculate an ADC it is necessary to estimate the average amount of time someone will need palliative care or average length of service (ALOS). If you have an ALOS in your country you can use that information. Otherwise, based on international experience, you can use 70-90 day length of stay for planning purposes. To calculate ADC multiply the number of patients needing palliative care in a year by the ALOS and divide by 365.

SPECIALIZED HEALTH SERVICES AND WORKFORCE NEEDED

The specialized services and workforce required to respond to palliative care needs depends on many variables, including prevalence and mortality, the structure and organization of the health care system, the capacity of conventional services such as primary care to look after advanced chronic care (ACC) patients, and the models of organization in specific settings.

A simple way of estimating this could be to provide at least accessible palliative care specialized services to complex patients in need, and assure appropriate good care for all non-complex patients in all settings as a long-term goal. The number of services needed could be shaped according to these criteria.

Some methods have been used to calculate the staffing needs for home-based care and inpatient care in high-income countries.

One is based on the projected average daily census:

Using the average daily census for home-based care, apply a ratio of one full-time equivalent (FTE) nurse for every 5 patients on daily service. For physicians, use one FTE for every 25 patients on service. In addition, other staff are needed for the clinical services including social workers, home care aides, therapists, and drivers. It is estimated that one FTE of other clinical services is needed for every 10 patients in service.

Using the population based approach, the following ratios are used:

For home-based care:

- 3 physicians per 100,000 population
- 12 nurses per 100,000 population
- 6 other clinical staff per 100,000 population

For inpatient care:

- 1.5 MDs for every 10 inpatients
- 15.5 nurses for every 10 inpatients
- 4 other clinical staff for every 10 inpatients

After calculating both methods, determine which one is most useful for planning purposes. These estimates do not include administrative staff. Determine an additional percentage of staff to carry out administrative services based on your experience in your health care system. In highly developed countries it is not unusual to have 25% additional administrative staff to provide leadership and to ensure compliance with regulatory and fiduciary responsibilities.

INPATIENT BED NEED

As stated previously, the number of beds depends on many factors, and must be tailored in every country according to needs and structure of the system.

PLAN FOR SCALING UP AND INTEGRATING PALLIATIVE CARE INTO THE HEALTH CARE SYSTEM

Once these needs are calculated, your needs assessment should include some recommendations for scaling up palliative care in your country. Using a timeline,

you can project growth in percentage of the need being met by year. It may be helpful to look at the need geographically to determine areas of the country where the need is greatest or where resources already exist. Some countries expand gradually out from population centers to rural areas. Some begin at regional centers and expand from there. Include private as well as public providers where they exist. It may be necessary to seek expert consultation on development of a national strategy for scaling up and integrating palliative care into your health care system.

RECOMMENDATIONS

At the end of the needs assessment it is useful to summarize what is recommended overall and specifically regarding plans for inclusion of palliative care in the health care system and how to proceed. The recommendations should address at least each of the major public health components of policy, medication access, education, and implementation.

APPENDIX A

METHODOLOGY FOR ESTIMATING THE NUMBER OF PEOPLE IN NEED OF PALLIATIVE CARE

The estimates used 2011 mortality data from the WHO Global Health Estimates. Although the WHO definition states that palliative care should be provided early after the diagnosis of a life-limiting condition, this chapter assesses only the need for palliative care at the end of life in view of the fact that there is mortality data available for all countries. Therefore, this assessment provides low level estimates as they reflect only terminal care.

In order to identify the diseases (ICD 10) requiring palliative care at the end of life, WHO conducted two Delphi studies with external experts and did a subsequent internal review. The results were the following:

- **Diseases requiring palliative care for adults (population aged 15 years and above):** Alzheimer's disease and other dementias, cancer, cardiovascular diseases, cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS; kidney failure; multiple sclerosis; Parkinson's disease; rheumatoid arthritis; drug-resistant tuberculosis.

- **Diseases requiring palliative care for children (population under age 15):** cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies, endocrine, blood, immune disorders, HIV/AIDS, meningitis, kidney disease, neurological disorders, neonatal conditions, protein energy malnutrition.

Caution is needed when using only diagnoses for the assessment, because not all patients with a certain diagnosis are in need of palliative care. There are generally three groups of patients: those who have a palliative period of advancing progressive disease; those who have a stable or no disease, relatively few symptoms but then deteriorate or die suddenly; and those who suffer from chronic disease, where the disease is not clearly progressing, but who might have periods of progression and symptoms where they would benefit from palliative care and then periods of remission.

Because it is not precisely known what the proportions are of those three groups of patients requiring palliative care, symptoms experienced in the last year of life can be used as indicator of palliative care needs.

The estimates in this chapter are based on pain prevalence as this is one of the most prevalent symptoms at the end of life for both adults and children suffering from malignant and non-malignant chronic conditions. In addition, pain relief for palliative care is considered an urgent humanitarian need requiring adequate medical care across all levels of the health system.

Review of pain prevalence evidence

With respect to symptom prevalence in adults, we have refined the pain prevalence data to some extent by disease. In addition to the original reference on pain by Higginson, probably the most useful source is the 2006 review of symptom prevalence across different non-cancer conditions. This gives pain prevalence as:

- Cancer: 84% 35-96%

- Heart disease: 41-77% 67% 70%

- Renal failure: 47-50%

- Chronic obstructive pulmonary diseases: 34-77% 67%

- HIV/AIDS: 63-80% 80%

- Cirrhosis of the liver: 67%

- Multiple sclerosis. 43%

- Parkinson's disease: 82%

- Alzheimer's disease and other dementias: 47%

- Rheumatoid arthritis: 89%

- Diabetes mellitus: 64%

- Multi-drug-resistant tuberculosis: 90%

The estimated pain prevalence at the end of life for children dying from life limiting conditions is also based on a literature review and is estimated for the three disease categories as follows:

Cancer: 80%

Progressive non-malignant: 67%

HIV/AIDS: 55%

Additional Assumptions from the Health Statistics and Informatics Department at WHO include the following:

- All estimated acute/sudden deaths from cardiovascular disease (33%) are removed from the disease group before applying the 67% of deaths with pain

- For neonatal deaths, before applying the 67% pain prevalence, most deaths on the day of birth are removed from the disease group (25%). Of the remaining deaths, 75% are removed because they are avertable with resuscitation.

- For congenital malformations half of the congenital heart anomalies are removed from the disease group. This is an estimate of those children with treatable conditions or those without significant symptomatology.

- Endocrine disorders are excluded from the endocrine, blood, immune disorders group.

The template below summarises the method for estimating the number of people in need of palliative care (PC) at the end of life.

Disease categories/ groups requiring palliative care at the end of life	Total Deaths from diseases requiring palliative care at the end of life Numeric (A)	Pain Prevalence at the end of life (%): B	Patients in need of palliative care at the end of life Numeric: C=AxB
CANCER			
Adults	7,786,470	84%	6,540,634
Children	83,282	80%	66,625
Total Cancer	7,869,752		6,607,260
HIV/AIDS			
Adults	1,373,267	80%	1,098,613
Children	217,684	55%	119,726
Total HIV/AIDS	1,590,952		1,218,340
PROGRESSIVE NON-MALIGNANT DISEASES			
Adults			
Alzheimer's disease and other dementias	673,454	47%	316,523
Cardiovascular diseases (excluding sudden deaths)	11,040,032	67%	7,396,821
Chronic obstructive pulmonary diseases	2,945,179	67%	1,973,270
Cirrhosis of the liver	961,060	34%	326,760
Diabetes mellitus	1,379,556	64%	882,915
Multiple sclerosis	18.130	43%	7,796
Kidney diseases	775,503	50%	387,751
Parkinson's disease	112,810	82%	92,504
Rheumatoid arthritis	58,614	89%	52,167
Drug-resistant tuberculosis	170,000	90%	153,000
Total PROGRESSIVE NON-MALIGNANT DISEASES	**18,134,342**		**11,589,511**

…

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Disease categories/ groups requiring palliative care at the end of life	Total Deaths from diseases requiring palliative care at the end of life Numeric (A)	Pain Prevalence at the end of life (%): B	Patients in need of palliative care at the end of life Numeric: C=AxB
PROGRESSIVE NON-MALIGNANT DISEASES			
Children			
Cardiovascular diseases	107,932	67%	72,315
Cirrhosis of the liver	18,481	67%	12,382
Congenital anomalies (excluding 50% heart anomalies)	437,583	67%	293,180
Endocrine, blood, immune disorders excluding endocrine conditions	102,122	67%	68,422
Meningitis	220,384	67%	147,657
Kidney diseases	39,257	67%	26,302
Protein energy malnutrition	246,493	67%	165,150
Neurological conditions (excluding epilepsy)	40,258	67%	26,973
*Neonatal Conditions (see formula for excluded conditions)	255,633	67%	171,274
Total PROGRESSIVE NON-MALIGNANT DISEASES	**1,468,147**		**983,658**
Total Adults	**27,294,080**		**19,228,760**
Total Children	**1,769,114**		**1,170,011**
Grand Total	**29,063,194**		**20,398,772**

*Neonatal conditions formula: ((X-A-B*0.75)-(C*0.75)

X= Neonatal conditions total deaths; A= Neonatal sepsis and infections

B= Birth asphyxia and birth trauma; C=Preterm birth complications

3
MODELS AND LEVELS OF ORGANIZATION

Emmanuel Luyirika, Xavier Gómez-Batiste, Stephen Connor

KEY POINTS

- Palliative care can be provided at all levels and in all settings of the health care system.
- There are different levels of palliative care complexity, from general actions of palliative approach in all settings to referral services or comprehensive / integrated networks in a district.
- Generic criteria of universal access consist of assuring that any patient in need can receive the palliative approach in any setting and, if he has complex needs, will have an accessible specialized service from all settings of a district.
- It is recommended that integrated models of palliative care be established to assure continuity of care across all settings.
- Palliative care programs must include the models and levels of organization.

AIMS OF THIS CHAPTER

This chapter summarises the different models, levels, and types of organisation of palliative care in the context of palliative care programs integrated into the health care systems.

DEFINITIONS

Key principles of palliative care provision include the concepts of **comprehensive care** (responding to all multidimensional needs of patients and families), **integrated care** (into all services and settings, with coordination of care), **quality** (responding with effectiveness and efficiency), and **universal access** (equity, coverage, integration into all levels of the health system). The **values** of

compassion and commitment are needed to care for persons who are in a frail and vulnerable situation.

MODELS OF ORGANISATION

Persons with palliative care needs are cared for and attended to in all settings of the health care system. Palliative care can be provided in all of these settings with different levels of complexity and organisation, according to the needs of patients and their families. In the context of universal coverage, all health care services need to address palliative care.

LEVELS OF ORGANISATION

Several levels of palliative care organisation can be identified (Figure 1).

Figure 1. Levels of palliative care complexity
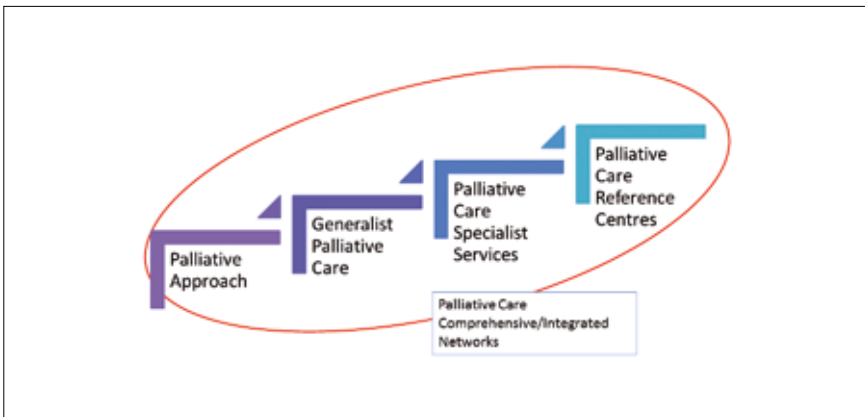
PALLIATIVE CARE APPROACH IN ALL SETTINGS OF CARE

Most health services attend to persons with advanced chronic conditions in different proportions and at different times in their disease process evolution/progression. To assure quality of care and universal coverage for palliative care patients, the palliative care approach must be implemented in all services in the health system, especially primary care (for early identification and with

a population perspective) and other services with the highest proportions of palliative care needs.

The conventional medical services attending higher proportions of patients with palliative care needs are primary care, oncology, geriatrics, HIV/AIDS, and nursing or care homes. But all services have patients in need of different proportions of palliative care involvement.

There are measures that can be taken in any service to guarantee good quality palliative care:

1. Establish and document a policy for palliative approach.
2. Identify patients in need using validated tools; these would identify needs, stratify the population at risk, and determine the prevalence.
3. Establish protocols, registers, and tools to assess patients' needs and respond to most common situations.
4. Train interdisciplinary health professionals and integrate palliative care training and review in the conventional training process (sessions, etc.).
5. Increase accessibility to continuing and emergency care, home care (if primary care services), and access for families in hospitals.
6. Identify the carers of patients and give them support and care, including bereavement support.
7. Increase team approach to jointly assess, plan, and implement care.
8. In services with high prevalence, devote specific times and professionals (see below) with advanced training to attend to palliative care patients (specific times in outpatient settings, specific dedicated areas in inpatient settings, etc.).
9. Establish links and criteria for intervention and access to palliative care specialized services in the area.
10. Evaluate results of the palliative approaches.

GENERALIST / BASIC PALLIATIVE CARE

In services with high proportions of palliative care patients or patients with complex needs, specific professionals could be devoted to look after the patients with more complex needs, give support and training to the other members of the services, and act as references and liaisons for patients and other specialized or conventional services.

Additionally, specific times could be devoted to attend to the patients with higher needs. Some examples could be specific outpatient clinics in an oncology service for advanced patients, or specific times for bereavement or family support,

specific home care visits, or programs of telephone support. In hospitals, patients with palliative care needs can be placed in designated areas (with individual bedrooms, etc.). Or in outpatient clinics, specific times and days can be devoted to these patients. This can also be the first stage before implementing a palliative care specialized service.

SPECIALIST PALLIATIVE CARE SERVICES

Palliative Care Specialized Service (PCSS) are composed of interdisciplinary teams with adequate training focused on and able to deal with complex needs of patients with advanced chronic conditions and their families, giving support to other services, and identified as reference by patients and other services. Teams can be either basic (doctor and nurse with support from other professionals) or having other components (psychologists, social workers, spiritual counsellors, occupational therapists, physiotherapists, pharmacists, and others) with various possible degrees of involvement. Volunteers are recommended as signs of community involvement.

The most relevant element of structure for the PCSS is advanced/specialist training. Structures include:

- Basic or complete multidisciplinary team
- Support teams: acting at hospital, home, or comprehensive networks
- Units: specific beds
- Hospices: organizations devoted exclusively to palliative care provision

PCSS can be based in and adapted to any setting of the health care system, or in specific organisations:

- Primary or community care
- Hospitals
- Nursing (or care) homes
- Socio-health/intermediate care centres that include rehabilitation and long-term care units
- Hospices: organizations exclusively devoted to palliative care
- Specific institutions: paediatric institutions or specific disease centres such as cancer institutes
- Universities that include departments devoted to advanced training and research on palliative care

The main activities performed by PCSS include (differing depending of the type of organisation or setting):

- Care of patients and families in hospital or at home (specialist units or other services): multidimensional assessment, evaluation of values and preferences, decision-making (ethical, advance care planning, elaboration of care plan, follow up, continuing care and case management, bereavement care).
- Support or consultation to other teams and services for needs of complex patients.
- Case management: shared and integrated care across settings, if possible by agreement with all services involved. It implies interdisciplinary team work for the elaboration of the therapeutic plan, follow up, and evaluation of results.
- Research.
- Training (internal/external).
- Evaluation and improvement of quality.
- Advocacy and links to society.

The ideal number for specialist services (teams, units, beds) required should be tailored to the situation of every country and its models of organisation. A generic criterion includes assuring that any patient needing a specialized service will have it accessible from all settings of a district.

MIXED PCSS

The specificity of palliative care services to care for specific types of patients can be decided according to some basic criteria. In some countries, this is a dynamic, stepwise issue, starting with cancer and then extending to other needs. According to the new epidemiologic data showing the higher proportion of non-cancer persons in need, the recommendation to go forward will probably support the implementation of models of mixed patients adapted to the needs of the population in the community and in general hospitals, and combined with specific SPCS in specialised institutions or settings (cancer institutes, paediatric settings, AIDS, dementia, etc.).

There are several criteria for responding to this challenge. In general, community (home care) services could attend all types of patients (looking at the community prevalence figures), whereas there are settings focused to look after specific patients (cancer, etc.). The tendency to promote early/timely palliative care requires an integrated organisation with specific services.

Some generic examples are:

- Community palliative care services need to adapt to the population (mortality and prevalence) needs. In low to middle-income countries of Africa and Latin America, there is high prevalence and mortality of AIDS, multi-resistant TB, malaria and cancer, respectively, whereas in countries with ageing societies, the majority of persons in need are older adults with multi-morbidity and chronic advanced conditions (frailty, dementia, dependency etc.), and specific organ failures.
- SPCS based in specific settings such as cancer institutes, paediatric services and hospitals, or long-term care institutions (geriatric, dementia, chronic) can be specific. The question of the care "atmosphere" is also a relevant factor, especially to care for persons with cognitive or behavioural disorders.
- In acute bed hospitals, the existing experiences have been mainly focused on cancer or individual services. Mixed patient models are currently being developed.
- Palliative care services for specific patients with low incidence and prevalence (Lateral Amyotrophic Sclerosis, Multiple Sclerosis, rare low incidence chronic conditions). These conditions require an individual approach in every country, according to its model of organisation.

EXPECTED OUTCOMES OF PCSS

Accountability and evaluation of results need to be provided, with a realistic level of complexity, based on existing resources, availability of information systems, and training on evaluation. The expected outcomes include:

- Effectiveness in reducing emotional impact of illness, promote adjustment, reduce suffering, improve symptom control and quality of life, and reduce risk of complicated grief;
- Efficiency in the use of resources: reduction of acute hospital and emergency use, unnecessary procedures, therapeutic balance, cost;
- Satisfaction: of patients, families, other services, stakeholders;
- Added value: person-centred care, family-centred care, ethical issues, multidisciplinary approach, care of persons in a vulnerable situation, compassion.

The issues that need to be agreed jointly are:

- Criteria for intervention: as early as possible, based on the complexity, degree of suffering, or demand;
- Mechanisms of intervention: assessment, recommendations, role in the follow up, role in continuing and emergency care, shared decision-making, reconciliation of the treatment between services, shared information system;
- Mechanisms of shared decision-making, coordination, and integrated care: joint meetings, multidisciplinary units, , joint clinical documentation available in all settings;
- Shared care, flexible patterns of intervention, joint policies highly recommended.

CENTRES OF EXCELLENCE

These are tertiary academic centres of excellence that support research, training and specialisation, and are referral centres for care of complex patients. They work together with primary, secondary, and other community initiatives to produce better evidence for palliative care approaches through research, and they train specialists. They are usually based in university hospitals or networks, and close to research institutes.

PALLIATIVE CARE COMPREHENSIVE NETWORKS

Defined as the model of integrated organization of palliative care provision in a demographic scenario (district, sector) in which there is an integrated care route or pathway involving all services, using a methodology of case or disease management, with a leading team intervening in all settings or an agreement between services to guarantee integrated care, coordination, and continuity of care.

In all countries or regions, it is advisable to define models of palliative care organisation according to the demographic scenarios. For instance, in a rural setting with limited population, a palliative care support team service intervening in all settings added to general measures in all settings might be a reasonable model

(even without specific beds), whereas in a metropolitan district, a complex system of palliative care including all levels of services and different units will be needed.

This approach requires leadership and agreements between services and providers, and it can be facilitated by national policies, funding models, leadership of policymakers, and demands of the population. It can also be planned with public health criteria as a palliative care program, including (figure 2):

Figure 2. District palliative care planning
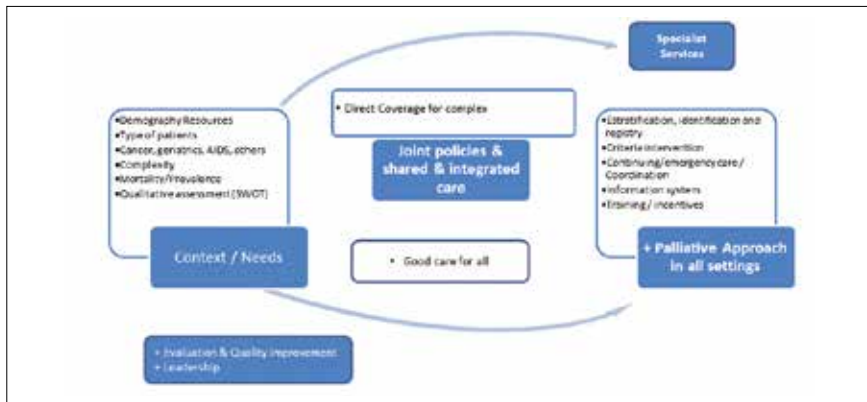
Models of planning, funding and provision of health care:

- Population needs assessment: quantitative and qualitative, based on demography, prevalence, mortality, availability of resources;
- General palliative care approach, with measures in all settings, especially in those with high prevalence of patients in need (general and basic);
- Palliative care specialized services: according to the size/demography of the district, these can be a basic support team acting in all settings for rural districts to several levels of complexity in metropolitan districts;
- The functional aspects must be defined by a formal joint agreement including:
    – How to identify the target population in a timely manner in all settings;
    – Defined roles of services and clinical pathways;
    – Criteria for intervention of conventional or specialized services;
    – Criteria and policy for follow up, continuing care, emergency care, and transitions of care.
- Common information system: shared and accessible by all settings;
- Common evaluation system;
- Funding system: capitated models (globally funding the health costs of a population) enhance integrated care for its efficiency;

- Training for all levels of care;
- Quality evaluation and improvement;
- Involvement of society: participation in the design and follow up.

PALLIATIVE CARE NATIONAL PROGRAMS

Systematic palliative care planning and provision to respond to population needs in a district, region, or country, usually led by the Ministry of Health, and with a public health approach.

EXAMPLES OF PALLIATIVE CARE MODELS

THE ISLAND HOSPICE MODEL IN ZIMBABWE

The Island Hospice is the oldest Hospice in Africa. This model according to Khumalo and Maarsdorp (2016) has six approaches of palliative care services, namely:

- Leveraging relations with private health facilities and Primary Health Care Clinic referrals are made to the Hospice.
- Utilising the referrals from physicians, the Island Hospice staff visit patients in their **homes** to provide services and also do a comprehensive family assessment covering household members and especially the children.
- The Island Hospice also performs **roadside clinics** for delivery of palliative care.
- By utilising volunteers in the community, patients are then able to utilise walk-in opportunities into the hospice.
- The Hospice also offers therapeutic and bereavement care to families.

Capacity building for caregivers is also provided as an aspect of the Island Hospice approach.

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4
DESIGN AND IMPLEMENTATION OF SPECIALIZED PALLIATIVE CARE SERVICES

Xavier Gómez-Batiste, Stephen Connor

KEY POINTS

- Definition: A specialized palliative care service is a health care resource devoted specifically to attending to the complex needs of patients with progressive, chronic life-limiting conditions and their families and to give support to other services. It is composed of a competent interdisciplinary team with advanced training, and clearly identified by patients and other services.
- There are several types and models of PC services, including different activities: support teams, units, outpatient clinics, day hospitals, hospices, comprehensive networks.
- The key factors to establish a new PC service include: leadership, training, institutional support, and the definition of the mission, values, aims, and internal and external consensus on the model of care and organization
- The most relevant aspect of the structure is a highly competent multidisciplinary team.
- The most relevant criteria for success are the combination of good leadership, a competent team, and institutional support.
- The process and activities of a specialized palliative care service are well described.
- There are also transitional models of development.
- Strategic planning and systematic quality evaluation and improvement are needed.

AIMS OF THIS CHAPTER

The aims of this chapter are to describe key elements and practical recommendations for designing and building specialized palliative care (SPC) services with a public health perspective while focusing on the initial founding measures.

DEFINITIONS AND CONCEPTS

A *specialized palliative care service* (SPCS) is a health care resource devoted specifically to attending to the complex needs of patients with progressive, chronic life-limiting conditions and their families and to give support to other medical services. It is composed of *a* competent interdisciplinary team with advanced training, and clearly identified by patients and other services. There are several models of services ranging from basic support teams, which are interdisciplinary teams providing advice and support, to other services at home, in hospital, or within comprehensive systems, inpatient units (beds in hospitals), outpatient clinics; and daycare hospitals. These services can be separate or combined, and can act as a comprehensive network if providing integrated care to all of the resources in a sector, or as a referral service if based in teaching institutions and offering complex interventions, training and research.

We define *transitional measures* as the implementation of specific resources not fulfilling all the criteria of an interdisciplinary team, but devoted to attending to advanced and end-stage patients and their families in services other than the PC service (i.e. individual doctors or nurses providing consultation).

TYPES OF PALLIATIVE CARESERVICES: STRUCTURE, PROCESS (ACTIVITIES AND RESOURCES), OUTPUTS AND OUTCOMES

STRUCTURE, PROCESS, OUTPUTS, OUTCOMES

The most relevant element of the structure of a specialized palliative care service (SPC) is a competent inter-disciplinary team with advanced training and resources, which is able to respond to complex situations. There are several levels of complexity depending on the structure and position in a sector. The processes and activities of a SPC service are described in table 1.

Results from a SPCS can be described in terms of clinical outcomes (effectiveness in relief of suffering, increased patient satisfaction/perception of care), organizational outputs, and utilization outcomes (referrals and admissions, services delivered, reduced length of hospital stay/ER use, length and timeliness of intervention), and others (cost, efficiency, social, or ethical).

Palliative care services can have diverse models of organization, according to the needs of patients and the settings, including inpatient care (in specialist units or support to other services), outpatient clinics, home care, daycare, telephone/online support, continuing care, or emergency care.

Table 1. Common activities (process) of palliative care specialist services

Common activities (process) of palliative care specialist services
Care of patients
Care of families and bereavement follow up
Ethical decision-making and advance care planning
Continuing care and case management
Liaison of resources
Support of other teams
Team work: meetings, roles, support, relations, climate
Registration and documentation
Evaluation of results
Internal training
External training to other services
Research and publications
Volunteers
Advocacy
Links to society

In many countries, a "service" is an administrative concept, and can include different activities or resources (outpatients, inpatient units, support teams, etc.). In others, every activity will be named "service". A "palliative care team" is the specialized professional group providing these services or activities.

ELEMENTS OF SPECIALIZED PALLIATIVE CARE SERVICES

- **Individual specialized (or intermediate level):** individual professionals (usually doctors or nurses) with advanced training acting in other services or in the community. British Macmillan nurses are one example of specialized nurses acting in the community.
- **Outpatient clinics and day care:** can be based in any setting of the health care system, and are crucial for early palliative care intervention and shared flexible models of cooperation.

- **Mobile (or support) teams:** Interdisciplinary teams acting in support of other services. These can be based on hospitals, community/home, or serve a district (acting in all or various settings). The basic mobile team will include a medical doctor and at least one nurse, complemented by others including psychosocial and spiritual professionals, therapy providers and community health workers. Volunteers support the mobile team.
- **Inpatient units** (called hospices in some premises with beds): can be based in any setting of the health care system (hospitals, intermediate care centres, long-term care, nursing homes):
  – Adapted to the organization of health care inpatient services;
  – Must respect privacy, and allow presence and access by families;
  – Units may specialize in caring for different types of patients (cancer, organ failure, geriatric, children, AIDS, dementia, etc., or mixed);
  – Can be based in acute, mid-term, or long-term settings or as individual stand-alone facilities;
  – Size and resources vary according to country and setting, regulations and standards;
  – Processes and model of care are common to all services;
  – Outputs and costs (mean age, length of stay, mortality) will be different according to types of patients.
- **Hospices**: organizations exclusively devoted to care of advanced/end-of-life care patients, and can include all types of activities including home and inpatient care. Generally owned by NGOs but can be part of any system. British hospices were the first organizations implementing modern palliative care in the 1960s, following the leadership and model of St Christopher's Hospice.
- **Comprehensive / integrated networks:** Organizations of specialized palliative care serving a population and acting in all settings of this scenario (hospitals, intermediate settings, nursing homes, community) and acting in an integrated way. In small districts, a specialized support team can be the only specialized resource needed to care in all settings. In districts with different providers, a common care pathway could be the formula for integrated care (figure 1). In metropolitan districts, a complex integrated model can include various levels of complexity.
- **Strategic planning:** mission, vision, values, aims; model of care and organization; Foundation measures / initial steps: aims, priorities, and activities in first year. Several actions need to be adopted in the initial phases of services implementation (table 2).

Figure 1. A model of District Palliative Care Comprehensive Approach
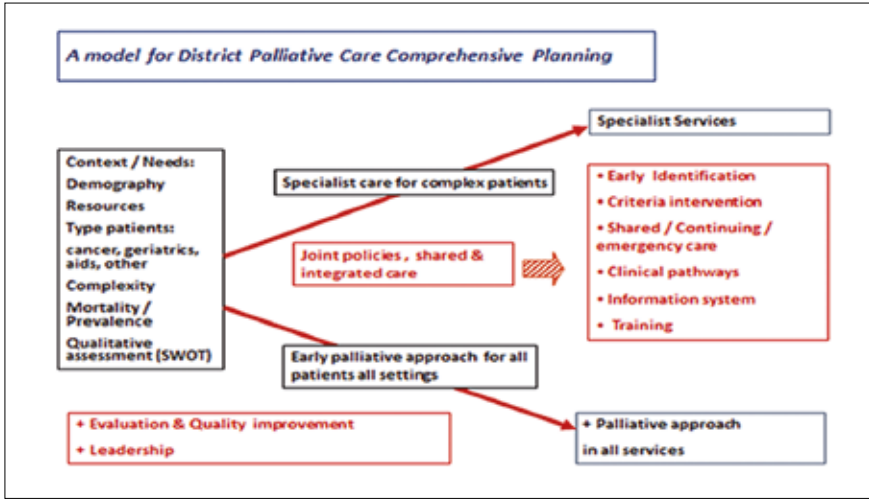
FOUNDATION MEASURES

Table 2. Foundation measures

1. Institutional commitment
2. Context analysis
3. Leadership
4. Defined type of service
5. Target patients and services
6. Mission, vision, principles, values
7. Internal consensus
8. Model of care and intervention
9. Building the team
10. Training
11. Starting clinical activities
12. External consensus
13. Indicators, standards, quality improvement
14. Budgeting
15. Follow up and review

INSTITUTIONAL COMMITMENT

The main stakeholders of a new PC service are the leaders of the institution where the service is planned for implementation.

CONTEXT ANALYSIS

Specialized palliative care services must have a "population" perspective, with the mission and aim of improving the quality of life and relieving the suffering of all persons with advanced chronic conditions in their area of influence as targets. These aims can be achieved with the combination of direct care intervention for patients with complex needs and provision of support and influence in other services through training and sharing information.

The analysis includes the quantitative needs assessment, qualitative assessments, and identification of possible alliances and barriers.

The elements of a context analysis would include:

- Demographic and general characteristics of the area and care setting data, or estimation of mortality and prevalence of cancer and other chronic progressive diseases (ageing, social, economic, cultural aspects);
- Background: previous initiatives and early results: Mapping the existing services and resources, especially in relation to PC including: prevalence of advanced and end-of-life patients and the demand for specialized PC services; defining target services (primary care, oncology, geriatrics, internal medicine, nursing homes); identifying high demand services (emergency wards);
- Qualitative analysis: evaluation of the main relevant dimensions, demands and opinions of patients, relatives, and health care professionals, with a SWOT analysis in collaboration with focal groups, focus groups, or nominal groups. This analysis can be very useful to identify the specific areas of improvement outlined by the different stakeholders and services and to tailor a program adapted to their needs.
- Basal surveys: Some simple basal studies can be very helpful in describing the situation, and also crucial in building up indicators to monitor progress of the service and to evaluate its impact. Some examples of basal studies are: needs of patients (including prevalence of symptoms, severity of key symptoms); use of key drugs (opioids) and changes in the legal status or appropriate use of drugs; use of resources (emergency service, length of hospital stays, admissions and costs of resources in the last weeks or months of life).
- Identification of resistances, barriers, and possible alliances: Barriers to palliative care implementation have been described. These include:

corporate power ("PC must remain in our service…"); denial ("we are already doing so…"); personal (resistance to accept end-of-life care); misunderstandings (PC seen as death or euthanasia); competition ("we have been doing so much better over many years"); and conflict. Some resistances may originate in our attitudes, commitment, or inability to achieve consensus. On the other hand, there are frequent alliances and opportunities to promote PC services. Nursing directors, departments of social work and psycho-oncology, quality-control experts, ethics committees, human rights groups, pastoral-care specialists, and patients associations are all common alliances for services because they identify needs of patients and have shared values of compassion and quality.

LEADERSHIP

The essential aspect of leadership is competence based on personal ability and social skills. There are several key components applied to services (Figure 2) including: core values and principles; clinical knowledge and skills of PC (needs of patients and families, model of care and intervention, therapeutics); organization (quality, organizational, managerial); leadership of persons and teams (motivation, empowerment, respect, support, communication, pre-emption or resolution of conflicts); management of the service product (relationships with stakeholders and clients); strategic vision (identifying tendencies and scenarios and defining ways to respond to challenges).

Figure 2. Competencies of leadership
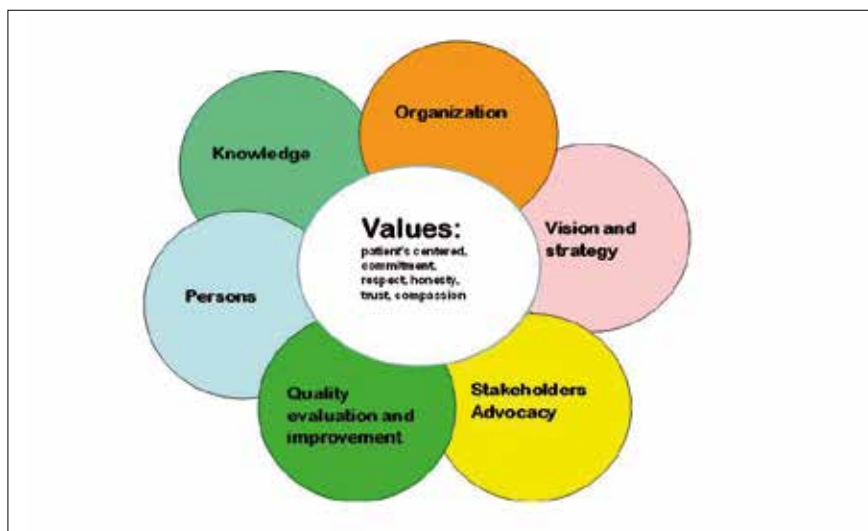
It is important to emphasize that being a competent clinician does not guarantee being a competent leader, and most leadership skills must and can be learned (table 3).

Table 3. Emotional intelligence domains of leadership (Modified from Goleman)[1]

Personal competencies	Self-management	Emotional self-awareness Self-assessment Self-confidence Self-control
	Self-empowerment	Achievement Initiative Optimism Adaptability Transparency
Social competencies	Social awareness	Empathy Organizational Focus on patients
	Relationship management	Empowerment of team members Collaboration and teamwork Inspiration Influence Change catalyst Building bonds Conflict management

DEFINING THE TYPE OF SERVICE AND THE INITIAL STEPS

There are several classifications of specialized services. It is advisable, in some circumstances, to implement gradually the different levels of complexity of the service. A useful strategy is to start with some transitional measures, followed by a support/mobile team, and then develop an outpatient clinic, PC unit, and day-care provision.

In high-income settings there are recent experiences of starting the implementation of a global program of "comprehensive and integrated care for persons with advanced chronic life limiting conditions and their families", of which the palliative care-specific structure is one of the pieces, but not the only one. This approach can be useful to involve all services from the beginning, practising a global perspective.

1. Goleman D. What makes a leader? Harv Bus Rev. 1998;76(6):93-102.

DEFINING TARGET PATIENTS AND SERVICES

The usual targets of an SPC service are advanced and end-of-life patients suffering from progressive chronic diseases with limited prognoses. According to the type of service and the setting, target patients can be specific (cancer or other disease) or mixed. Frequently, SPC begins with cancer patients and is then extended to the care for other types of patients. The alternative approach is to start by providing care for patients near the end of life with a one-way pattern of intervention. Subsequently, there can be a gradual introduction of early intervention and a flexible pattern based more on the complexity of needs. The defined target services must also be introduced gradually. Frequently, the initial selection is based more on feasibility and attitudes rather than on needs.

MISSION, VISION, PRINCIPLES, VALUES

The mission of an individual service is its reason to exist, with an open, high and wide conception. It is recommendable to transcend the common objectives focused in the care or patients and propose a wider ambitious scope. An example could be "Relief suffering and promoting quality of life in a context" (setting, district, etc) instead of "looking after terminal patients", which is more an operational objective than a mission.

The vision is the definition of development and excellence at the long term, usually built up after looking at most developed models in similar contexts. There are solid international references of the various types of palliative care services that could be adapted and adopted in the project.

The principles and values are the statements which dominate our project. Traditional values of palliative care services are to provide comprehensive care of people in a vulnerable situation, compassion, respect, ethical commitment, multidisciplinary attitude. These can be associated with the principles and values of public health approaches, as equity and accessibility, quality (competence, effectiveness, efficiency, accessibility, safety), and accountability and sustainability, among others.

INTERNAL CONSENSUS

The teams need to share principles and values and to invest in achieving the core consensus, which will enable the service to be built on solid foundations. The most important areas of internal consensus are:

- **Conceptual and strategic consensus**: Mission, vision, principles and values.

The mission of an individual service is the reason for its existence; the concept of the mission being open, high, and broad. Vision defines the long-term development and quest for excellence, usually built up after evaluating other models developed within similar contexts. Principles and values are the statements governing the project. Traditional values of SPC services are to provide comprehensive interdisciplinary care for individuals in a vulnerable situation by employing clinical competence, compassion, respect, and ethical commitment. These attributes can be incorporated within the principles and values of a National Health Service and are highlighted as equality of access, quality of care (competence, effectiveness, efficiency, accessibility, and safety), accessibility, accountability and sustainability.

AN AGREED MODEL OF CARE AND INTERVENTION BASED ON THE PRINCIPLES OF SPC

The models of care and of intervention must be clearly defined since, together with advanced training, these are the most relevant issues that guarantee good care for patients and their families. We define the micro-organization of SPC as: the systematic approach to multi-dimensional needs of patients and their families; SPC practiced by a competent inter-disciplinary team using clinical ethics and advance care planning as the method for decision-making; and the application of continuity and case management methodology for follow-up. The proposed model of care is based on the model of needs identified by patients and their families, and the model of intervention is defined within the context of care.

Therapeutic consensus consists of defining and standardising the basic therapeutic principles based on experience and evidence. The agreement is consensual among team members with respect to the treatment of the patient's condition, and the requirements of their families. This consensus is built by devoting time and effort to discussing cases and bringing together the experience of all members of the team (Figure 3).

BUILDING UP THE INTERDISCIPLINARY TEAM

The criteria for selecting members of the team would include experience, interest in SPCS, and good clinical training in PC as well as in allied fields. Personal aspects include: respect for the values, beliefs and opinions of others; ability to relate to and interact effectively with individuals and groups; a willingness to cooperate in reaching common goals; respect among peers and other leaders; time to devote to the initiative. If there is no previous SPC experience or training, this aspect must be considered as the first priority, since advanced competence

is the most relevant factor for success. Local experienced professionals are more accepted by target services.

Figure 3. Table of Care and Organization

TRAINING (CLINICAL, ORGANIZATIONAL, LEADERSHIP)

It is crucial to define and implement clinical training of key members of the team so as to provide care that is seen to be exemplary. Advanced clinical training aims to achieve a high level of knowledge and skills to be able to respond to complex needs of patients and their families. In lieu of formal mechanisms of training (such as a formal medical training or Macmillan-type nursing specialty), an improved level of training can be achieved by programmed visits of health care personnel to existing advanced services, combined with on-site monitoring and tutoring from established experts. Organizational training is oriented towards dealing with the challenges of services as organizations, and is focused mainly on team leaders. The specific organization of PC services can be achieved with a formal methodological/managerial training, and by team leaders visiting sites of advanced services in similar settings. Leaders must have training in leadership skills in dealing with organizations, individuals and teams. Another component of training for service leaders is to achieve a global public health perspective.

In the initial phases of development, it is also advisable to have external expert support, tutorship, mentorship, modelling, and counselling. Twinning with already-established services can be a good reference point for new projects.

STARTING CLINICAL ACTIVITIES

Different activities (including inpatient care vs. home care, support of other teams, outpatient clinics and day care hospital units) can be started gradually. It is advisable to start care activities based on feasibility and resources available. Planned activity in the initial phases must devote time and space to the task of team building. Frequently, small over-committed teams in high-need areas make the mistake of offering services and activities that are not sustainable over the mid- to long-term due to the limited resources available. This can lead to excessive workload and "burnout".

Some examples of this gradual approach include: in-hospital support teams; focusing on a few target services for inpatients alone; increasing and subsequently expanding other services and outpatient clinics; then in-home care services. A good approach is to select the most accessible clinical area and to focus on target patients (such as cancer patients, initially) in primary care and to expand gradually into other areas. There are many limitations in early stages of implementation that will need to be acknowledged, and accepted, by the team. Some examples are: late intervention when the patient is nearing end of life; limitations with respect to the team's own capabilities (e.g. difficulty in offering 24-hour coverage with a restricted number of healt hcare personnel); absence of other resources (lack of specialist beds, or home-care services, or both).

Developmental Phases of Teams and Services

There are several ways of describing the evolution of services and teams. One view is based on the time and phases of consolidation of services ranging from project initiation to its consolidation and to progress towards more advanced phases. Each phase has its specific objectives. These include: leadership and strategic planning in the project; building the team; basic consensus in the initial phase; activities towards developing the consolidation phase, maturation, and coverage in the advanced phase.

Tuckman's model[2] proposed the following typical phases in team development: "forming" (the team members start working together and build up the basic rules and functions, to feel part of a group); "storming" (members are more active and clear about their roles, some conflicts can appear); "norming" (procedures, decisions, and conflicts resolution); "performing" (tasks definitions); "evaluating and reviewing" (systematic review to identify areas for improvement and to propose actions).

2. Tuckman, B. Psychological Bulletin; 1965 (6): 384–99.

EXTERNAL CONSENSUS: RELATIONSHIPS WITH OTHER SERVICES AND SPECIALIST-GENERALIST SERVICE INTERFACE

External consensus needs to be built initially with stakeholders or partners (managers, board members, internal clients). Organizational leadership needs to support the introduction of SPC.

The "internal clients" of support/mobile teams and all specialized services are the other services within a defined health care provision, either primary care, or other specialist services.

For palliative care services based in specific settings or services (cancer institutes, community services, etc.), the best model is full integration and shared care, including joint assessment, elaboration of therapeutic plans, and follow-up from early phases of disease.

There are several recommendations to take into consideration in defining the criteria for intervention in other existing services, or admission of patients in the new service:

- SPC must have a "proactive" attitude of cooperation with target services, based on the early identification and joint criteria of their intervention of patients in need, and tailoring the intervention according to the needs and demands of these services.
- The weighting of prognosis as a criterion tends to diminish as the service becomes more developed. Once the service is consolidated, the most important intervention criteria for a specialized service must be the level of complexity/suffering and needs of the patients and their families.
- The offer of services needs to take limitations on both sides into account (e.g. continuing or emergency care) according to the resources available and realistic goals, and to clarify the demands of other services involved.
- Promoting proactive, early, flexible, cooperative, shared and bi-directional formulae of care planning is preferred in which the reference SPC service defines and shares responsibilities according to changing needs and demands of patients and their families, while avoiding rigidity.
  – A dynamic model of shared care intervention is developed.

The model of intervention jointly agreed with generalist services includes:

- Criteria of intervention based on screening of patients in need of specialized intervention (figure 4);
- Methods for evaluating patients;

Figure 4. Criteria for SPC Intervention
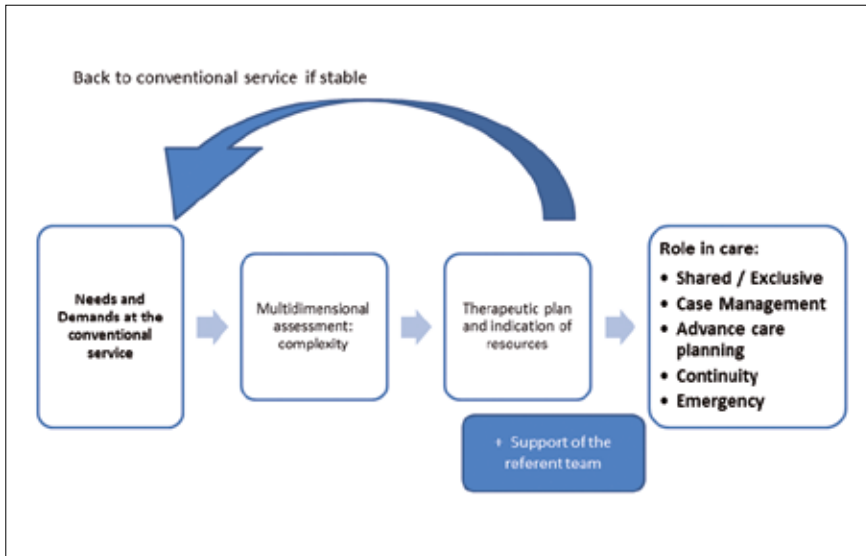
- All interventions need to be based on a multi-dimensional assessment and the establishment of a multidimensional interdisciplinary therapeutic care plan;
- Roles in the follow-up must be defined:
  – Shared vs. exclusive
  – Continuity and case management roles
  – Decision-making and advance care planning
  – Criteria for crisis prevention and management
  – Criteria for transitions among services
  – Emergency care
- Agree on the information system.

Organizational consensus

This is oriented towards building up basic aspects (workload, timetable, common documentation, care for patients and their families, and team activities) and the processes of care. Optimal workload can be achieved later. Another key issue is to organise regularly scheduled team meetings, with clear objectives and agenda. Team consensus is focused on establishing the roles, functions, and criteria for intervention by members of the team with a view towards quality of internal relations, and the prevention of crises through the development of an interdisciplinary team care plan. Communication, flexibility, respect, assertiveness, crisis prevention, and empowerment are values needed for a team approach.

Consensus on quality and evaluation will establish agreements on indicators and standards for evaluating the service.

EVALUATION AND QUALITY IMPROVEMENT

A formal evaluation and quality improvement process must be designed from the beginning. Some outputs and outcomes and indicators can be selected to describe and evaluate the services in the initial phases. To describe a service, there are several components:

- Context (served population, target population, target services, institutions, stakeholders, settings, etc.);
- Mission, vision, aims, principles, values;
- Demographics of patients: diagnoses, age, sex, primary caregiver, acuity, complexity;
- Structure:
  – Team
  – Training of the team members (the most relevant component of structure)
  – Units, beds, clinics, technical devices
  – Documentation, policies, protocols
- Outputs:
  – Activity done: new patients admitted, interventions, place/quantity of home visits by discipline, consults performed, hospital days, clinic visits, day care days
  – Length of interventions, advance care planning
  – (In units): average and median length of stay/service, mortality
  – Shared care (with other services)
- Outcomes:
  – Clinical:
    – Effectiveness (degree of improvement): pain and other symptoms, suffering, etc.
  – Satisfaction/experience of care: of patients, families, other teams, stakeholders
  – Economic:
    – Cost
    – Efficiency
  – Other:
    – Social impact

BUDGETING

In order to budget for a SPC service it is necessary to know the costs of care in a particular country and setting. Several methods for costing palliative care have been published and can be used to conduct a costing exercise. Ideally payment for palliative care services should come from government health funds as the cost of caring for the sickest patients is already affecting the health budget and there are many reasons that palliative care can help alleviate costs through prevention of unnecessary testing, treatment, and especially hospitalization.

FOLLOW-UP AND REVIEW

Services must regularly review their quality, performance, and strategic plans. A mixed methodology combining quantitative and qualitative methods with the active participation of professionals, patients and families, and key stakeholders is suggested.

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Palliative Care Toolkit and Training Manual: Improving care in resource poor settings. Worldwide Hospice Palliative Care Alliance. Accessed November 2016 at: http://www.thewhpca.org/resources/category/palliative-care-toolkits-and-training-manual Canadian Hospice Palliative Care Association.Applying A Model to Guide Hospice Palliative Care: An Essential Companion Toolkit for Planners, Policy Makers, Caregivers, Educators, Managers,Administrators and Researchers. 2005. Accessed November 2016 at: http://www.chpca.net/media/7458/Applying_a-Model-to-Guide-Hospice-Palliative-Care-Toolkit.pdf

5
IMPLEMENTING A PALLIATIVE CARE APPROACH IN THE COMMUNITY AND ALL SETTINGS OF CARE

Geoff Mitchell, Xavier Gómez-Batiste, Scott Murray

KEY POINTS

- There is a growing prevalence of mortality from advanced progressive chronic conditions.
- Patients with palliative care needs are present in all settings of care.
- Most are living in the community, at home or in care homes.
- There are simple, effective and feasible tools and methods for timely identification of these patients in all services.
- There are effective methods described to look after these patients to improve the quality of palliative care, and to develop integrated models of organization in all settings.
- Palliative care must be one of the elements integrated in a health care system, and inserted in the policies of chronic care programs.
- The community must be involved in increasing awareness about and the development of palliative care support in the community.

AIMS OF THIS CHAPTER

To describe the concepts of integrated palliative care using a global palliative approach and a community-oriented perspective, and propose methods to implement this in all settings of care.

INTRODUCTION

The promotion of palliative care as an essential element of every health system was ratified by the World Health Assembly in May 2014[1]. This very significant step

1. World Health Assembly. Resolution WHA67.19. Available at: http://apps.who.int/medicinedocs/en/d/Js21454en/ Accessed August 2016.

recognized the provision of high quality care for persons with advanced chronic conditions at the end of life as fundamental to the provision of good quality health care more broadly. The objective of this chapter is to explain how much of the care of dying people can be provided in the community and indeed in all settings of the health care system, mainly by health professionals who undertake this care as generalists, not by specialist practitioners, and how to achieve this.

WHY A PUBLIC HEALTH APPROACH?

The care of people with chronic advanced conditions, and palliative care needs is one of the most relevant challenges for health care systems. There is a growing prevalence (more than 1% of the population) and mortality (more than 60% of deaths) due to advanced chronic conditions (ACC) in all countries. These patients are mostly based in the community, but present in all settings of care. They use all types of resources.

The current approach to the care of these patients is late, fragmented, and reactive to crisis. It uses a model mainly seen in the care of end-stage cancer patients, with a tendency to use emergency and hospital beds at a high cost. There is also an enormous amount of suffering that could be alleviated by a more comprehensive approach.

The response to this challenge consists of a public health approach, with a population-based perspective responding equitably to the need for palliative care rather than according to diagnosis. Implementing the palliative approach can be done in all settings by promoting integrated systems of care, combining this general approach with referral to specialized palliative care services to manage the complex cases. This approach will promote and achieve coverage for all types of patients and their families, in all settings of care, meeting all dimensions of need with principles of universal access, equity, quality, and efficiency.

WHY A PRIMARY CARE AND COMMUNITY PERSPECTIVE?

Most people with advanced chronic conditions with palliative care needs are living in the community, and can be identified there by their primary care professionals. This is a crucial issue for establishing a population-based policy aimed at achieving universal palliative care coverage. Additionally, there are people with palliative care needs in all settings of care in variable proportions.

Murray et al., describe the scope of primary palliative care, which is to strive to:

- reach patients with all chronic conditions and limited life prognosis;
- start a palliative approach early in the course of the illness and treatment;
- meet all dimensions of need: physical, social, psychological and spiritual;
- provide care in all settings: clinics, care homes and at home, thus preventing unnecessary hospital admissions;
- support family caregivers and provide bereavement care;
- promote community involvement in supporting people with advanced illnesses.

Primary care practitioners and community nurses are in a good position to achieve these objectives. They are located in the community, among those with whom they work. They know their communities' resources and how to access them. They work with individuals and their families, thereby understanding their contexts, attitudes, and beliefs. In some settings, they are the gatekeepers to the secondary and tertiary sectors of the health system. They can use all of these strengths to treat people in an effective way. It has been well established that the greater the investment in the primary care system, the healthier the population[2]. The WHO has developed a public health strategy for palliative care, which encourages examining the challenges of providing end-of-life care[3].

HOW DO THESE CHALLENGES PLAY OUT IN COMMUNITY-BASED END-OF-LIFE CARE?

Murray and colleagues developed a tool to assess the facilitators and barriers to effective primary care involvement in palliative care, using a conceptual model of a public health approach to palliative care development that has four elements: policy, education, implementation, and drug availability[4]. They conducted a Europe-wide survey identifying the facilitators and barriers to primary care participation at the end of life. Table 1 reflects their main findings from twenty countries representing a range of health systems.

2. Starfield B. Primary care: an increasingly important contributor to effectiveness, equity, and efficiency of health services. SESPAS report 2012. Gac Sanit. 2012 Mar;26 Suppl 1:20-6.
3. World Health Organization. Infographics on Palliative Care. Available at: http://www.who.int/ncds/management/palliative-care/pc-infographics/en/ Accessed October 2016.
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Table 1. Facilitators and barriers to high quality primary care involvement in end of life care in Europe

Barriers	Facilitators (examples from some countries)
Implementation: **Lack of professional or specialist support structure** **Financial systems not permitting reimbursements for palliative care** **Competing demands in primary care** **Limited public understanding of palliative care**	Examples of established multidisciplinary primary care infrastructure and financial incentives Developing clinical networks and referral pathways GP accessibility to all patients
Education: **Poor identification of patients requiring palliative care** **Lack of knowledge and skills within primary care**	Training opportunities available in some countries
Policy and availability of medicines: **Problems with opiate prescription**	National strategies supporting palliative care and access to medicines Increasing political support and public advocacy campaigns since WHA resolution 2014

WHO: World Health Organization; GP: general practitioner.

Almost all high-income countries have established general practice/primary care networks. The involvement of primary care in palliative care in each country is variable, but depends on the organization of its health system. The main barriers to participation include: lack of remuneration for palliative care activities, payment for home visits or for keeping a register and review of identified patients); the presence or absence of community nursing working in conjunction with primary care; and the absence in many places of specialist support and referrals.

The presence and capacity of primary care varies widely in low and middle-income countries. Some form of primary care is usually available through doctors or community nurses, although in some parts of the world a significant percentage of the population may never see a professional health worker in their lifetime.

IDENTIFICATION AND CARE OF PEOPLE WITH ADVANCED CHRONIC CONDITIONS IN PRIMARY CARE AND OTHER SERVICES

The above discussion highlights the issues from the system perspective. However, there are several points that guide the clinical management of end-of-life care.

IDENTIFY PEOPLE WITH PALLIATIVE CARE NEEDS AND LIMITED LIFE PROGNOSIS

Identification is the vital first step before promoting the gradual insertion of a palliative approach and perspective-oriented quality of life in the care of these patients, as well as a prognostic awareness that might help to establish therapeutic goals. This starts with the assessment of multidimensional needs and launch of an advance care plan and case management processes. This approach will minimize some of the risks of identifying the wrong people such as foregoing curative opportunities.

One of the greatest challenges facing primary care practitioners is the timely identification of patients who need palliative care. Problems include finding reliable means of early identification or screening that allows for planning, and then determining how to apply such instruments. Several such instruments have been developed (table 2)[5].

These tools have many common and some specific contents, and are in various stages of testing for validity and reliability (table 3). They have to use information available to the clinician, and be able to identify the majority of people in need of palliative care and at some risk of deterioration and dying. For this reason, tools may be context-dependent, as different health systems will collect different clinical data. For example, a hospital-based instrument to anticipate impending death may not work in community settings because of different data being available.

The next question is whether people should be identified within general practice by screening patient lists. Screening is likely to work better in settings with a defined population or with a high prevalence of patients at risk, for example elderly care facilities. In centres looking after a population, the target population of patients with advanced chronic conditions likely to have those needs is easily identified by applying the tools to a previously selected cluster of the population of people by conditions (complex chronic, multi-morbid, advan-

5. Maas EAT, Murray SA, Engels Y, et al. What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice. BMJ Supportive & Palliative Care 2013;3:444–451.

ced frailty), old age, or using criteria such as acute emergencies, home care or hospital admissions, or medication use.

Table 2. Tools available for identifying patients at risk of dying in the foreseeable future

Prognostic Indicator Guide at the Gold Standards framework (PIG)[1]
Supportive and Palliative Care Indicator Tool (SPICT)[2]
NECesidades PALiativas (NECPAL–CCOMS-ICO)[3]
RADPAC[4]
Residential Care Homes Steps End of Life Care Tool Kit[5]
The CARING criteria[6]

1 Prognostic Indicator Guidance (PIG). 4th ed., October 2011. The Gold Standards Framework Centre In End of Life Care CIC, http://www.goldstandardsframework.org.uk (accessed August 2016).
2 Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Support Palliat Care. 2014 Sep;4(3):285–90.
3 Gómez-Batiste X, Martínez-Muñoz M, Blay C, et al. Identifying chronic patients in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. BMJ Support Palliat Care 2013;3:300–308.
4 Thoonsen B, Engels Y, van Rijswijk E, Verhagen S, van Weel C, Groot M, et al. Early identification of palliative care patients in general practice: development of RADboud indicators for Palliative Care Needs (RADPAC). Br J Gen Pract J R Coll Gen Pract. 2012 Sep; 62(602):e625–31.
5 StChristopher's 2016. Available at: http://www.stchristophers.org.uk/steps (accessed October 2016)
6 Fischer SM, Wendolyn SG, Sauaia A, Sung-Joon M, Kutner JS, and Kramer A. A practical tool to identify patients who may benefit from a palliative approach: The CARING criteria. J Pain Sym Man. 2006;31(4):285-292.

Table 3. Content of the different tools available (summary)

List of possible targets: Old age, chronic conditions, use of resources
Patient request to start palliative care or limit disease treatment, or need identified by professionals
Surprise question: Would you be surprised if this patient were to die in the next 12 months?
Clinical decline (sustained, progressive, not related to acute crisis): Functional, nutritional, and/or cognitive Advanced frailty Persistent symptoms Psychosocial distress Geriatric syndromes: Falls, dysphagia, delirium, sores, infections
Multi-morbidity
Recent use of acute and/or emergency services, repeat hospitalization, increase in demand for care
Disease specific indicators of progression to death eg CKD 4 or 5

UTILITY OF THE CURRENT TOOLS: PREVALENCE OF PEOPLE WITH PALLIATIVE CARE NEEDS, AND PROGNOSTIC ISSUES[6]

The current tools can be used for identifying people with palliative care needs[7] and needing a palliative approach, and therefore establishing the prevalence of these people in services[8] or populations[9]. Some of the tools can be also used as checklists to describe their needs. Although this was not the primary aim of developing the tools, there is growing evidence about their usefulness for identifying people at risk of deterioration and dying[10].

ADDRESSING THE ETHICAL CHALLENGES OF EARLY IDENTIFICATION

The ethical challenges of early identification are related to minimization of the risks (stigmatization, losing curative opportunities, or impact on patients and families). The best option consists of promoting the real benefits of introducing the palliative care approach early, multidimensional assessment, advance care planning and case management. The active participation of patients, combined with clear information shared to all services involved, and training to fall professionals is important. The participation of ethical committees to assess for possible harm and distress is also recommended.

6. Cancer, Moss AH, Lunney JR, Culp S, Auber M, Kurian S, Rogers J, et al. Prognostic significance of the "surprise" question in cancer patients. J Palliat Med. 2010 Jul;13(7):837–40.

7. Emanuel LL, Alpert HR, Emanuel EE. Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. J PalliatMed. 2001;4(4):465–74.

8. Grbich C, Maddocks I, Parker D, et al. Identification of patients with non cancer diseases for palliative care services. Palliat Support Care 2005; 3(1): 5–14.

9. Gómez-Batiste X, Martínez-Muñoz M, Blay C, et al. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: A cross-sectional study. Pall Med 2014; 28 (4): 302-311.

10. Elliott, M., Nicholson, C. A qualitative study exploring use of the surprise question in the care of older people: perceptions of general practitioners and challenges for practice. BMJ Supportive & Palliative Care 2014. doi:10.1136/bmjspcare-2014-000679.

Espaulella J, Arnau A, Cubí D, Amblàs J, Yánez A. Time-dependent prognostic factors of 6-month mortality in frail elderly patients admitted to post-acute care. Age Ageing. 2007;36(4):407–13.

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IMPROVING CARE OF IDENTIFIED PATIENTS AND ESTABLISHING A SYSTEMATIC APPROACH OF PROACTIVE CARE PLANNING

The actions following identification of patients are listed in table 4.

Table 4. Elements of comprehensive care planning for identified patients

Systematically assess needs of patients and caregivers
Identify values, goals, preferences: advance health directives
Review diseases and conditions
Review pharmacological treatment
Build a shared comprehensive advance care plan including preferred place of care,
Identify and support family caregivers
Start case management and design team responsible for continuing and emergency care
Share and coordinate with other services
Address related ethical issues

STARTING ADVANCE CARE PLANNING

Develop a process that takes into account how primary care is organized and how medical records are kept. The important tasks of proactive planning include:

- Conduct multidimensional assessment with validated tools addressing needs identified in all dimensions (physical, emotional, social, spiritual, financial, bereavement, and other);
- Review the point of the patient in the illness trajectory:
  - Identify possible complications
  - Identify possible scenarios of needs and care
- Identify patients' values and preferences and establish/update the goals of care with patient (see next 3 points);
- Review the current treatment and adapt to the new goals:
  - Adequate to new established goals
  - Describing if needed
  - Coordination among the different services involved

Once a person is identified as being in need of palliative care and at risk of dying, it is an ethical imperative and incumbent upon the clinician to respond by developing a plan to deal with the likely problems that may arise. Problems at this stage of life cover a wide spectrum, including symptom control, psycho-social

and spiritual concerns, and practical concerns like finances, power of attorney and provision of home nursing, identifying and addressing carer needs, and after-hours arrangements.

ENGAGE THE PATIENT AND FAMILY IN DECISION-MAKING

A comprehensive plan cannot be made without input from the sick person and their family. Understanding their goals of care and what sorts of treatments they want or do not want is essential in developing the plan. This process takes time, and may be a task undertaken by dedicated clinical staff and over a few consultations. The outcome of this planning process is often a document termed an advance health directive or living will. Some countries have enacted laws that give these documents legal status. This sort of planning is very effective in influencing the nature and place of care offered.

A clinical approach to care planning and a clear understanding of the goals of care expressed by the sick person and their caregivers can be combined to ensure that a comprehensive clinical care plan can be developed and enacted. Within the family, the caregivers need to be identified and involved in the plan of care, empowering their capacity for practical and emotional care of patients, and offering education and support to adjust to the situation and reduce the risk of burnout. Identification and attempts to meet their needs can improve their well-being, and also improve the care of the person they are caring for. Two tools are available for use. The CSNAT is a tool validated for caregivers of people in palliative care settings, and the NAT-C is a checklist that can guide a general practitioner to identify and address caregivers' needs.

ORGANIZE THEIR CARE IN THE SERVICE AND IN OTHER SETTINGS

Once the goals of care have been agreed upon and therapeutic plans defined, a plan of care must be designed and implemented with case management methodology, with a preventive approach, and including:

- Sharing assessment, plans, and follow-up with the team;
- Defining the team leader for this person;
- Defining the role of the service and others in:
  – Conventional follow-up
  – Shared or individual decision-making

- Prevention and care of urgent situations
- Planning transfers between services
- Sharing goals and information with other involved services in the district.

HOW TO IMPROVE THE QUALITY OF PALLIATIVE CARE IN PRIMARY CARE AND OTHER CONVENTIONAL SERVICES

All health care services – especially primary care, geriatrics and palliative care – need to establish specific policies to respond to the needs of these patients and their families (table 5).

Table 5. Actions to improve palliative approach and care in primary and other health care services

Establish and document a formal policy for enabling a palliative approach for all people.
Identify patients in need with validated tools: this would identify needs, stratify the population at risk, and determine prevalence.
Establish protocols, registers, and tools to assess patients' needs and respond to most common situations.
Train professionals and insert principles of palliative care training and review into the conventional training process.
Increase accessibility to continuing and emergency care, home care (if primary care services), access to families (in hospitals).
Identify the caregivers of patients and give them support and care, including for bereavement needs and their own medical needs.
Increase team approach to jointly assess, plan, and implement care.
In-services with high prevalence; devote specific times and professionals with advanced training to attend palliative care patients (possibly with specific times in outpatient settings, specific dedicated areas in inpatient settings, etc.).
Coordination and integrated care in the area: Establish links and criteria for intervention and access to Palliative Care Specialized Services (PCSS) in the area and with all specialities.
Evaluate results of the palliative approach.
Address the ethical challenges of over and under early identification.
Involve patients and society in the design and evaluation.

INVOLVING THE COMMUNITY IN PALLIATIVE CARE PROGRAMS: THE KERALA MODEL AND THE COMPASSIONATE COMMUNITIES PROJECTS

The process of death and dying is a social and community matter. The community needs to be involved actively in planning, implementing, and evaluating palliative care policies. Additionally, this approach will empower the community and promote a change of social perspectives and adjustment to the process of death and dying to consider death a natural event.

The hospice movement has always been strongly linked to community through the involvement of society, volunteers, and donors.

The Kerala model of Public Health Palliative Care involved the community in the planning of services, the identification of persons in need, the activation of the community response to global and individual needs, and the funding.

More recently, programs of "compassionate communities" have been designed, with the aims of involving more actively all of the society in a change of perspective towards death and dying, the care of dying persons in need of support, and enhancement of all social agents (NGOs, social organizations, schools, local administrations) to address their policies and activities. These are example of promoting health and wellbeing in the face of death, and similar innovations should be considered to fit the local culture, using a Health Promoting Palliative Care Approach as advocated by Kellehear[11].

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6
ACCESS TO ESSENTIAL MEDICINES

Liliana de Lima, Gilles Forte

KEY POINTS

- Essential medicines (EM) are the minimum medicines for a basic health care system, including the most efficacious, safe, and cost-effective medications for priority conditions that satisfy the primary health care needs of the population. EM should always be available, affordable, and used adequately.
- Access to EM as part of the right to the highest attainable standard of health ('the right to health') is well founded in international law.
- Millions of people do not have access to EM, including medications needed to relieve pain and treat symptoms common in palliative care.
- More than 4 billion people live in countries where regulatory, cultural, and economic barriers and lack of education leave patients suffering excruciating pain.
- The WHO constantly updates its Model List of Essential Medicines and has published guidelines that can help countries develop and implement a comprehensive policy appropriate to their own needs and resources.

Non-governmental associations and academia play critical roles in offering technical support and guidance to governments. They can also provide valuable information to government representatives and policy makers about access to treatment and care.

AIMS OF THIS CHAPTER

The main objective of this chapter is to provide information and tools to governments and procurement officers so that they take the necessary steps to ensure that patients with palliative care needs have access to the medications needed to relieve suffering.

Secondary objectives are to:

- Describe the concept of essential medicines and the process for developing a list of essential medicines for pain and other symptoms common in palliative care.
- Provide guidance to national governments to implement appropriate medicine policies at the national level.
- Present the World Health Organization Model List of Essential Medicines as a sample for governments to use.

INTRODUCTION

The "Essential Medicines" (EM) concept developed by the World Health Organization (WHO) states that there is a list of minimum medicines for a basic health care system, including the most efficacious, safe, and cost-effective ones for priority conditions that satisfy the primary health care needs of the population[1].

Thus, EM should always be available, affordable, and used adequately. The core of the concept is that use of a limited number of carefully selected medicines that are effective, safe, and affordable leads to a better access of medicines with demonstrated public health value, to their improved rational prescribing and use, and to better health for the people.

ACCESS TO ESSENTIAL MEDICINES IS PART OF THE RIGHT TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH

Access to EM as part of the right to the highest attainable standard of health ('the right to health') is well founded in international law. The right to health first emerged as a social right in the WHO Constitution[2] and in the Universal Declaration of Human Rights[3]. The binding International Covenant on Economic,

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1. WHO. Essential Medicines: Definition and Concept. Available in http://www.who.int/medicines/services/essmedicines_def/en/index.html. Accessed March 6, 2015.
2. WHO. Constitution of the World Health Organization (July 1946). Available in http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf. Accessed February 26, 2015.
3. UN. The Universal Declaration of Human Rights Article 25 (1948). Available in http://www.un.org/en/documents/udhr/. Accessed April 1, 2015.

Social, and Cultural Rights (ICESCR) of 1966 details the progressive realization of the right to health through four concrete steps, including access to health facilities, goods, and services[4]. The General Comment 14 further applies the principles of accessibility, availability, appropriateness, and assured quality to goods and services, which include EM as defined by the WHO[5].

Access to EM is one of the 6 WHO Leadership Priorities for 2014-2019 endorsed by WHO member states; the 2014 World Health Assembly (WHA) Resolution on Access to Essential Medicines; the 2014 WHA Resolution on Palliative Care; The UN Global Action Plan on Non-communicable Diseases; and The 2010 WHO World Health Report on Universal Health Coverage.

The first section of this chapter provides an overview of the current situation of access to essential medicines in general, access to essential medicines for pain treatment, and the process for developing a list of essential medicines for pain and other symptoms common in palliative care. The second section of the chapter provides a summary of the WHO strategies and recommendations for essential medicines at the national level, as well as guidance to develop and implement National Medicine Policy for member states.

ACCESS TO ESSENTIAL MEDICINES IN PALLIATIVE CARE

GLOBAL SITUATION

Although there are no reports specifically on access to EM used in palliative care, many global reports include medicines used in palliative care such as strong analgesics, antidepressants, laxatives, and others. Lack of access to opioids is a problem that has been highlighted by UN agencies[6], as well as by Non-Governmental Organizations (NGOs)[7]. The WHO estimates that 80% of the world's

4. International Covenant on Economic, Social and Cultural Rights. Article 12. NY: UN (1996). Available in http://www.ohchr.org/en/professionalinterest/pages/cescr.aspx. Accessed March 30, 2015.
5. UN. ECOSOC. General Comment No. 14. The right to the highest attainable standard of health NY: UN (2000 E/C.12/2000/4).
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   INCB. Three quarters of the world has limited or no access to pain relief medications, says INCB Report. Press Release, UNIS/NAR/1230; Vienna: INCB, March 2015. Available in http://www.unis.unvienna.org/unis/en/pressrels/2015/unisnar1230.html. Accessed March 30, 2015.
7. UICC. Global Access to Pain Relief Initiative (GAPRI). Available in http://www.uicc.org/programmes/gapri. Accessed April 2, 2015.
   ESMO. Global Opioid Policy Initiative – Striving for patient access to pain relief medicines.

population, including tens of millions of people worldwide who suffer from moderate to severe pain, does not have adequate access to pain treatment. This includes 5.5 million terminal cancer and 1 million end-stage AIDS patients[8]. Results from the Global Opioid Policy Initiative (GOPI) reveal that due to a lack of access to inexpensive and effective essential opioids, more than 4 billion people live in countries where regulatory, cultural, economic and educational barriers leave cancer patients suffering excruciating pain[9].

All countries have barriers that have interfered and continue to interfere with availability and access to treatment with opioid analgesics. These barriers fall under four basic categories: legislative and policy barriers, knowledge barriers, attitudes, and economic barriers[10]. Unfortunately, many of these issues are also applicable not only to analgesics under international control, but also to other medicines essential for palliative care. The WHO has published guidelines to help governments eliminate unnecessary barriers to the legitimate access to controlled medicines and has made them available in several languages, which may be downloaded from the WHO website at no cost[11]. In addition, the WHO has developed a number of tools and guidelines for addressing prescribing, supply chain and cost barriers, quality and safety, traditional medicines and others which are available in the training section in the WHO website.

The UN Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or Punishment has stated that "*the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment*" and brought attention to critical obstacles that "*unnecessarily impede access to morphine and adversely affect its availability*"[12].

European School of Medical Oncology. Available in http://www.esmo.org/Policy/Global-Opioid-Policy-Initiative. Accessed April 2, 2015.

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ESSENTIAL MEDICINES IN THE WHA PALLIATIVE CARE RESOLUTION

On May 2014, in addition to the Resolution on Essential Medicines mentioned above, the WHA unanimously also approved a palliative care resolution called *Strengthening of palliative care as a component of comprehensive care throughout the life course,* which emphasizes the importance of access to palliative care and to essential medicines for medical and scientific purposes, including opioid analgesics such as morphine[13]. This resolution calls on governments to ensure adequate domestic funding and allocation of human resources, supporting the availability and appropriate use of EM, and to update national EM lists in the light of the addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children. Having palliative medicines in the WHO list is critical and may contribute to their better use and raise awareness of access to medicines for palliative care.

In 2008, a group of paediatric palliative care specialists submitted an application for a list of EM for the WHO EM list in children[14]. The application included a list of the most distressing symptoms in paediatric palliative care and recommended 17 medicines to be included in the EM list for children. The WHO Expert Committee in the Selection and Use of Essential Medicines accepted this application and the 2nd Model List of EM for Children included a section with medicines essential for palliative care. In the fall of 2012, the WHO Department of Essential Drugs and Medicines Policies requested the International Association for Hospice and Palliative Care (IAHPC) to prepare a summary of available evidence in support of the development of a special section for medicines for palliative care to be included in the 18th WHO EM list for adults and in order to promote improved access to appropriate medicines for the pharmacological management of the most prevalent and distressing symptoms in adult patients with life-threatening and life-limiting conditions worldwide.

Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf. Accessed February 28, 2015.

13. WHA 67-19. Strengthening of palliative care as a component of comprehensive care throughout the life course (May 24, 2014). Available in http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf. Accessed February 24, 2015.

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INCLUDING A SPECIAL SECTION FOR ESSENTIAL MEDICINES IN PALLIATIVE CARE IN WHO MODEL LISTS

A Working Group (WG) of directors from the IAHPC was formed to work on this project. The WG defined and implemented several of the following steps:

Step 1: Identification of the most common causes of death. Trends in mortality over the last 50 years indicate that Non-communicable Diseases (NCDs) are becoming the most common cause of death, with the exception of Sub Saharan Africa and a few nations in other regions, where communicable diseases are the main causes of death[15]. The most common causes of death globally for 2008 were heart disease, cancer, stroke, chronic respiratory disease, injury, and diabetes[16].

Step 2: Identification of the most common and distressing symptoms in palliative care. An electronic search strategy of different databases, scientific journals, and government reports was utilized to identify the most common symptoms occurring in the identified causes of mortality. Analysis of available evidence suggested 11 symptoms occurring in the advanced stages and end of life stage for the conditions identified in Step 1. These are listed in Box 1:

Box 1. Symptoms occurring most frequently in palliative care

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Anorexia
Anxiety
Constipation
Delirium
Depression
Diarrhoea
Dyspnoea
Fatigue
Nausea and vomiting
Pain
Respiratory tract secretions
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Step 3: Identification of the medicines recommended for the treatment of the symptoms:

The WG identified the evidence to support the pharmacological management of these symptoms. Fifteen medications were identified as essential for the treatments of these symptoms. All the recommended medications are off patent and available in generic forms and the majority are already included in other sections of the WHO EM list as well as in the WHO Guidelines for Pharmaco-

15. UN. World Mortality Report 211. (2012) United Nations Department of Economic and Social Affairs. NY: United Nations. Available in http://www.un.org/en/development/desa/population/publications/pdf/mortality/worldMortalityReport2011.pdf. Accessed February 12, 2015.
16. WHO. Cause-Specific Mortality Estimates 2000-2012. Health statistics and informatics Department. Available in http://www.who.int/healthinfo/global_burden_disease/en/

logical Treatment of Persistent Pain in Children[17]. The application was submitted to the WHO Secretariat in January 2013[18].

In April 2013, the WHO Expert Committee on the Selection and Use of Essential Medicines approved the application submitted by IAHPC with one exception, and such a list is now an integral part of the WHO Model List of EM[19]. In addition, a new, separate section (section 2) called Medicines for Pain and Palliative Care was created in the Model Lists for both Adults and for Children. In previous editions of the WHO Model List, medicines for palliative care were a category under the oncology section

STRATEGIES AND RECOMMENDATIONS AT THE NATIONAL LEVEL

BUILDING NATIONAL LISTS OF ESSENTIAL MEDICINES

Selection of Medicines

The selection of EM, including those for palliative care, is a two-step process. First, market approval of a pharmaceutical product is usually granted on the basis of efficacy, safety, and quality, rarely on the basis of a comparison with other products already on the market or cost. This regulatory decision defines the availability of a medicine in the country. In addition, public medicine procurement and insurance schemes usually have mechanisms to limit procurement or reimbursements of medicine costs. For these decisions, an evaluation process is necessary, based on comparison between various medicine products and on considerations of value for money. This second step leads to a list of essential medicines. Many countries use the WHO Model List of EM as the reference document to update and develop their own list (please refer to the WHO Selection and Use of Essential Medicines, Technical Series Report 985[20], for details on the selection criteria used and the process for selection).

17. WHO. Guidelines on the Pharmacological Treatment of Persistent Pain in Children with Medical Illnesses (2012). WHO: Geneva. Available in http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf. Accessed May 24, 2015.
18. IAHPC. Essential Medicines in Palliative Care – Application to the Expert Committee on the Selection and Use of Essential Medicines (2013). Available inhttp://www.who.int/selection_medicines/committees/expert/19/applications/PalliativeCare_8_A_R.pdf. Accessed March 12, 2015.
19. WHO. Model List of Essential Medicines. 2013. Available in http://www.who.int/medicines/publications/essentialmedicines/18th_EML_Final_web_8Jul13.pdf. Accessed March 22, 2015.
20. World Health Organization. The selection and use of essential medicines: report of the WHO Expert Committee, 2013 (including the 18th WHO model list of essential medicines and the 4th WHO model list of essential medicines for children). Accessed 30 April 2015 at: http://www.who.int/medicines/publications/essentialmeds_committeereports/en/

Selection Criteria

Which treatment is recommended and which medicines are selected for palliative care as well as for other conditions depends on many factors, such as the pattern of prevalent diseases and symptoms, service provision, the training and experience of available personnel, financial resources, and demographic and environmental factors.

How to Implement a National List of Essential Medicines

When the clinical guidelines and the essential medicines list are finalized, they should be made widely available. The intended use, legitimacy, and authority of the list should be clear to all. Unfortunately, and as described in the section above, the vast majority of the patients around the world who have palliative care needs and are in pain do not have access to these essential medicines. Countries should implement strategic plans to ensure access to these medications. Some key factors for successful implementation of a list of EM, including internationally controlled medications, are listed in Box 2:

Box 2. Key factors for successful implementation of an essential medicines list

- Establish a transparent process for creating and updating the list of essential medicines, provide a voice for key stakeholders, but ensure a scientific, evidence-based process.
- Link the essential medicines list to clinical guidelines for diagnosis and treatment, involving both specialists and primary care providers.
- Actively engage support from medical opinion leaders, senior clinicians, training institutions, professional organizations, non-governmental organizations, and the public.
- Make the list of essential medicines, formulary manuals, and clinical guidelines widely available in all health care facilities and to all health care providers in both printed and electronic versions.
- Consider launching new or revised lists with the involvement of government officials, such as the Minister of Health or the President, and intensive press coverage.
- Make clear the specific legal or administrative authority of the essential medicines list for training, procurement, reimbursement, and public information.
- Consider establishing an administrative or budgetary "safety valve" for the limited supply and use of non-listed medicines, e.g., by certain specialist units. This is especially important with controlled substances such as opioids, in order to prevent stock outs.
- Regularly update the list so that it reflects therapeutic advances and changes in cost, resistance patterns, and public health relevance.

IMPROVING ACCESS TO ESSENTIAL PALLIATIVE MEDICINES

Once essential palliative medicines have been added to the country's EM list, additional steps need to be taken to achieve full access for clinical use.

APPROVAL/PERMISSION BY MINISTRY OF HEALTH (MOH) TO REGISTER THE MEDICINE

A controlled substance is a drug, medicine, or chemical whose manufacture, possession, or use is regulated by a government, and included in one of the schedules in any of the International Drug Conventions. After a pharmaceutical product is granted market approval, it should become available. However this is not always the case, especially for controlled medicines. In order for the Minister to approve the medicine, there must be agreement from a variety of constituents. These include the drug regulatory departments controlling access to medicines and in charge of supply. The functions of these departments vary by country but include monitoring the use of controlled medicines, registration of new medicines, reporting consumption, and forecasting expected use to the International Narcotics Control Board (INCB). In addition, the drug policing authority (sometimes under the Ministry of Interior) needs to be involved and may resist inclusion of new controlled substances due to fear of diversion to illicit use of these medicines.

IMPORTATION

Once a decision is taken to register a new controlled substance, an importer is needed to find a supplier and negotiate purchase and sale. In some countries the government acts as the importer and distributor. In most countries controlled substances are already being imported and distributed, and it may be easiest to negotiate the addition and registration of new controlled substances with existing manufacturers or suppliers. If the new controlled medicine is not available from existing suppliers, the importer needs to find a new willing supplier. In the case of oral morphine tablets or liquids, there are not very many suppliers interested in this market due to low profit margins, especially in smaller countries.

CONTRACTING, PRICING, ESTIMATING

Once a supplier is found, the importer needs to negotiate an agreement for purchase of the new controlled substance. Before doing so the supplier will want to know how much of the product will be ordered. The importer will want the order not to be too large or too small. If too large there is a risk that expired medicine will be wasted and money lost. If too small there is a risk of running out of essential medicines and a stock out; in general, the larger the order the lower the cost per unit. To estimate the quantities of medication such as oral morphine needed for cancer and HIV patients, the INCB has published guidelines for estimation[21].

21. INCB. Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medi-

REGISTRATION

Once agreement with the supplier is concluded, the new controlled substance can be formally registered in the country. If the medicine is on the national essential medicines list, it may be possible to waive the usual supplier fees for registration. A full dossier needs to be prepared by the supplier and approved by the MoH for registration to proceed. This includes all information on the medicine and its production, results of laboratory testing, dissolution profile, and packaging details.

IMPORT EXPORT LICENSING

When the registration is completed, arrangements must be made to obtain approval for the supplier to export the medicine and the importer to import it if the medicine is coming from outside the country. These licences come from the authorities in each country and are currently made on paper. If any errors are made, the process must be redone, which can result in delays. The INCB has recently launched a new electronic import/export system (IE12) that will greatly streamline the import/export approval process for countries that participate.

STORAGE, DISTRIBUTION, AND STOCKING

The importer is responsible for receiving shipments of controlled substances and securely storing them for distribution to dispensaries such as hospitals, clinics, and commercial pharmacies. Local regulations govern how stock is maintained by these dispensaries to fulfil prescriptions and orders for controlled substances. It is important that there are enough pharmacies or dispensaries available throughout the country so that patients do not have to travel long distances to obtain medications.

EDUCATION OF PRESCRIBERS

Having strong controlled analgesics in dispensaries does not ensure that patients will receive these medications for symptom relief. If medical doctors and other prescribers do not order or prescribe these medications, they will go unused. Prescribers, who have been taught to avoid opioids out of fear of misuse and dependence potential, need to receive training in pain and/or palliative

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cal and Scientific Purposes. Accessed 19 April 2015 at: http://www.incb.org/documents/Publications/AnnualReports/AR2010/Supplement-AR10_availability_English.pdf

care, preferably at the bedside, and up-to-date pain and symptom management guidelines to achieve the knowledge and skills to safely use these medications.

COMMUNITY EDUCATION

At the same time palliative care and new treatments are being introduced, the public should be made aware of these developments. In countries where access to effective pain relief has been unavailable, a prevailing belief is that if you have cancer or another advanced chronic life limiting illness, you must suffer and there is nothing that can be done. The public has a right to know that palliative care and pain and symptom relief can be provided and that they have a right to such care and treatment.

CONCLUSION

The Essential Medicines concept is central to a National Medicine Policy as it helps to set priorities for the health care system and is as relevant today as it was when it was launched more than 30 years ago. National medicine policies are crucial because they promote equity and sustainability in the pharmaceutical sector and provide a framework to identify national goals and commitments.

With an increasing number of countries seeking WHO's advice and support in organizing their pharmaceutical sector, WHO will continue to provide assistance in medicine access and the rational use of medicines including essential medicines for palliative care. The WHO Model Lists and guidelines described here help countries to develop and implement a comprehensive policy, appropriate to their own needs and resources. These steps will lead towards better country information, comprehensive multi-stakeholder plans and strengthening the medicines components of WHO's Country Collaboration Strategies, as well as improved patient care and the relief of suffering of millions of patients around the globe with palliative care needs.

7
HOW TO ESTABLISH PALLIATIVE CARE EDUCATION AND TRAINING

Xavier Gómez-Batiste, Cristina Lasmarías, Stephen Connor, Elizabeth Gwyther

KEY POINTS

- Training is one of the main points of a Palliative Care Public Health Program.
- Education and training standards need to differentiate the aims, levels, targets, and methods of any training activity.
- Strategies of training development in PC should be adapted to the level of development of palliative care for each country, according to legislation, national plans and programs.
- The strategy for education and training must be adapted to the aims of each of the phases of development of the national program.
- Palliative care training content and methodology need to be adapted to targets.
- Palliative care content need to be inserted in the conventional training at pre and postgraduate training for all professionals.
- Education of society in an excellent complement to professional training.
- There needs to be basic, intermediate, specialist training as per WHA resolution.

AIMS OF THIS CHAPTER

To describe and develop the main elements of education and training in palliative care as an essential component of the implementation of Palliative Care Public Health Programs.

To focus on the initial phases of design, development and implementation the national education and training plan for generalist through to specialist services in PC.

OVERVIEW OF THE CURRENT SITUATION

The resolution WHA67.19 on *Strengthening of palliative care as a component of comprehensive care throughout the life course* was adopted by the World Health Assembly in May 2014. The resolution calls for better integration of palliative care into core health systems, for all ages, and all diseases.

One of the most important measures to encourage changes for improving quality of care is the availability of training and educational programs addressed at policy makers, managers, health care and social professionals, patients and caregivers.

Training in palliative care (end of life care, hospice care, palliative medicine, palliative nursing, supportive care…) emerged, especially in high in-come countries, in the 1970-80s. During the last 20 years, training in palliative care has been included in basic, intermediate and high levels of educational programs in a wide range of academic institutions (pre and post graduate), scientific societies, associations, and social initiatives. In addition, basic and specific training has been expanded to developed palliative care courses for residents, especially in family medicine, geriatrics and oncology, and in continuing education and then work to build the capacity of faculty that are fully qualified in palliative care to teach other specialists.

A lack of global information about education and training plans in PC over the world has recently been identified. According to the Global Atlas of WHPCA[1] published in 2014, only 20% of countries have developed PC services and most countries do not have a specific national plan for PC. However, some of them have integrated PC proposals into other national plans, as cancer plans, plans for care of the elderly or HIV plans. It is noted that education and training plans do not correspond to national health and welfare strategies in PC, even though training programs in PC have been identified in these countries.

Most of the training proposals or programs are based on different aspects: professional specialization (palliative medicine or nursing have been recognized in some countries such the USA, Canada or some European countries); complexity of intervention level (basic, intermediate or advanced level of contents); simple disciplinary approach (based on specific competencies for each discipline). Standards and recommendations for training have been defined by the most important scientific societies of Palliative Care (EAPC, American, African, and

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1. Connor S, Sepulveda MC (eds.). Global Atlas of Palliative Care at the End of Life. Worldwide Palliative Care Alliance, 2014.

Asian Pacific) and have described how training is being implemented in those countries under their influence[2].

Although the need for a global data base of information about palliative care resources has been clearly identified, there are some useful guidance documents and resources of information are available to facilitate recommendations about how to implement best models and strategies of palliative care training[3] Such strategies should be adapted to the level of development of palliative care for each country, according to legislation, national plan and programs (figure 1).

Figure 1. General proposals to develop palliative care training programs

2. http://www.epec.net/

http://www.aacn.nche.edu/elnec

http://aphn.org/in-the-region/directory/

http://www.eapcnet.eu/Themes/Education/Links.aspx

http://www.hospicecare.com/global-palliative-care/global-directory-of-education-programs/
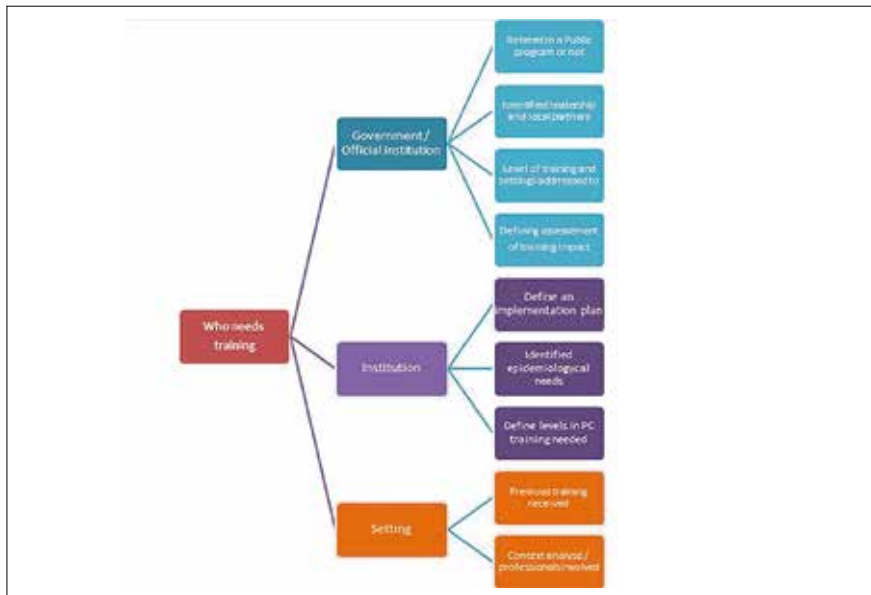
APCA (2012). Core Competencies: A framework of core competencies for palliative care providers in Africa. APCA, Uganda.

3. WHO Europe. Palliative care. The solid facts. Edited by Elizabeth Davies& Irene J. Higginson 2004, Accessible in http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/publications/pre-2009/palliative-care.-the-solid-facts

Sternsward Jan, et al. The public Health strategy for palliative care. J Pain Symptom Manage.2007;33(5):486–93.

European Association for Palliative Care (EAPC). Recommendations of the EAPC for the Development of under graduate curricula in palliative medicine at European medical schools. EAPC 2013.

Worldwide Palliative Care Alliance. 2014. Global Atlas Report of Palliative Care at the End of Life.

The most adequate proposals to develop training programs in Palliative Care are described in this chapter.

PRINCIPLES, AIMS AND ELEMENTS OF A NATIONAL EDUCATION PLAN

The main principle of education is to provide good quality of care for all patients in need of palliative care in all settings. Regarding the impact of the training, it must be necessary to emphasize that it should modify the perception of patients, families, organizations and society. The aims of education have to be linked to the targets of the learning ("What do we want to change?"). The four targets described are: attitudes, knowledge, skills and behaviours. For instance, a good plenary lecture might be an excellent way of changing attitudes, but cannot offer skills that change practice. Additionally, the best way of assuring the change of behaviours is the modelling of in situ practice with a good mentor.

According to best models of palliative care recommendations, and taking into account the model of public programs, there are some elements composing a National Education Plan:

- Principles, values, basis
- Aims: short, mid, long terms
- Needs assessment
- Levels
- Targets for education
- Actors: academics, leaders, clinicians, policymakers
- Training materials
- Curriculums / Components / Content
- Funding
- Society involvement

FIRST STEPS IN THE DESIGN AND DEVELOPMENT OF A NATIONAL EDUCATION PLAN

The initial aims might be:

1. **Conduct situational analysis**
   Including:
   - Needs of population
   - Situation of palliative care development

- Situation of palliative care education: Existing offer of palliative care training, academic institutions, possible reference centres
- Identification of leaders, key reference centres and key educational centres
- Identification of relevant barriers (cultural, administrative, economic, etc.)

2. **Select and conduct initial activities**
   - Advocacy to key decision-makers and targets (Ministry of Health, Politicians, Policymakers, Academics, Managers, Clinicians, Providers, Patient's organizations)
   - Select the best approach, content, and methodology for every target
   - Promote awareness

3. **Identify and train**
   - National leaders: people who can lead the process nationally
   - Clinical leaders: with solid clinical experience and skills. Identify the clinical leaders of the different related disciplines (oncology, primary care, geriatrics, internal medicine, anaesthesiology, others)
   - Organizational leaders: able to design and develop services

4. **Build a core solid nucleus of reference services**
   - Based on feasibility (leadership, institutional support)
   - Try to build different references
   - Identify ideal settings of the initial services among different places (hospitals, primary care, nursing homes) according to their leadership, institutional support, visibility, impact, reputation, and so forth

5. **Establish methods to provide training, support, follow up and accompany the leaders**
   - Formal activities: courses, workshops
   - "Clinical" Fellowships: to learn clinical skills
   - "Organizational" Fellowships: visiting reference centres according to the service which is being built to learn models of organization
   - Tutorship, mentorship, in place training by international experts
   - Train to show early clinical and organizational outcomes with simple descriptions that can disseminate the impact
     – Effectiveness in the control of symptoms (for clinicians as targets)
     – Efficiency and cost-effectiveness (for managers)
     – Satisfaction of patients and families (for patient's associations and NGOs)
     – Dealing better with common dilemmas (euthanasia, sedation, etc.) for politicians
   - Benchmarking processes: bringing together the initial experiences to share the challenges of implementation

6. **Design and develop the strategy of implementation at short-, mid-, and long-term**
   - Create a group as part of the Palliative Care National Commission to build the National Education Strategy with consensus (Clinical and Academic Leaders, Policymakers, Managers)
   - Define the aims and actions in short-, mid-, long-term (table 1)
   - Build specific activities, contents, and educational formats for specific targets. For instance, distinguish actions to train managers, leaders, basic clinicians, policymakers, etc.
7. **Define the National Educational Standards based on national and international consensus**
   It should be necessary to design and define:
   - Contents (clinical, organizational)
   - Levels (basic, intermediate, advanced or specialist)
   - Methods (courses, workshops, stages, tutorials, mentorships, present/online, etc.)
   - Targets (according to placement in the system, mono or multidisciplinary)
   - Faculty (based on experience and competence)
   - Accreditation system: of centres, faculty, activities
   - Evaluation of the impact (according to standards)
8. **Identify specific targets, barriers and resistances and design specific strategies to face**
   Design strategies to face and resolve barriers and resistances (either personal, corporative, or based in interests or prejudices)

BUILDING CLINICAL AND ORGANIZATIONAL LEADERSHIPS

Among the different criteria for success of services and programs, leadership is one of the most relevant. As we have mentioned before, in the initial phases of development, it is crucial to identify, train, and accompany the national / local leaders to grow and develop services and be a reference for the professionals in the field. In most cases, there are "personal history" factors, and the experience and the training will consolidate their role.

There are several key components applied to services, including the core values and principles (centred on patient's and families' needs, compassion, humanity and respect) clinical knowledge and skills of palliative care (needs of patients and families, model of care and intervention, therapeutics), organizational (leading change, design, develop, organize, evaluate and sustain the service, quality, organi-

Table 1. Aims, targets, methods, activities and outcomes according to stage of development of the training

	AIMS	TARGETS	METHODS	ACTIVITIES	EXPECTED OUTCOMES	COMMENTS
Short (0-2 years)	Start the process Create a core nucleus of national, organizational, and clinical leaders Start implementation of reference services Design the National Plan (general and education) Define palliative care core competences	Decision-makers Policymakers Clinical leaders Organizational national and local leaders	Advocacy, awareness Attitudes Showing experiences Fellowships (international, national) Mentorships, tutorships (support international experts and organizations)	Meetings Basic and introductory courses: clinical, leadership, Workshops to the national palliative care group Workshops "how to develop services" Fellowships Visits to international advanced centres/experiences In place tutorships, mentorships Subgroup of the National Palliative Care Committee focused in Education	National plan approved and going on Core nucleus of specialist reference services Core nucleus of clinical and organizational leaders fully trained Core Services acting as references for results, training and research	Pre-graduate training not a priority at this stage Cancer Institutes, University hospitals, reference services as initial places
Mid (2-5 years)	Consolidation and extension Consolidate end expand services Start training other services (intermediate levels) Start pre-graduate training Academic positions Define specialty and academic pathways	Clinical and organizational leaders Training for related specialists Start pre-graduate experiences	Extend clinical and organizational training for leaders and clinicians Training for trainers Training for evaluation of results, advocacy, research Promote academic positions	Reference services spreading training and reference Benchmark between services Stages, Courses, workshops, basic and intermediate level	Extension to settings and professionals Core Services acting as references for results, training and research Some academic positions (Chairs) started	
Long (> 5 years)	Coverage Full coverage pre and postgraduate all levels	All targets covered All levels All settings Palliative care training present in all training	Courses pre-graduate Intermediate: courses and stages in specialist services Advanced: specialty or subspecialty	Stages, courses, specialty, all types	Coverage: Pre-graduate Post-graduate All professionals All levels Specialty	

zation, managerial), leadership of persons and teams (motivation, empowerment, respect, support, communication, negotiation, prevention and resolution of conflicts), (figure 2 and table 2) quality assessment and improvement (as guarantee of the quality of care), to act as product manager of the service, relationships with stakeholders (other services, funders, policymakers, politicians, academics, and clients), relations and advocacy to society (politicians, social media, etc) and strategic vision to identify tendencies and scenarios and define ways to respond to challenges.

Figure 2. Components and skills of palliative care services' leaders

Table 2. Emotional intelligence domains of leadership (Modified from Goleman)

Personal competencies	Self-management	Emotional self-awareness Self-assessment Self-confidence Self-control
	Self-empowerment	Achievement Initiative Optimism Adaptability Transparency
Social competencies	Social awareness	Empathy Organizational Focus on patients
	Relationship management	Empowerment of team members Collaboration and teamwork Motivation Inspirational Influence Change catalyst Building bonds Conflict management

Figure 3 shows Maxwell's levels of leadership, as reasons for people to follow leaders, from "obligation" to the position of reference of who you are and represent.

Figure 3. Maxwell's levels of leadership

Pinacle: *People follow you because who you are and you represent*
People development: *People follow you because you have done for them*
Production: *People follow you because you have done for the organisation*
Permission: *People follow you because they want to*
Position: *People follow you because they have to*

In the initial phases of development, one of the most relevant actions will be to select people for the clinical and organizational leadership roles, and invest in their training, support, and follow-up. Mentorship, tutorship, and counselling are good methodologies to empower and consolidate leaders.

There are some differences in the capacities and methods to train clinical or organizational leaders. Solid clinical competence will need at least some formal courses, workshops, and a mid-term stage in a reference centre (many times, international), followed by in-place tutorship.

Organizational leadership will need specific training (managerial organizational, quality) added to stages visiting different centres with similar experience to the service being developed (mostly international). This will train and also help to build up the vision of the service in the long-term.

BUILDING UP CLINICAL SKILLS

Clinical Skills have to be based on:

- The needs of patients and families
- The process for providing care
- Core palliative care skills for all health care professionals, e.g., doctors, nurses, pharmacists, social workers, psychologists, chaplains
  – Trainees
  – Practising professionals

- Advanced palliative care skills for health care professionals seeing a lot of patients with advanced illnesses, e.g., cancer, CHF, COPD, diabetes, liver & renal failure, motor neuron disease, dementia
- Expert palliative care skills for palliative care professionals who will be consultants on palliative care services, or manage patients at home, in long-term care facilities, or in specialized palliative care units

Consider using existing teaching materials, rather than developing all new teaching modules:
- Investment to develop the content will be much less
- It will ensure a standard of practice consistent with international practices, and grounded in evidence-based medicine

Existing materials will need to be adapted to the situation in the country
- Cultural and social characteristics
- Organizational characteristics (for instance, the role of nurses, the level of development of primary care
- Ethical principles guiding clinical practice
- Local laws guiding clinical practice, particularly medication prescribing and available medications

BUILDING LEVELS OF PALLIATIVE CARE EDUCATION AND TRAINING: THE NATIONAL STANDARDS FOR EDUCATION AND TRAINING)

As it has been listed before, there are good examples of palliative care curriculums of different levels, from the basic to the specialty or master's degrees. The levels, aims, times, and targets of palliative care education for health care and other professionals in the long term are described in table 3.

It is necessary to build a national consensus on the content, methods, targets, and levels of palliative care education, applicable to pre and postgraduate, specific professionals or multidisciplinary.

Additionally, the establishment of Palliative Care Chairs will enhance the academic presence and visibility.

In general, the eventual goal is to have basic palliative care curricula in all the above health professional schools, intermediate palliative care curricula in the training of post graduates, and advanced training leading to certification of specialists or sub-specialists in palliative care.

Table 3. Levels, aims, times, and targets of palliative care education for health care and other professionals in the long term

Level	Targets	Aims & competences	Preferred method	Preferred Time
Basic	All care professionals	Attitudes and Basic knowledge	Course basic Sessions in services On-line material	Pregraduate or any time after
Intermediate	Professionals dealing with high prevalence of patients in need: Chronic care specialties (geriatrics, internal medicine, oncology, medical specialties, primary care) Professionals working in long-term, nursing homes, services, primary care Reference professionals (case managers, liaison sisters, emergency)	Knowledge and skills to respond to common situations Knowledge and skills to respond to specific situations	Fellowship in specialist service Intermediate course Postgraduate course Workshops	Training specialty period
Specialist	Professionals willing to work in specialist services Reference professionals in services with high prevalence	Knowledge and skills to respond to complex situations	Specialty formal 3-year fellowship Sub-specialty 1-year fellowship after training in other related specialties Master's degree	Postgraduate, as any other specialty After other specialties
Specific training(or adapted to special situations)	Professionals dealing with impact situations (policemen, firemen, rescue, etc.)	To respond to specific issues	Workshops Courses Short stays	When required
Special targets, specific methods, content, and phase	Clinical and organizational palliative care leaders Managers Policymakers Academics Social leaders Journalists	Leadership Managerial issues Training for trainers Research Planning Evaluation Quality assessment and improvement	Organizational Stages Workshops Courses	Crucial in the initial phases When required

EXAMPLES (SOURCES OF INFORMATION)

AIIHPC: All Ireland Institute for Hospice and Palliative Care offers a list of Irish (42) and International (140) on line training resources: http://aiihpc.org/education/online-education/online-resources/

APHN: Asia Pacifica hospice and palliative care network offers a Directory of Palliative Care Services (over 600services) which includes training and educational institutions from 22 pacific and Asian countries. http://aphn.org/in-the-region/directory/

EAPC: European Association for Palliative Care offers a list of 20 international and regional links about training in palliative care. http://www.eapcnet.eu/Themes/Education/Links.aspx

IAHPC: the International Association for Hospice and Palliative Care offers a Global Directory of Education in Palliative Care, which includes 136 different training programs (bothface to face or on line). http://www.hospicecare.com/global-palliative-care/global-directory-of-education-programs/

WHPCA: The Worldwide Hospice Palliative Care Alliance provides a list of over 60 international and regional resources (associations, institutions, websites, and so forth), of PC.

Speciality Training Curriculum For Palliative Medicine August 2010. Joint Royal Colleges of Physicians Training Board. http://www.gmc-uk.org/Palliative_curriculum_220410_V0.13.pdf_32485351.pdf

Undergraduate curriculum. http://www.pcc4u.org/

RV: New Community-Based Palliative Care Certification Option for Home Health & Hospice Launches July 1, 2016. Standards Available Now! | Joint Commission. https://www.jointcommission.org/community-based_palliative_care_certification_option_july_1_2016/

RE: Palliative Care Curriculum for Undergraduates (PCC4U). https://www.caresearch.com.au/caresearch/tabid/91/Default.aspx

RV: curriculum toolkit. http://www.ed.ac.uk/files/atoms/files/curriculum_toolkit_-_ks_final_07_10_15_2_final.pdf

EPEC Program. http://www.epec.net/

End of Life Nursing Education Consortium (ELNEC). http://www.aacn.nche.edu/elnec

Curriculum Objectives: Palliative Care | Family Medicine - McGill University.

https://www.mcgill.ca/familymed/education/postgrad/curriculum-overview/objectives/palliative-care

Palliative Care Training Curriculum | Palliative Care Leadership Centers (PCLC) | CAPC. https://www.capc.org/palliative-care-leadership-centers/palliative-care-training-curriculum/

GMC | Palliative medicine curriculum. http://www.gmc-uk.org/education/palliative_medicine.asp

Hpna clinical education standards. http://hpna.advancingexpertcare.org/wp-content/uploads/2015/08/HPNA-Clinical-Education-Standards.pdf

Core competencies in palliative care: an EAPC White Paper on palliative care education. http://www.eapcnet.eu/LinkClick.aspx?fileticket=XPrM1LNaSbo%3D

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8
INDICATORS, STANDARDS, AND LEGISLATION

Xavier Gómez-Batiste, Stephen Connor

KEY POINTS

- A thorough review of existing laws and regulations impacting the provision of palliative care is needed.
- Modifications to law or regulation, where necessary, should be carried out.
- National standards for operating a palliative care program or service are needed.
- Measurement of palliative care is necessary and supports quality assessment and performance improvement.

AIMS OF THIS CHAPTER

This chapter is intended to give national authorities assistance when developing or improving palliative care services. After conducting the assessment of need for palliative care, it is important to then conduct a review of all laws and regulations that could impact the establishment or delivery of palliative care services.

Following from this, it is recommended that national palliative care standards be established that describe what is necessary when developing and operating a specialized palliative care service. These standards should include the delivery of palliative care in all settings as applicable, including inpatient care, inpatient consult services, outpatient clinic services, day care services, and home-based care.

Related to standards is the importance of identifying and implementing indicators to measure the structure, process, and outcomes of palliative care. Doing this from the onset of palliative care development helps authorities determine the value of palliative care to the national health care system and helps to ensure that access to quality palliative care service is being realized.

LEGAL AND REGULATORY REVIEW

FORMATION OF A WORKING GROUP

To begin, a working group is formed that can be made up of representatives from at least the following constituencies:

- Ministry of Health (MoH) leadership
- Legal department of MoH
- Palliative care clinicians including medical, nursing, and mental health
- NGO representation including representation of the patient's perspective
- Internal affairs or law enforcement
- Drug control authority
- Funding agency
- Expert on approval of health care specialties

Funding for a lawyer with expertise in palliative care may be necessary to have someone with competence in writing draft legislative and regulatory language for consideration by the group. An external expert on palliative care should be available to advise the working group and review the work produced. The chair of the group should be someone with authority, such as a deputy minister of health. The first step is to conduct an inventory of existing legal and regulatory documents.

INVENTORY OF LEGAL AND REGULATORY DOCUMENTS

Countries differ in how these documents are named and used (legislation, regulation, by-laws, decrees, orders, national strategies, and so forth). It is important to differentiate existing documents that must be modified by changes in law from those that can be changed by the government. The types of documents that may need to be found in an audit include documents that:

- Define the target patients and their main characteristics;
- Define what health care services are to be provided;
- Identify which areas of medical specialization are recognized;
- Describe the types of medicines that can be used;
- Place limitations on how medicines can be used and who can prescribe them;
- Describe the duties of health care professionals;

- Establish priorities for health care conditions or funding for free or discounted services;
- Describe clinical guidelines and protocols for the delivery of health care;
- Define existing standards of health care practice;
- Describe funding models;
- Outline national strategies for non-communicable diseases, HIV/AIDS, TB, or cancer.

Once the audit is completed, a strategy is needed to address inclusion of palliative care and removal of conflicts that could prevent its provision. The strategy should include whether it will be necessary to create a new law or whether it is better to modify existing legal documents.

A first step is to ensure that palliative care is defined as a recognized service that is part of the health care system. This can be done by introducing the current World Health Organization definition of palliative care, including palliative care for all types of adult patients and children with advanced chronic conditions.

ACCESS TO ESSENTIAL PALLIATIVE CARE MEDICINES

One of the most common barriers limiting the effective provision of palliative care is excessive restriction on the use of controlled substances, particularly opioids for pain relief. Restrictions on use of controlled substances are necessary in every country. However, the UN Office on Drugs and Crime, as well as the International Narcotics Control Board, have identified excessive restrictions that do not balance prevention of illicit use with access for medical and scientific purposes as a global problem[1].

The types of restrictions that can interfere with palliative (and other) health care include:

- Limits on who can prescribe controlled substances (only oncologists).
- The use of special prescription forms and limitations on who can access these forms.
- Limits on how many days a prescription can be written for (often 1-3 days instead of 14-30 days).
- Limits on the quantity of medication that can be prescribed in one prescription (per day or per patient).

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1. www.incb.org/documents/Publications/AnnualReports/AR2015/English/Supplement-AR15_availability_English.pdf

- Time limits on when a prescription can be filled (within 1-3 days).
- Requirements that multiple authorities must countersign prescriptions or that a special commission has to approve any patient receiving controlled substances.
- Limiting use of controlled substances on certain diagnoses (cancer) or stages of illness (Stage IV).
- Extensive and sometimes duplicate record-keeping requirements to satisfy multiple regulatory agencies.
- Interference by police authorities in the legal and approved practice of medicine.
- Requirements that hospitals, clinics, or pharmacies provide information about patients and their prescriptions to the police.
- Lack of registration of essential palliative care medicines including opioids such as oral morphine (both immediate and slow release).
- Requirements that physicians log, monitor, and have witness to destruction of all used or unused medicines, including injectable ampoules of controlled medicines.
- Excessive burdens on pharmacies, with the effect of discouraging dispensation, such as:
  – Requiring armed guard around the clock,
  – Alarms direct to police authorities,
  – Special metal doors and seals,
  – Multiple manual registration journals.

NATIONAL STANDARDS OF OPERATION

While there are no required or recommended international standards for operation of palliative care services, over 30 countries have national palliative care standards of operation (see http://thewhpca.org/resources/category/standards-clinical-guidelines-and-protocols for examples), which can be used as models for each country that develops its own approach. Model standard formats for existing health care providers currently used in the country can also be used to structure national standards for palliative care.

National standards for operation of health care services are distinct from but related to clinical standards, guidelines, protocols, and standard operating procedures that are usually used to describe how to care for a patient or symptom. Each country may have different definitions for these terms, so it is important to clarify definitions of terms at the outset. For the purpose of this publication,

we are referring to standards that describe how a unit, department, team, or program of palliative care services is organized and operated.

SUGGESTED CONTENT FOR ORGANIZATION OF NATIONAL STANDARDS FOR PALLIATIVE CARE

National standards can vary in complexity and content. At minimum the following content should be included:

- Background on the country's palliative care development including history, philosophy, important developments, summary of identified needs.
- Governance and management of palliative care services.
- Eligibility for palliative care.
- Description of the interdisciplinary team including all disciplines that are required or optional.
- Description of the qualifications and training required to work in a palliative care service.
- Description of the types of services that must be provided by each discipline.
- Recommended staffing ratios and caseload.
- Education, training, and staff support.
- Clinical assessment and interdisciplinary plan of care development.
- Record-keeping requirements and medical record maintenance.
- Safety and infection control policies.
- Medications, supplies, and equipment.
- Continuity of care.
- Ethical issues.
- Quality assessment and performance improvement.
- Palliative care in different settings (inpatient, clinic, day care, home care).
- Palliative care for special populations (children, patients with communicable diseases, non-cancer patients, stigmatized populations).

MEASURING PALLIATIVE CARE

Palliative care poses some special challenges when it comes to measurement. Patients are very ill and have difficulty communicating. Family members can evaluate their own care but are not always the best surrogates to evaluate the patient's experience. Person-centred care is difficult to measure, as there is con-

siderable subjectivity to the experience of care and many things that are unrelated to the delivery of palliative care can affect quality of life. Nonetheless, it is important to establish standardized measures at the initiation of palliative care services that can be used to evaluate the quality of care being delivered and to help improve care planning. Indicators are measures that show us evidence of whether certain results have or have not been achieved.

Evaluating the quality of health care often involves use of the Donabedian Triad[2] of structure – process – outcome measurement. Applying these major components to the established domains of palliative care[3] ensures that all important aspects of palliative care are measured.

STATUS OF INDICATOR DEVELOPMENT IN PALLIATIVE CARE

Two reviews of quality indicator development in palliative care[4], have noted that there are a number of published quality indicators available for consideration for use in quality measurement. These indicators are mostly outcome or process indicators. Psychosocial, spiritual, and cultural measures are under-represented. At least 16 measure sets are currently available. While further work is needed on their validation, existing measures can be put into place now. It is recommended that initiatives to assess the quality of palliative care should start from existing quality indicator sets.

A consensus on palliative care domains was completed and can serve as a framework for measuring quality palliative care. These domains are as follows:

1. Structure and Process of Care (e.g., training and education for professionals; providing continuity of care);
2. Physical Aspects of Care (measuring and documenting pain and other symptoms; assessing and managing symptoms and side effects);
3. Psychological and Psychiatric Aspects of Care (measuring, documenting, and managing anxiety, depression, and other psychological symptoms; assessing and managing the psychological reactions of patients/families);
4. Social Aspects of Care (conducting regular patient/family care conferences to provide information, discuss goals of care, and offer support to patient or family; developing and implementing comprehensive social care plans);

2. Donabedian A. Quality assurance: structure, process and outcome. Nurs Stand 1992; 7(11):4-5.
3. Ferrell B, Connor SR, Cordes A, et al. The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. *J Pain Symptom Manage* 2007; 33(6):737-744.
4. Pasman HR, Brandt HE, Deliens L, et al. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009; 38(1):145-56.
   De Roo M, Leemans K, Claessen SJ, et al. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage;* 2013, 46(4):556-572.

5. Spiritual, Religious, and Existential Aspects of Care (providing information about availability of spiritual care services to patient or family);

6. Cultural Aspects of Care (incorporating cultural assessments such as the locus of decision-making and preferences of patient or family regarding the disclosure of information and truth telling, language, and rituals);

7. Care of the Imminently Dying Patient (recognizing and documenting the transition to the active dying phase; ascertaining and documenting patient/family wishes about the place of death; implementing a bereavement care plan);

8. Ethical and Legal Aspects of Care (documenting patient/surrogate preferences for care goals, treatment options and the care setting; making advance directives; promoting advance care planning).
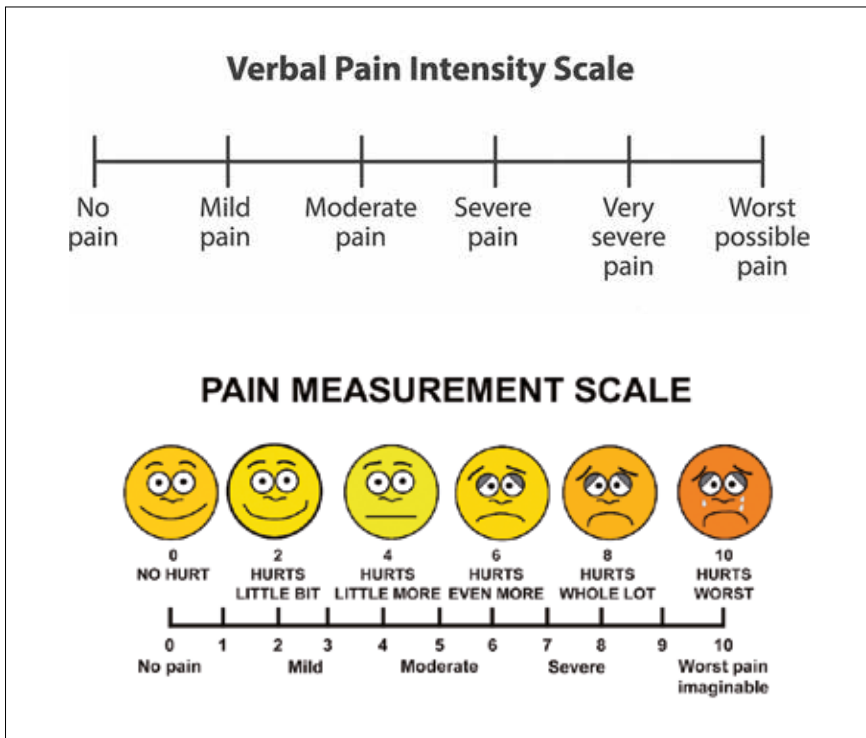
A complete listing of all 326 possible indicators for palliative care included in these eight domains can be found at: http://www.jpsmjournal.com/article/S0885-3924%2813%2900143-7/addons.

In addition, standardized clinical tools should be utilized to regularly measure symptom burden and functional ability. Frequently used scales include:

- The Palliative Performance Scale: a 100-point scale with zero being death and 100 being perfect ability to perform. Useful in documenting declining ability and in determining eligibility for palliative care. Download at: www.npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf
- Pain Rating Scales
  – Numeric pain rating scale (NRS): A variety of rating scales are available to measure pain levels. The NRS is the most commonly used and validated. Patients are asked to rate their pain with zero being no pain at all and 10 being the worst pain imaginable. Available at: http://www.va.gov/painmanagement/docs/painnrs.pdf
  – Visual analogue scales.
  – Verbal rating scales.
  – In addition there is a 'faces' scale for use with children.

PATIENT AND FAMILY PERCEPTION OF CARE MEASUREMENT

How recipients of palliative care, including patients and their family members, evaluate the services they receive is an important indicator of quality. The likelihood that such evaluations will be distorted by leniency bias is also great. The rate of satisfaction with services is also likely to be high due to low expectations for health care. Measuring specific aspects of care without using value-laden

Verbal Pain Intensity Scale

| No pain | Mild pain | Moderate pain | Severe pain | Very severe pain | Worst possible pain |

PAIN MEASUREMENT SCALE

| 0 NO HURT | 2 HURTS LITTLE BIT | 4 HURTS LITTLE MORE | 6 HURTS EVEN MORE | 8 HURTS WHOLE LOT | 10 HURTS WORST |

| 0 No pain | 1 | 2 Mild | 3 | 4 | 5 Moderate | 6 | 7 | 8 Severe | 9 | 10 Worst pain imaginable |

measures helps to overcome these biases. For example, it is better to ask if the person got too much, too little, or the right amount of a service than to ask them to rate how satisfied they were. Examples of survey questions can be found in the listing of 326 indicators above.

UTILIZATION OUTCOMES

Most research on the cost impact of palliative care has demonstrated more appropriate use of health care resources[5], and reductions in hospitalizations. Measuring the utilization of health care resources is important, especially the use of inpatient care, which is the most expensive resource in any health care system. Some additional costs will be needed to institute home-based services, but this may be more than offset by reductions in the use of other health care services.

5. Smith S, Smith A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine;* 2014; 28(2): 130-150.

Gómez-Batiste X, Tuca A, Corrales E, Porta-Sales J, Amor M, Espinosa J, Castellsagué, X. Resource consumption and costs of palliative care services in Spain: A multicenter prospective study. *J Pain & Symptom Mgmt;* 2006: 31(6):522–532.

PUBLIC AWARENESS MEASUREMENT

Public attitudes toward palliative care and relief of suffering are also important to measure. Standardized representative surveys of the public can be undertaken over time to measure changes in attitude. These surveys usually ask the public what services they believe would be important if they or someone they love were to be faced with a life-threatening illness, whether it is better to be cared for at home or in a hospital or other institution, how important it is to ensure pain relief, and so forth.

USING INDICATORS IN QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT (QAPI)

All providers of palliative care should conduct QAPI activities, with a commitment to continuous improvement of the quality of their services. Data collected from quality indicators is a primary source of information to drive QAPI activities. When possible, palliative care services should also be able to compare their quality indicator results with other similar providers.

When a problem or opportunity for improvement is identified, an intervention or change in operation should be implemented. Once implemented, the results of the intervention should be measured to see if there is improvement in the indicator(s).

The assessment and improvement of the quality of services is one of the activities that must be performed regularly. The aims consist of the detection of areas of improvement that permit the establishment of a formal quality improvement process. Some recommendations are listed in the following table:

Focus on the quality of care and adapt to practice
Insert into the culture of the organization
Promote participation and empowerment
Systematize
Combine methods: qualitative, qualitative, mixed
Involve professionals, patients, families, and stakeholders
Register, measure, use indicators
Implement and follow up actions of improvement

There are several described methods of quality improvement[6].

One QAPI system frequently used to structure performance improvement is the PDCA (plan do check act) model. Quality improvement needs to be continuous and the goal is to continually strive to improve.

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The European Foundation for Quality Management (EFQM) model of assessment and improvement of quality can be applied to palliative care, focusing on the evaluation of the performance of services to address patients' and families' needs (for every dimension of these needs), combined with the process of care and organization (team dynamics, evaluation, training, research, etc.)[7].
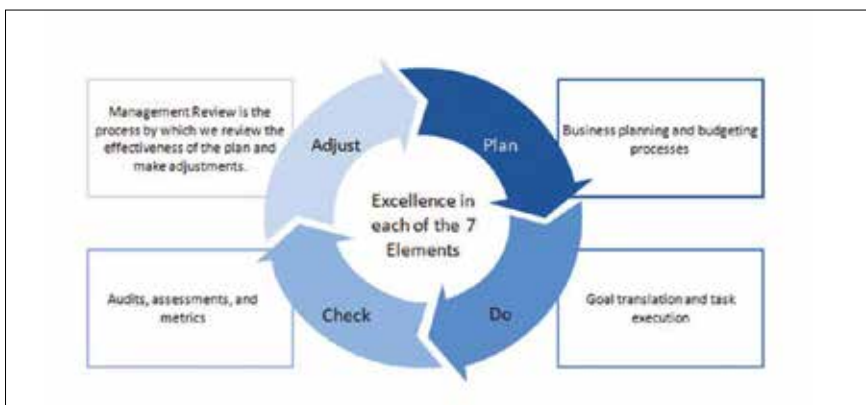
6. Ferris F, Gómez-Batiste X, Furst CJ, Connor S. Implementing quality palliative care. J Pain Symptom Manage, 2007; 33:5, 533-541.

7. Gómez-Batiste X, Ferris F., et al. Ensure good quality palliative care. A Spanish Model. Eur J Palliat Care, 2008; 15(3): 142-147.

Table 2. EQFM Model of quality assessment and improvement

Aspects of service	Principles	Quantitative evaluation	Strong points	Weak points	Areas for improvement	Objectives	Actions	Team members responsible for process indicators
Patient care	Need for a policy when there is no response to treatment with first-choice opioid	30% of patients with non-responsive pain	Commitment Knowledge of opioids Opioids available Pharmacy service available	Lack of ability to predict treatment response Length of decision to change treatment Lack of knowledge of alternative opioids	Identification of patients at risk Time it takes to change treatment Use and dosage of alternative opioids	Early detection and assessment Rapid treatment change Use of alternative opioids	Use Edmonton Symptom Assessment System during the first visit Three specific sessions devoted to opioid rotation	% of patients with Edmonton staging done Written protocol for opioid rotation (OR) done Three sessions (on OR) performed
Family care								
Teamwork	Multidisciplinary sessions are a key activity for the team	There should be at least one per week	Commitment More than 70% of sessions done	Late start No order of interventions Lack of registration	Time-keeping Order-keeping Register decisions and evaluations	Order and regulation of the multidisciplinary team sessions	Use moderator Use session protocols Start on time Register decisions	Moderator Protocol done >90% of sessions done in time >80% of clinical charts having written actions
Decision-making								
Evaluation, monitoring, documentation								
Coordination, liaison	Palliative care services must be coordinated within the district	50% of patients are 'shared' with home care support teams and other units	Informal daily phone liaison Individual patients referred Good personal relationships	No formal interventions criteria No formal links or meetings	Criteria for interventions Formal and established links	Networking Interventions based on established criteria Formal liaison	Written document on criteria for interventions of services Set up monthly formal meetings	Document done Nine meetings held
Accessibility, continuity								
Training, research, other								

9
COST, FUNDING AND REIMBURSEMENT MODELS FOR PALLIATIVE CARE

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KEY POINTS

- Estimating the cost of palliative care is an essential part of planning for its implementation.
- Palliative care can provide value in health care by reducing unnecessary costs associated with hospitalization and with futile assessment and treatments.
- Home and community-based services are emphasized over building inpatient palliative care services.
- Palliative care can and should be integrated into existing services and facilities.
- Palliative care services can be funded through different models including budget modification, reimbursement, and community support.

AIMS OF THIS CHAPTER

The purpose of this chapter is to put forward methods and options that can be used to understand the cost and financing of palliative care services. Additionally, palliative care has shown to be extremely efficient in the use and cost of resources during the last months of life. This chapter is directed to government officials in Ministries of Health, Finance, Justice, and Executive offices. It may also inform non-governmental organizations that operate to promote or to deliver palliative care services. The aim of the chapter is to assist government and the private sector in planning for and delivering cost-effective, quality palliative care services to those in need.

BACKGROUND

Planning for palliative care development requires changes to how existing health care resources are budgeted, reimbursed, and delivered. Such changes are challenging to implement. This chapter will examine methods for determining the costs of major components of palliative care and, from there, different methods of budgeting for, financing, purchasing and delivering palliative care.

More than 70% of total health care expenditures in the course of a lifetime are in the last six months of life, mainly due to the costs of hospital and emergency admissions, the use of treatments and examinations, and increased demands for health care interventions. Most research on palliative care demonstrates that by providing mostly home-based care and hospital consultations, the amount of inpatient hospitalization can be minimized to appropriate levels. It is not suggested that the goal of palliative care is to limit patients' choices about hospitalization but to ensure the preventable and unnecessary hospitalizations and treatments are avoided. In some situations the net result of this intervention may be to actually lower the cost of the health care.

EXISTING EXPERIENCES AND GOOD PRACTICES

COSTING PALLIATIVE CARE

Determining the cost of providing palliative care services is not different than for other health care services. There are direct and indirect costs. Direct costs include both fixed and variable expenses. It is useful to determine the units of measurement that will help for planning purposes. This can be total annual budget, or in units such as cost per day, cost per patient per month, cost per inpatient day, cost per inpatient episode of care, cost per home visit or clinic visit.

Existing Models for Costing Palliative Care: One existing model, recently developed in Romania[1], can be used to calculate four metrics: (1) cost per inpatient day, (2) cost per home visit, (3) home care cost per month, and (4) cost per case. Two Excel spreadsheets are available, one to calculate inpatient cost and one for home-based care cost. Local costs for personnel, medications, supplies, and so forth are inserted in the workbook to generate results. Excel templates

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1. Mosoiu D, Dumitrescu M, Connor SR. Developing a costing framework for palliative care services. J Pain Symptom Manage. 2014;48(4): 719-729.

can be downloaded for Home care costing at: http://thewhpca.org/resources/item/romania-model-for-costing-framework-of-a-homebased-care-visit-2 and for the inpatient template at: http://thewhpca.org/resources/item/romania-model-for-costing-framework-for-inpatient-units

The cost of palliative care services is mostly for personnel (70%), unlike other health care services, in which the costs of medical treatment are higher. Cost also depends on the complexity of the target patients (higher for advanced cancer or organ failure or AIDS patients in the course of specific disease treatments), the setting where the service is based (more expensive in acute university settings than nursing homes), and the local personnel costs. It can be also described as a percentage of the cost of other resources (the cost of palliative care beds in hospital being 40 percent, and in socio-health/intermediate centres 25 percent, as compared with conventional acute beds). Funding is another key issue, as most services adapt to their available funding.

A second example of a model for costing palliative care comes from the Hospice and Palliative Care Association of South Africa. Like the Romanian model[1] an Excel spreadsheet is used to input local costs. The outputs from this model include either home-based care or inpatient unit: (1) cost per patient day, (2) cost per month, (3) cost per patient per month, and (4) cost per average episode of care.

Outcomes of Costing Models: The Romanian costing model yielded a cost of $96.58 per inpatient day, $30.37 for a home visit (average for all disciplines), $723.60 per month of home care, and $1367.71 per episode of home care, which included an average of 45 visits. In South Africa, the average cost for home care per month was $96 and for an inpatient day $91. Palliative care cost is only one part of the equation, however. This cost can be offset by reductions in other expenses, especially hospitalization (see section on cost impact).

FUNDING PALLIATIVE CARE SERVICES

Existing Models for Funding Palliative Care Services: There are a number of ways to consider funding or reimbursing providers to provide palliative care services. The following are examples for consideration:

Budgeting: Developing a budget for operation of a palliative care department or service can be done as with other services. Considering that the patients receiving palliative care are most likely already being cared for by a medical centre, it may simply require modification to an existing budget to transfer monies from one department to another. Some new costs may have to be accounted for such as the cost of transportation for staff to visit patients at home.

Reimbursement Models

Fee for Service: Health care providers may bill health funding bodies for services rendered if they have a contract to provide services. This is the least efficient reimbursement model and may lead to over-utilization.

Per Diem: A set reimbursement amount may be paid to a provider organization for each day the patient is enrolled or receiving palliative care services. This system is usually bundled so that it includes all services, medications, and supplies provided to the patient and family. The provider must deliver the required services within the reimbursement provided. This is a shared risk model.

Per Patient Per Month: Similar to per diem payments, may be made of a set amount per month or portion of a month for all palliative care services and supplies. This model may shift more risk on the provider.

Per Admission: This model reimburses a set amount for agreed services per patient admitted to palliative care and shifts most risk to the provider since the amount of time and services is unknown at the time of admission.

Per structure: Funding the personnel costs of the team and adding some percentage for other costs. This model can be used to fund palliative care support, consultations and mobile teams.

Combined methods: The models above can be combined (e.g., per diem for inpatients, structure for support teams, activity for outpatient clinics).

Capitative methods: The budget is assigned to cover the costs of health care for a population. This consists of the stratification and identification of persons at high risk, development of policies, and implementation of methods like case or care management. These methods might promote the development of systems of integrated care for persons with complex and/or advanced chronic conditions.

Public and Private Funding for Palliative Care Services: In many countries palliative care may be provided by non-governmental organizations or companies delivering health care outside publicly run hospitals and health facilities. These organizations may receive some of their funding from government sources and/or may be able to secure financial resources from charitable sources or from fees charged to the patients and families to deliver palliative care services. It is important that those patients with limited resources are able to access palliative care services, so a minimum provision should be made for governmental support for the poor.

Table 1. Characteristics of some models of financing[2]

Advantages and Disadvantages of the Most Frequently Described Financial Models		
Model	**Advantages**	**Disadvantages**
Structure-based	Little risk of "medicalizing" the care provided Easily applicable	Facilitates the proliferation of services (health care structures) Little attention to health care processes and activities
Process-based	Encourages clinical activity Favours continued care	Easily evolves to overactive services (risk of overwhelming jobs)
Capitative (population-based)	Favours equity, efficiency, and cost control Promotes the quality assessment of health care Facilitates the development of alternative resources to usual hospital services (e.g., community care)	Gives little consideration to activities considered necessary but less developed (e.g., research, education)

INTEGRATION OF PALLIATIVE CARE IN EXISTING HEALTH CARE FINANCING

COST IMPACT OF PALLIATIVE CARE

Studies of hospital-based palliative care consultations[3] show reductions in hospital costs for patients who die during their last admission ($4908 - $7563). and in most studies for patients discharged alive ($1696 – $4098)[4]. Studies of home-based palliative care show reductions in overall cost of care (Euro 436)[5],

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3. Penrod JD, Deb P, Luhrs C, Dellenbaugh C, Zhu CW, Hochman T, Morrison RS. Cost and utilisation outcomes of patients receiving hospital-based palliative care consultation. J Palliat Med 2006; 9(4):855–860.

4. Morrison RS, Penrod JD, Litke A, Meier DE, Cassel JB, Caust-Ellenbogen M, Spragens L. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med 2008; 168(16):1783–1790.

Morrison RS, Meier DE, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J. The care span: Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. Health Aff 2011; 30(3):454–463.

5. Serra-Prat M, Gallo P, Picaza JM. Home palliative care as a cost-saving alternative: Evidence from Catalonia. Palliat Med 2001; 15(4):271–278.

(USD 7552)[6], and (USD 5936)[7] per cancer patient. Palliative care entails having consistent conversations with patients about goals of care that lead to improved outcomes and reduced expenditures (USD 1041)[8], and for the bereaved that get consistent follow-up (USD 3560 per widowed person)[9]. Two recent literature reviews on the cost impact of hospice and palliative care have found that palliative care is less costly than comparison groups[10]. In almost all cases the cost difference is statistically significant (see table 2). Reports from Europe, India, and South Africa show reductions in health care expenditures when palliative care is introduced[11]. Another study has estimated the global cost savings by a regional palliative care program, and shown that the palliative care network achieves more savings that its structure costs.

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9. Connor, S. (1996). Hospice, bereavement intervention, and use of health care services by surviving spouses, HMO Practice, 10(1), p. 20-23.

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   Jung hM, Kim J, heo Ds, Baek sK. health economics of a palliative care unit for terminal cancer patients: a retrospective cohort study. Support Care Cancer 2012; 20(1):29-37.

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   McDermott E, Selman L, Wright M, & Clark D. Hospice and Palliative Care Development in India: A Multimethod Review of Services and Experiences. J Pain Symptom Manage 2008; 35(6):583-593.

   Hongoro C, Dinat N. (2011) A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa. J Pain Symptom Manage, 41(6):1015-1024.

   Difillipi K, Cameron S. Expanding the Reach of Palliative Care to Community-Based Home Care Programs. J Pain Symptom Manage, 2010; 40(1):3-5.

Case Study - USA

Reports describing the impact of hospice care on the US Medicare program show a reduction in medicare expenditures for hospice patients with various diagnoses (USD 1097 to USD 8935)[12], with cancer (USD 648)[13], and for all, depending on length of care (USD 2309)[14], (USD 2561)[15].

Case Study - Catalonia

The reduction of costs has been shown by home care support teams (1,000 euros per patient per month), the palliative care networks (3,286 euros per patient per 6 weeks) and globally in the region.

CONCLUSION: COST-EFFECTIVENESS OF PALLIATIVE CARE

The implementation of palliative care services could have an important impact, not only on the improvement of the quality of care for persons with advanced chronic conditions (ACC), but also in the efficiency of the global health care system. This has been demonstrated in the care of terminal cancer patients with a very limited prognosis, and could have even more impact looking at early palliative care for persons with ACCs.

Cost effectiveness is more than cost impact and includes the value proposition that quality is included in the analysis. Even if a service costs more than conventional care it may be worthwhile due to better quality or other value for the health care system. There is a growing body of evidence for the superior quality of palliative care versus conventional care. However, there are few studies that have examined both cost and quality of palliative care services simultaneously. At least based on how consumers rate the quality of services provided by palliative care providers, there is an argument that can be made that palliative care seems to reduce cost and is better, more person-centred care than conventional care.

12. Pyenson B, Connor S, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. J Pain Symptom Manage 2004; 28(3):200–210.
13. Campbell DE, Lynn J, Louis TA, Shugarman LR. Medicare program expenditures associated with hospice use. Ann Intern Med 2004; 140(4):269–277.
14. Taylor DH, Ostermann J, Van Houtven CH, Tulsky JA, Steinhauser K. What length of hospice use maximises reduction in medical expenditures near death in the US Medicare program? Soc Sci Med 2007; 65(7):1466-1478.
15. Kelley AS et al Hospice Enrolment Saves Money For Medicare And Improves Care Quality Across A Number Of Different Lengths-Of-Stay. Health Aff. March 2013 32:3552-561.

Table 2. Summary of Cost Impact of Palliative Care

Author	Population	Period	Avg. Cost Savings
Brumley et al. (2007)[1]	Home-based palliative care cancer only	Episode of care	$7552
Campbell et al. (2004)[2]	Medicare hospice cancer patients	Last year of life	$648
Connor et al. (1996)[3]	Widowed persons	Year after spousal death	$3560
Kelley et al. (2013)[4]	Medicare hospice patients	Based on LOS	$2650 (1-7 days) $5040 (8-14 days) $6430 (15-30 days $2561 (53-105) days
Pyenson et al. (2004)[5]	Medicare hospice patients	Last 3 years of life	$1097 - $8935 (depending on dx.)
Enguidanos et al. (2005)[6]	Home-based palliative care cancer only	Last year of life	$5936
Morrison et al. (2008)[7]	Hospitalized Medicare patients	Hospitalization	$1696 (live DC) $4908 (death)
Morrison et al. (2011)[8]	Hospitalized Medicaid patients	Hospitalization	$4098 (live DC) $7563 (death)
Serra-Prat et al. (2001)[9]	Home-based palliative care cancer only	Episode of care	€436.6
Taylor et al. (2007)[10]	Medicare hospice patients	Last year of life	$2309
Zhang et al (2009)[11]	Seriously ill advance care discussion	Last week of life	$1041

1. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, McIlwane J, Hillary K, Gonzalez J. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. J Am Geriatr Soc. 2007 Jul;55(7):993-1000.
2. Campbell DE, Lynn J, Louis TA, Shugarman LR. Medicare program expenditures associated with hospice use. Ann Intern Med. 2004 Feb 17;140(4):269-77.
3. Connor SR, Monroe B. Hospice, bereavement intervention and use of health care services by surviving spouses. HMO Practice, 1996;10:20-23.
4. Kellwy AS, Deb P, Du Q, Aldridge Carlson M, Morrison RS. Hospice enrollment saves money for medicare and improves care quality across a number of different lengths-of-stay. Health Aff (Millwood). 2013 Mar; 32(3): 552–561.
5. Pyenson B, Connor S, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. J Pain Symptom Manage 2004;28(3):200-210.
6. Enguidanos SM, Cherin D, Brumley R. Home-based palliative care study: site of death, and costs of medical care for patients with congestive heart failure, chronic obstructive pulmonary disease, and cancer. J Soc Work End Life Palliat Care 2005;1(3):37-56.
7. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, Meier DE, Palliative Care Leadership Centers' Outcomes Group. Arch Intern Med. 2008;168(16):1783-1790.
8. Morrison RS, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J, Meier DE. Palliative Care Consultation Teams cut hospital costs for Medicaid beneficiaries. Health Aff 2011;30(3):454-463.
9. Serra-Prat M, Gallo P, Picaza JM. Home palliative care as a cost-saving alternative: evidence from Catalonia. Palliat Med 2001; 15(4): 271-278.
10. Taylor DH, Osterman J, Van Houtven CH, Tulsky JA, Steinhauser K. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? Soc Sci Med 2007;65:1466–1478.
11. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health Care Costs in the Last Week of Life: Associations With End-of-Life Conversations. Arch Intern Med. 2009;169(5):480-488.

MODELS IN LMICS

Financing palliative care programs and services is a challenge in LMICs, and there have been initiatives to fund the initial development of programs and the start of specific services.[16]

FURTHER RECOMMENDED READING

Cochrane Review. Effectiveness and cost-effectiveness of home-based palliative care services for adults with advanced illness and their caregivers. At: http://www.cochrane.org/CD007760/SYMPT_effectiveness-and-cost-effectiveness-home-based-palliative-care-services-adults-advanced-illness-and

Merck Manual. Overview of Health Care Financing. At: https://www.merckmanuals.com/home/fundamentals/financial-issues-in-health-care/overview-of-health-care-financing

Smith S, Brick A, O'Hara S, & Norman C. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliat Med* 2013; 0(0):1-21. DOI: 10.1177/0269216313493466.

World Health Organization Bulletin. Countries test new ways to finance health care. At: http://www.who.int/bulletin/volumes/84/11/06-011106/en

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16. Callaway M, Foley KM, De Lima L, Connor SC, Dix O, Lynch T, Wright M, Clark D. Funding for Palliative Care Programs in Developing Countries. J Pain Symptom Manage 2007; 33:509e513.

10
ADVOCACY AND HUMAN RIGHTS ISSUES

Diederik Lohman, Duncan Wilson, Joan Marston

KEY POINTS

- Palliative care is a human right. Many UN documents now acknowledge this right.
- In 2014 the World Health Assembly called on all member states to prioritize palliative care as part of their health care systems.
- Health resources should be available, accessible, acceptable, and of good quality.
- Governments have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment.
- Critical to the success of rights-based programs, however, is the existence of a dynamic civil society, high-level political leadership, and an enabling policy and legal environment.
- A human rights-based advocacy approach to palliative care and access to pain medicines can be understood to emphasize four key strategies:
  - Elevate the voices of people affected by the rights violation;
  - Analyze structural barriers;
  - Clarify government obligations;
  - Advocate for change.
- Access to essential medicines is now on the agenda of the UN drug control bodies including CND, INCB, UNODC, and WHO.
- Efforts by coalitions, which bring diverse expertise, authority, and perspectives, can provide critical momentum to the development of new norms and can increase pressure on international organizations to change their priorities and practices.
- A human rights-based advocacy approach provides new tools and tactics to complement the traditional skill-building provided by palliative care advocates.

PALLIATIVE CARE AS A HUMAN RIGHT

Ensuring the availability of palliative care is not just an ethical obligation of health systems or of good medical and public health practice, it is also an obligation under international human rights law. Nearly all countries in the world have signed on to one or more treaties that recognize the right to the highest attainable standard of physical and mental health[1].

The right to health has been authoritatively interpreted to include palliative care. For example, the United Nations Committee on Economic, Social and Cultural Rights, the independent body charged with monitoring compliance with the right to health under the International Covenant on Social and Economic Rights, has clarified that the right to health is an inclusive right which extends to timely and appropriate "preventative, curative and palliative health services." The committee has also called for "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."[2]

The right to health requires that countries take steps to the maximum of their available resources to ensure that health facilities, goods and services, including those required for palliative care, are:

- Available: in sufficient quantity, including trained health workers and essential medicines;
- Accessible: on the basis of non-discrimination (including in different regions of the country), economically, physically, and on the basis of access to information for health;
- Acceptable: in that they respect medical ethics and are culturally appropriate; and sufficient;
- Quality: scientifically and medically appropriate and of good quality, including skilled health workers and approved and unexpired medicines.

In recognition that states have different levels of resources, each country must "take steps… to the maximum of its available resources" to progressively achieve the full realization of the right to health (known as progressive realiza-

1. The right to health is guaranteed in a wide range of international and regional human rights treaties including, for example, the International Covenant on Economic Social and Cultural Rights, (in Article 12) and the Convention on the Rights of the Child (in Article 24). The latter treaty has been ratified by every country in the world with the exception of Somalia and the United States. See http://indicators.ohchr.org/
2. UN Committee on Economic, Social and Cultural Rights, *General Comment Number 14, The Right to Health*, (2000), UN Doc. E/CC.12/2000/4, para. 34.

tion)[3]. High-income countries will generally have to provide health care services at a higher level than those with limited resources, but all countries are expected to take concrete steps toward increased services.

The UN Committee on Economic, Social and Cultural Rights has identified certain core obligations that are so fundamental that states must immediately prioritize them. These include obligations:

- To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
- To provide essential medicines, as by the World Health Organization (WHO) in its Model List of Essential Medicines;
- To ensure equitable distribution of all health facilities, goods and services and;
- To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population[4.]

The Committee lists the obligation to provide appropriate training for health personnel as "of comparable priority."[5]

These core obligations correspond closely to the recommendations of the WHO. In its 2014 report to the World Health Assembly (WHA), the WHO recommended that governments formulate and implement a number of specific policies that it considers essential for expanding palliative care, including:

- Health system policies to ensure the integration of palliative care into the structure and financing of national health care systems at all levels of care;
- Policies for strengthening and expanding human resources, including education and training of health professionals, in order to ensure adequate responses to palliative care needs, together with training of volunteers and education of the public;
- A medicines policy in order to ensure the availability of essential medicines for the management of symptoms, including pain and psychological distress and, in particular, opioid analgesics for relief of pain and respiratory distress and;

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3. International Covenant on Economic Social and Cultural Rights, adopted by General Assembly resolution 2200A (XXI) of 16 December 1966, http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx (accessed August 6, 2013), art. 2(1).
4. UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, para. 43.
5. Ibid., para. 44.

- A policy for research into assessing the needs for palliative care and identifying standards and models of service that work, particularly in limited resource settings.

The WHA resolution on palliative care unanimously adopted on May 23, 2014, closely mirrors these recommendations[6].

Apart from proactive steps to meet these core obligations, countries must also "refrain from interfering directly or indirectly with the enjoyment of the right to health."[7] In other words, states may not deny or limit equal access for all persons, enforce discriminatory health policies, arbitrarily impede existing health services or limit access to information about health. Applied to palliative care, this obligation means that states may not put in place medicine control regulations that unnecessarily impede the availability and accessibility of essential palliative care medications such as morphine and other opioid analgesics.

It is important to note that a person does not lose their right to health when they receive a poor diagnosis or prognosis. In other words, the fact that someone can no longer be cured does not mean that he or she ceases to have a right to adequate health care services. The Committee on Economic, Social and Cultural Rights has held that people are entitled to a "system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health,"[8] including chronic or terminal illness. The Committee has called for an integrated approach to the provision of different types of health services that includes elements of "preventive, curative and rehabilitative health treatment."[9] It has also been held that investments should not disproportionately favor expensive curative health services, which are often accessible only to a small, privileged fraction of the population, rather than primary and preventive health care benefiting a far larger part of the population[10].

Similarly, the UN Committee on the Rights of the Child, the UN body responsible for monitoring the Convention on the Rights of the Child, has recognized that "children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services. At the primary level, these services must be available in sufficient quantity and quality, functional, within the physical and financial reach of all sections of the

6. WHA resolution 67.19, "Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course," May 14, 2014, http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (accessed June 26, 2014).
7. Ibid., para. 33.
8. UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, para. 8.
9. Ibid., para. 25.
10. Ibid., para. 19.

child population, and acceptable to all."[11] Meanwhile the Committee on the Elimination of All Forms of Discrimination against Women recommended that states adopt a comprehensive health care policy aimed at protecting the health needs of older women, "including care that allows for independent living and palliative care."[12]

The right to health is not the only right that affords protections for people with life-limiting illness. The right to be free from torture, cruel, inhuman, or degrading treatment or punishment does so as well[13]. Apart from prohibiting the use of cruel, inhuman, or degrading treatment, the right also creates a positive obligation for states to protect persons in their jurisdiction from such treatment[14]. This obligation includes protecting people from unnecessary pain related to a health condition. Manfred Nowak, then UN Special Rapporteur on Torture, Cruel, Inhuman or Degrading Treatment or Punishment (an independent expert who reports to the UN Human Rights Council on these issues) wrote in a joint letter with the UN Special Rapporteur on the Right to Health to the Commission on Narcotic Drugs in December 2008:

> "Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation."[15]

In a report to the UN Human Rights Council, Nowak later specified that, in his expert opinion, "the *de facto* denial of access to pain relief, if it causes severe

11. UN Committee on the Rights of the Child, General Comment Number 15, (2013), UN Doc. CRC/C/GC/15.
12. CEDAW General Recommendation No. 27 on older women and the protection of their human rights, CEDAW/C/2010/47/GC.1, 19 October 2010.
13. International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976, art. 7 ("No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment"); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Convention against Torture), adopted December 10, 1984, G.A. res. 39/46, annex, 39 U.N. GAOR Supp. (No. 51) at 197, U.N. Doc. A/39/51 (1984), entered into force June 26, 1987, art. 16.
14. See, e.g., the judgment of the European Court of Rights in Z v United Kingdom (2001) 34 EHRR 97.
15. A copy of the letter is available at: http://www.ihra.net/Assets/1384/1/SpecialRapporteursLettertoCND012009.pdf (accessed January 16, 2013).

pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment."[16]

Other human rights that are particularly engaged in relation to palliative care include rights to information, autonomy, independent living and access to community-based services, the rights of the child, and the rights of persons with disabilities, among others.

The right to autonomy and self-determination, an integral part of the right to privacy and family life, is highly relevant to palliative care as it grants people a right to make decisions concerning their own health, including at the end of life[17]. The European Court of Human Rights, for example, has affirmed that people have the right to make decisions concerning their own health, including whether to continue with aggressive treatment options, even if such decisions may result in death. As the Court said:

> "The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy (…) for this freedom to be meaningful, patients must have the right to make choices that accord with their own views and values, regardless of how irrational, unwise or imprudent such choices may appear to others."[18]

The Court has also found a positive obligation to protect individuals from interference with their legal capacity from others[19]; and to take reasonable steps to uncover previously stated wishes[20].

The right to autonomy extends to everyone. For children with life-limiting illness, the general principles of the Convention on the Rights of the Child (CRC) are extremely relevant, particularly those enshrined in Articles 3 and 12 of the CRC. Article 3 refers to the child's best interest as the determining factor in all actions dealing with him or her, taking precedence over the interests of the adults concerned (e.g., parents, teachers, guardians). Article 12 refers to the child's right

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16. Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, January 14, 2009, http://daccessdds.un.org/doc/UNDOC/GEN/G09/103/12/PDF/G0910312.pdf?OpenElement (accessed August 4, 2013), para. 72.

17. See for example *Evans v UK*, Grand Chamber (application 6339/05) judgment of 10 April 2007; *Pretty v UK*.

18. European Court of Human Rights, Case of Jehovah's Witness of Moscow and Others v. Russia, Application no. 302/02, August 2010.

19. *Storck v Germany*, (Application no. 61603/00), judgment of 16 June 2005.

20. See for example *Glass v UK*, Application No 61827/00. Decision of 9 March 2004.

to express an opinion and to have that opinion taken into account in any matter affecting him or her. In some cases the child's wishes or their best interests may conflict with the views of guardians. In such situations, the opinions of the child should be given due weight, based on their age and stage of development.

In relation to people with disabilities the Convention on the Rights of Persons with Disabilities (which applies to people with life-limiting illnesses when they lead to long-term physical, mental, intellectual or sensory impairments), the relevant UN committee has also clarified that the autonomy and capacity of persons with disabilities – including mental or intellectual disabilities as a result of, for example dementia – to make decisions must be respected and supported at all times. Accordingly, states have a positive obligation to provide persons with disabilities with access to support in the exercise of their decision-making capacity, replacing substitute decision-making regimes by supported decision-making[21].

The need for palliative care in humanitarian situations is a very neglected area. The issue has come to the foreground due to the major increase in displaced persons, migrants, and refugees as a result of recent conflict in the Middle East, instability in Africa, and severe weather due to climate change. Countries such as Jordan, Syria, Lebanon, Turkey, Greece, Italy, and many other European nations are seeing the greatest influx of displaced persons since World War II. Most of these persons are often very young or very old and disproportionately female. Existing chronic conditions are exacerbated and often access to the existing health facilities is very limited or unavailable. There is a strong unmet need to include palliative care into the global response to humanitarian crises as noted below.

**Palliative Care for Vulnerable Populations
Humanitarian Crises**

The United Nations Office for Coordination of Humanitarian Affairs (UNOCHA) in their Global Humanitarian Overview of 2016 identified an estimated 87 million people in 37 countries required humanitarian aid.

At present little is known of the need for palliative care, patient palliative care needs, and provision in humanitarian situations and emergencies. Reports from Medicins sans Frontieres (MSF) identify the need for palliative care but a lack of guidelines, palliative care expertise, and inclusion of palliative care in the Sphere Handbook of minimum standards for humanitarian response. (2). MSF does prioritize the following patients for treatment: HIV, Tuberculosis, complex non-communicable diseases, traumatic injuries, very premature neonates, children with life-threatening illnesses, congenital, genetic and nutritional conditions and those in pain. And as with palliative care, the humanitarian response aims to reduce suffering and improve quality of life. Within the system of triage there are five levels of treatment and T4 (expectant priority) is for those unlikely to survive.

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21. UN Committee on the Rights of Persons with Disabilities, General Comment Number 1 (2014), UN Doc. CRPD/C/GC/1.

…

> Despite the World Health Assembly Resolution 67 of 2014 calling on countries to integrate palliative care into health systems; and recognition of palliative care as a human right 774 palliative care is still omitted from humanitarian relief strategies .
>
> There is a recent movement to correct this situation with palliative care practitioners, academics, ethicists and humanitarian response practitioners collaborating to advocate for the inclusion of palliative care in humanitarian situations. PALCHASE Palliative Care in Humanitarian Aid Situations and Emergencies has been set up to bring together those working in this field; to carry out research and to advocate for inclusion.
>
> The World Health Organisation has set up a community of practice to develop materials and guidance.
>
> A research survey has been distributed by Mc Master University and pilot projects are being planned by the Worldwide Hospice Palliative Care Alliance and the Glasgow End of Life study group.
>
> Some palliative care services are being provided in a number of countries including Uganda, Germany, Greece, and Jordan. Refuges are being identified and cared for within hospice programmes in Austria and bereavement services are provided in Greece. A project by the University of Warwick and supported by EMMS International has appointed a nurse to provide palliative care in a post-natural disaster in Nepal and preliminary reports are very positive.
>
> With the large numbers and high mobility of refugees and migrants palliative care must be integrated into existing services to reach those in need.

ADVOCACY[22]

Palliative care has been defined as care that is person-centered and attentive to physical symptoms and psychological, social, and existential distress in patients with severe or life-threatening illness[23]. The goal of palliative care is to optimize the quality of life of patients and to address the needs of their families or close friends[24]. Palliative care can be provided in parallel with curative treatment, but its main purpose is to ease or prevent suffering. The World Health Organization (WHO) has emphasized that palliative care is particularly important in developing countries, where many terminally ill patients first seek medical attention when their illness is so advanced that it is beyond cure, and has urged countries with limited resources to focus on developing home-based palliative care services[25].

22. This section on advocacy was adapted from an open access article by D Lohman & J Amon, "Evaluating a human rights based advocacy approach to expanding access to pain medicines and palliative care," originally published in *Health and Human Rights Journal*. 2015; 17(2). http://www.hhrjournal.org/2015/12/evaluating-a-human-rights-based-advocacy-approach-to-expanding-access-to-pain-medicines-and-palliative-care-global-advocacy-and-case-studies-from-india-kenya-and-ukraine/

23. Ahmedzai S, Costa A, Blengini C, et al. A new international framework for palliative care. Eur J Cancer 2004; 40(15):2192–2200.

24. Harding R, Easterbrook P, Dinat N, Higginson I. Pain and symptom control in HIV disease: Under-researched and poorly managed. Clin Infect Dis 2005;40(3):491–492.

25. Hewitt D, McDonald M, Portenoy RK et al. Pain syndromes and etiologies in ambulatory AIDS patients. Pain 1997;70(2–3):117–123.

An important part of palliative care is addressing chronic and severe pain. Chronic pain is one of the most significant causes of suffering and disability worldwide, and is a common symptom of both communicable (for example, HIV and TB) and non-communicable (for example, cancer and diabetes) diseases, as well as accidents[26]. Pain has a profound impact on quality of life and can have physical, psychological, and social consequences. It can lead to reduced mobility and a consequent loss of strength, compromise the immune system, and interfere with a person's ability to eat, concentrate, sleep, and interact with others[27]. People who live with chronic pain have been found to be four times more likely to suffer from depression or anxiety than people who are not in pain[28]. The physical and psychological effects of chronic pain can also negatively influence the course of disease and indirectly influence disease outcomes by reducing treatment adherence.

Most pain in palliative care patients can be well controlled. WHO's "pain relief ladder" recommends the administration of different types of pain medications, depending on the severity of pain, and is the basis of modern pain management[29]. For mild pain, WHO calls for basic pain relievers, usually widely available without prescription. For mild to moderate pain, it recommends a combination of basic pain relievers and a weak opioid, such as codeine. For moderate to severe pain, WHO has recognized that strong opioids, such as morphine, are "absolutely necessary."[30] Because oral morphine can be produced cheaply and is easily taken at home, it is commonly used for home-based palliative care.

The identification of access to palliative care and pain treatment as a human rights issue first emerged among palliative care advocates, physicians, and lawyers in the 1990s[31]. This notion, especially with regard to pain treatment, has since gained wide recognition. For example, in 2008 the United Nations Special Rapporteur on the right to health and the Special Rapporteur on torture jointly recognized that a failure to address barriers to palliative care can be a violation of human rights:

26. Lohman D, Schleifer R, Amon JJ. Access to pain treatment as a human right. *BMC Med* 2010;8(8). doi: http://www.biomedcentral.com/1741-7015/8/8.
27. Brennan F, Carr D, Cousins M. Pain management: A fundamental human right. Anesth Analg 2007;105(1):205–221.
28. Gureje O, Von Korff M, Simon G, Gater R. Persistent pain and well-being: A World Health Organization study in primary care. JAMA 1998;280(2):147–151; Rosenfeld B, Breitbart W, McDonald MV, et al. Pain in ambulatory AIDS patients. II: Impact of pain on psychological functioning and quality of life. Pain 1996;68(2–3):323–328.
29. World Health Organization (WHO), *National Cancer Control Programme: Policies and managerial guidelines* (Geneva: WHO, 2002).
30. O'Neill J, Selwyn P, Schietinger H (eds.). *A clinical guide to supportive ad palliative care for HIV/AIDS.* (Rockville, MD: Health Resources and Services Administration, 2003).
31. WHO, *Achieving balance in national opioids control policy* (Geneva: WHO, 2000).

Many countries do not recognize palliative care and pain treatment as priorities in health care have no relevant policies, have never assessed the need for pain treatment or examined whether that need is met, and have not examined the obstacles to such treatment… The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment. International human rights law requires that governments must provide essential medicines – which include, among others, opioid analgesics – as part of their minimum core obligations under the right to health[32].

Human Rights Watch began working on access to pain treatment and palliative care in 2007 and issued a report tied to the high-level segment of the Commission on Narcotic Drugs in 2009. Like the Special Rapporteurs' report, the analysis focused on two main rights that may be violated by a lack of access to palliative care: the right to the highest attainable standard of health and the right to be free from cruel, inhuman, and degrading treatment[33].

Given that palliative care is an essential part of health care, the right to health requires that countries use the maximum available resources to ensure that it is available[34]. Indeed, the UN Committee on Economic, Social and Cultural Rights has called for "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."[35] Two different state obligations flow from this:

32. Somerville M. Human rights and medicine: The relief of suffering. in Cotler I. and Eliadis F. (eds.), *International human rights law: Theory and practice* (Montreal: Canadian Human Rights Foundation, 1992); 2nd Global Summit of National Hospice and Palliative Care Associations, Declaration on Hospice and Palliative Care" (2005). Available at http://www.coe.int/t/dg3/health/ Source/KoreaDeclaration2005_en.pdf; International Hospice and Palliative Care Association and Worldwide Palliative Care Alliance, Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights (2008). Available at http://www.apcp.com.pt/up-loads/jdsc.pdf; Brennan F and Cousins M. Pain relief as a human right. *Pain: Clinical Updates* 2004;12(5). Available at http://hospicecare.com/uploads/2011/8/pain_relief_as_a_human_right_pain_ clinical_updates_2004.pdf; Brennan F. Palliative care as an international human right. *J Pain Symptom Manage* 2007;33(5):494–499.
33. Nowak M., UN Special Rapporteur on the prevention of torture and cruel, inhuman, or degrading treatment or punishment and Grover A., UN Special Rapporteur on right of everyone to the highest attainable standard of physical and mental health, Letter to Chairperson of the Commission on Narcotic Drugs, UN Doc. G/SO 214 (52-21) (2008).
34. Human Rights Watch. *"Please do not make us suffer anymore"*: *Access to pain treatment as a human right* (New York: Human Rights Watch, 2009).
35. International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966); Convention on the Rights of the Child, G.A. Res. 44/25 (1989); International Convention on the Elimination of All Forms of Discrimination against Women, G.A. Res. 34/180 (1979); Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106(2006).

(1) a negative obligation to refrain from enacting policies or undertaking actions that arbitrarily interfere with the provision or development of palliative care; and

(2) a positive obligation to take reasonable steps to ensure the integration of palliative care into existing health services, both public and private, through the use of regulatory and other powers, as well as funding streams. While the positive obligation is subject to progressive realization, countries must comply with core obligations, including the provision of essential medicines as determined by WHO, irrespective of financial constraints[36].

In many countries, however, access to palliative care and to opioid analgesics for pain is very limited. Because strong pain medicines such as morphine (which are commonly used in palliative care and are included in WHO's Model List of Essential Medicines) are controlled substances, they are subject to strict regulation and control under the 1961 Single Convention on Narcotic Drugs[37]. Under the system set up by the convention, states must estimate their need for such medicines and closely monitor and regulate their use, and pharmaceutical suppliers must obtain import and export licences to transport these medicines across international borders[38].

Although the 1961 convention specifically declares the medical use of narcotic drugs indispensable for the relief of pain and mandates their adequate availability, many states fail to properly ensure the availability of opioid pain medicines or severely restrict access through onerous regulations. The International Narcotics Control Board, charged with monitoring the implementation of the UN drug conventions, clarified in 1995 that the Single Convention on Narcotic Drugs "establishes a dual drug control obligation: to ensure adequate availability of narcotic drugs, including opiates, for medical and scientific purposes, while at the same time preventing illicit production of, trafficking in, and use of such drugs."[39]

Yet despite a clear consensus among medical authorities and an obligation outlined in international human rights and drug control treaties, approximately 80% of the world's population lives in countries with either no or insufficient access to treatment for moderate to severe pain[40]. Millions of people suffer from

36. UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4 (2000), para. 25.

37. Ibid., para. 43 520 U.N.T.S. 151 (1961).

38 Single Convention on Narcotic Drugs 520 U.N.T.S. 151 (1961).

39. International Narcotics Control Board, *Report of the International Narcotics Control Board for 1995* (Vienna: International Narcotics Control Board, 1995).

40. WHO, *Briefing note: Access to controlled medications programme* (Geneva: WHO, 2008).

such pain each year, especially in low- and middle-income countries, which consume only 6% of the morphine used worldwide[41].

In many countries, the lack of access to palliative care stands in stark contrast to the investment by health systems in more expensive curative care for the minority of individuals who can access it. Although governments must address the health needs of entire populations, their health policies, strategies, and indicators often revolve entirely around curative therapies. Similarly, curricula and other training programs for medical students and physicians routinely do not teach even basic knowledge of palliative care. Between 2007 and 2015, Human Rights Watch worked with a number of human rights, palliative care, and public health groups, including the International Association of Hospice and Palliative Care, the Open Society Foundations, the Union for International Cancer Control, and the Worldwide Hospice Palliative Care Alliance, as well as numerous local partners, to conduct human rights research and advocacy in nine countries—Armenia, Guatemala, India, Kenya, Mexico, Morocco, Russia, Senegal, and Ukraine—on the lack of access to pain medicines and palliative care.

A RIGHTS-BASED ADVOCACY APPROACH TO IMPROVING ACCESS TO PAIN MEDICINE AND PALLIATIVE CARE

Public health programs adopting human rights-based approaches have been shown to improve service delivery, focus attention on marginalized populations, and enhance equality, equity, inclusiveness, and accountability[42]. Critical to the success of rights-based programs, however, is the existence of a dynamic civil society, high-level political leadership, and an enabling policy and legal environment[43]. This paper, by contrast, presents a rights-based *advocacy* approach to expanding access to pain medicines and palliative care and, drawing on case studies, examines the unique challenges of evaluating the impact of seeking changes to legal and policy environments and fostering political will.

Traditionally, palliative care advocates have focused on improving the availability of palliative care through investment in expanding services, training caregivers, and developing guidelines and other clinical or health programming

41. International Narcotics Control Board, *Report of the International Narcotics Control Board for 2004* (Vienna: International Narcotics Control Board, 2005).

42. Gruskin S, Ferguson L, Tarantola D, Beaglehole R. Noncommunicable diseases and human rights: A promising synergy. Am J Public Health 2014;104(5):773–775

43. Bustreo F, Hunt P, Gruskin S, et al. *Women's and children's health: Evidence of impact of human rights* (Geneva: WHO, 2013).

tools, sometimes defining these efforts as a human rights-based programmatic approach. With a few exceptions—notably the work of the Pain and Policy Studies Group at the University of Wisconsin—little attention has been paid to public advocacy. Even when public advocacy is part of the work, its focus is generally technical in nature.

By contrast, a human rights-based advocacy approach to palliative care and access to pain medicines can be understood to emphasize four key strategies:

- *Raise the voices of people affected by the rights violation.* The testimonies of people with incurable illnesses, as well as those of their families should be included. These testimonies provide powerful and specific evidence of the consequences of the lack of access to pain medicines and palliative care, and they humanize the issue and the need for change.
- *Analyze structural barriers. I*n examining why individuals were unable to access pain medicines or palliative care, we focused on identifying structural barriers and the way that laws, policies, and their enforcement influenced such access[44].
- *Clarify government obligations.* Beyond simply asserting that governments have an obligation to progressively realize the right to health, we examined specific absolute (or non-derogable) and core minimum obligations related to access to pain medicines and palliative care, including government obligations to develop national palliative care strategies, to refrain from arbitrary interference in the provision of medical care and access to essential medicines, to ensure non-discrimination, and to protect vulnerable populations[45].
- *Advocate for change.* Our advocacy emphasized holding governments accountable for their failure to address, or their explicit responsibility in creating, barriers to relieving needless suffering. Our advocacy approach involved both long-term direct engagement of government officials at the national and international levels and public pressure through media. Working with health care providers, families, and palliative care activists, we and our partners sought to engage governments to commit to change and to ensure that this commitment was enacted in law, policy, and practice[46].

44. Amon JJ. The political epidemiology of HIV. J Int AIDS Soc 2014;17:19327.
45. Thomas L, Lohman D, Amon J. Access to pain treatment and palliative care: A human rights analysis. Temple Int Comp Law J 2010;24:365.
46. Amon JJ, Wurth M, McLemore M. Evaluating human rights advocacy on criminal justice and sex work. Health Hum Rights 2015;17(1):91–101.

The four elements of our strategy humanized the issue of palliative care, identified key barriers, clarified government obligations, and prioritized advocacy as a means to hold governments accountable.

GLOBAL ADVOCACY

In addition to our work to address palliative care in specific countries, we prioritized global advocacy. This advocacy focused on three distinct areas where we and our partners felt there were strategic opportunities to advance palliative care: (1) strengthening recognition of access to palliative care and pain treatment as a human rights issue among human rights bodies; (2) ensuring greater focus on access to controlled medicines in global drug policy debates, and; (3) advocating for attention to palliative care in global health policy debates.

In 2007, before we and our partners began implementing the human rights-based advocacy approach to palliative care, no UN human rights bodies or special procedures had recognized or articulated a right to palliative care or access to pain medicine. Seeing such recognition as critical to our ability to advance global commitment to the issue, we prioritized working with the Special Rapporteurs on torture and health, treaty bodies, and the Human Rights Council to address this gap.

As a part of this work, our coalition briefed the Special Rapporteurs and the UN Committee against Torture, in addition to organizing a side event at the Human Rights Council where we provided relevant information on research findings. Starting with the joint statement of the Special Rapporteurs on health and torture in 2008, there has been an increasing body of statements supporting a right of access to palliative care (see Table 1).

As the UN and regional human rights bodies began to address the lack of effective protection against human rights abuses for older people, we also tried to ensure that new standards explicitly recognize the right to access palliative care. The recently adopted Inter-American Convention on Protecting the Human Rights of Older Persons of the Organization of American States contains extensive provisions on palliative care, as does the Council of Europe's recommendation on the rights of older people[47].

Our second objective—to increase attention to access to controlled medicines in global drug policy debates—stemmed from the recognition that drug control

47. Council of Europe, Committee of Ministers, Recommendation CM/Rec(2014)2 of the Committee of Ministers to member states on the promotion of human rights of older persons (2014); Inter-American Convention on Pro- tecting the Human Rights of Older Persons, Organization of American States OAS Doc. AG/doc.5493/15 corr. 1 (2015).

Table 1. Statements supporting a right of access to palliative care

Organization	Document/Report/Declaration	Relevant Text
Council of Europe (2014)[1]	Recommendation of the Committee of Minister to Member States on the Promotion of Human Rights of Older Persons	*Member States should offer palliative care for older persons who suffer from a life-threatening or life-limiting illness to ensure their well-being and allow them to live and die with dignity. [para. 44]* Trained specialists in the field of palliative care should be available to lead education and research in the field. Programmes of palliative care education should be incorporated into the training of all health and social-care workers concerned and co-operation of professionals in palliative care should be encouraged. [para. 48] *Member States should ensure the adequate availability and accessibility of palliative-care medicines. [para. 49]*
Committee on the Rights of the Child (2013)[2]	General Comment No. 15 on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health	*Children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services. [para. 25]*
Special Rapporteur on Torture (2013)[3]	Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	*Governments must guarantee essential medicines – which include, among others, opioid analgesics – as part of their minimum core obligations under the right to health, and take measures to protect people under their jurisdiction from inhuman and degrading treatment. [para. 56] [N]ot every case where a person suffers from severe pain but has no access to appropriate treatment will constitute cruel, inhuman, or degrading treatment or punishment. This will only be the case when the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment; when the State is, or should be, aware of the suffering, including when no appropriate treatment was offered; and when the Government failed to take all reasonable steps to protect individuals' physical and mental integrity. [para. 54]*

1. Council of Europe, Committee of Ministers, Recommendation CM/Rec(2014)2 of the Committee of Ministers to Member States on the Promotion of Human Rights of Older Persons (2014).
2. UN Committee on the Rights of the Child, General Comment No. 15 (2013) on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (Art. 24), UN Doc. CRC/C/GC/15 (2013).
3. UN Human Rights Council, Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, UN Doc. A/HRC/22/53 (2013).

Organization	Document/Report/Declaration	Relevant Text
Special Rapporteur on the Right to Health (2012)[4]	Submission to the Committee against Torture regarding Drug Control Law	*Access to controlled medicines is essential in the management of moderate to severe pain, including as part of palliative care for people with life-limiting illnesses; certain emergency obstetric situations; and management of epilepsy. The right to health requires States to provide essential drugs mentioned in the WHO list of essential medicines.* [para. 22]
Committee on the Rights of the Child (2011)[5]	Consideration of Reports Submitted by States Parties Under Article 44 of the Convention, Concluding Observations: Belarus	*The Committee recommends that the State party establish a funding mechanism for the provision of palliative care for children and support the palliative care services provided by non-governmental organizations.* [para. 56]
Special Rapporteur on the Right to Health (2011)[6]	Thematic Report on the Realization of the Right to Health of Older Persons	*Palliative care requires important funding and mobilisation of numerous actors and stakeholders within the medical sector, and it is absolutely crucial in order to prolong the lives of older persons affected by life-threatening diseases and to ensure their death in dignity.* [para. 60]
UN High Commissioner on Human Rights (2011) [7]	Opening Statement at the Human Rights Council 18th Session, Panel on the Right to Health of Older Persons	*Adequate access to palliative care is essential to ensure that these people can live and – ultimately – die with dignity.* [para. 15]
Committee on the Elimination of All Forms of Discrimination against Women (2010)[8]	General Recommendation No. 27 on Older Women and Protection of Their Human Rights	*States parties should adopt a comprehensive health-care policy aimed at protecting the health needs of older women… Such policy should ensure affordable and accessible health care to all older women through… long-term health and social care, including care that allows for independent living and palliative care.* [para. 45]

4. Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Submission to the Committee against Torture regarding Drug Control Laws (October 19, 2012). Available at http://www.ohchr.org/Documents/Issues/Health/drugPolicyLaw.pdf
5. UN Committee on the Rights of the Child, Concluding Observations on Belarus, UN Doc. CRC/C/BLR/CO/3-4 (2011).
6. UN Human Rights Council, Thematic Study on the Realization of the Right to Health of Older Persons by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/18/37 (2011).
7. Office of the United Nations High Commissioner for Human Rights, Opening Statem*ent by the United Nations High Commissioner for Human Rights Ms. Navi Pillay to the Human Rights Council 18th session, panel on the right to health of older persons, Geneva, 16 September 2011. Available at* http://www.ohchr.org/EN/NewsEvents/Pages/ DisplayNews.aspx?NewsID=11531&LangID=E
8. UN Committee on the Elimination of Discrimination against Women, General Recommendation No. 27 on Older Women and Protection of Their Human Rights, UN Doc. CEDAW/C/GC/27 (2010).

Organization	Document/Report/Declaration	Relevant Text
Special Rapporteur on Torture (2009)[9]	Promotion and Protection of All Human Rights, Civil Political, Economic, Social and Cultural Rights, including the Right to Development	*Similarly, the Special Rapporteur is of the opinion that the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.* [para. 72] *Given that lack of access to pain treatment and opioid analgesics for patients in need might amount to cruel, inhuman and degrading treatment, all measures should be taken to ensure full access and to overcome current regulatory, educational and attitudinal obstacles to ensure full access to palliative care. [para. 74(e)].*
Special Rapporteurs on Torture and the Right to Health (2008)	Letter to Chairperson of the Commission on Narcotic Drugs	*Many countries do not recognize palliative care and pain treatment as priorities in health care, have no relevant policies, have never assessed the need for pain treatment or examined whether that need is met, and have not examined the obstacles to such treatment. … The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment. International human rights law requires that governments must provide essential medicines – which include, among others, opioid analgesics – as part of their minimum core obligations under the right to health. [p. 4]*
Committee on Economic, Social and Cultural Rights (2001)[10]	General Comment No. 14 on the Right to the Highest Attainable Standard of Health	*In particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services. [para. 34]*

9. UN Human Rights Council, Promotion and Protection of All Human Rights, Civil, Political, Economic, Social and Cultural Rights, Including the Right to Development: Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Manfred Nowak, UN Doc. A/HRC/10/44 (2009).
10. UN Committee on Economic, Social and Cultural Rights (see note 14).1 Council of Europe, Committee of Ministers, Recommendation CM/Rec(2014)2 of the Committee of Ministers to Member States on the Promotion of Human Rights of Older Persons (2014).

regulations were frequently responsible for the lack of availability of pain medicines. Yet access to opioid analgesics such as morphine was barely part of global drug policy discussions. For example, in 1998, UN member states negotiated a political declaration on the world drug problem that proclaims drugs "a grave threat to the health and well-being of all mankind" without a single word on the

medical uses of controlled substances or the treaty obligation to ensure their adequate availability for medical use[48].

Access to opioid medicines was not on the agenda of the Commission on Narcotic Drugs, the annual UN gathering at which global drug policy issues are discussed, or on the radar of the UN Office on Drugs and Crime, which works with states on controlling the supply of illicit drugs and expanding access to drug dependency treatment and other health issues related to drug use[49]. Only the International Narcotics Control Board made periodic statements expressing its concern about the limited availability of controlled medicines in many countries[50].

In pursuing our advocacy, we and our partners believed that changing the discussion at the international level to include access to controlled medicines—and the role of drug control regulations in making them inaccessible—would be critical for influencing such regulations at the national level. Through briefings at the Commission on Narcotic Drugs, as well as coalition-building with drug policy non-governmental organizations and a number of UN member states, we consistently pressed for attention to opioid medicines at the Commission on Narcotic Drugs, the UN Office on Drugs and Crime, and the International Narcotics Control Board.

Progress toward this objective has been significant. In 2009, UN member states negotiated a new political declaration at the Commission on Narcotic Drugs, along with a 10-year action plan "on international cooperation toward an integrated and balanced strategy to counter the world drug problem," which contained references to access to controlled substances for medical purposes[51]. The commission adopted resolutions on the issue in 2010 and 2011 and added controlled medicines as a standing item to its agenda in 2010[52]. In 2011, the International Narcotics Control Board issued a detailed report on the topic[53]. That

48. United Nations, Political Declaration, G.A. Res. S-20/2, UN Doc. A/RES/S-20/2 (1998).
49. United Nations Office on Drugs and Crime, *About UNODC*. Available at http://www.unodc.org/unodc/en/about-unodc/index.html?ref=menutop
50. International Narcotics Control Board (1995, see note 18); International Narcotics Control Board, *Report of the International Narcotics Control Board on the availability of internationally controlled drugs: Ensuring adequate access for medical and scientific purposes* (Vienna: International Narcotics Control Board, 2010).
51. High-Level Segment Commission on Narcotic Drugs, Political Declaration and Plan of Action on International Cooperation towards an Integrated and Balanced Strategy to Counter the World Drug Problem, Vienna, March 11–12, 2009.
52. Commission on Narcotic Drugs, Resolution 53/4, Promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse (2010); Commission on Narcotic Drugs, Resolution 54/6, Promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse (2011).
53. International Narcotics Control Board (2010, see note 47).

same year, the UN Office on Drugs and Crime published a discussion paper and initiated a review of its model drug law[54]. The 2014 Joint Ministerial Statement of the Commission on Narcotic Drugs contained several paragraphs on the issue[55]. The topic of controlled medicines is now firmly on the agenda for the planned 2016 UN General Assembly Special Session on Drugs, which will consider the successes and shortfalls of the 2009 global drug strategy and represents an opportunity for the international community to commit to greater action to address the limited availability of medicines like morphine in much of the world.

To address our third advocacy objective—an increased focus on palliative care and access to pain medicine by global health policy agencies—we first conducted a review of resolutions adopted by the World Health Assembly between 2000 and 2010, which confirmed that the assembly had not once addressed palliative care in that period. World Health Assembly resolutions provide direction to the work of WHO and UN member states. The assembly's failure to discuss palliative care as a stand-alone topic during the past decade, despite the fact that tens of millions of people from around the world require it every year, provided us with a strong argument for the topic's inclusion during future meetings. At the same time, we reviewed the WHO technical guidance on palliative care and found major gaps in this guidance regarding diseases other than cancer and HIV, as well as a lack of attention to symptoms other than pain.

To encourage the World Health Assembly to address the issue of pain medicine and palliative care, we organized a number of briefings during assembly meetings, built coalitions of civil society groups and UN member states supportive of palliative care, and held meetings with WHO staff to encourage greater action on the topic. As a result of this work, in May 2014 the World Health Assembly adopted a detailed resolution on palliative care with 37 cosponsoring countries[56]. The resolution contained specific recommendations for action by member states, WHO, and several other UN agencies. Following the passage of the resolution, WHO hired staff to develop an implementation strategy for the resolution, as well as to undertake the implementation itself. The strategy is currently under development.

54. United Nations Office of Drugs and Crime, E*nsuring availability of controlled medications for the relief of pain and preventing diversion and abuse: Striking the right balance to achieve the optimal public health outcome* (Vienna: United Nations Office of Drugs and Crime, 2011).
55. Commission on Narcotic Drugs, *Joint ministerial statement 2014 of the high-level review by the Commission on Narcotic Drugs of the implementation by member states of the political declaration and plan of action on international cooperation towards an integrated and balanced strategy to counter the world drug problem* (New York: United Nations, 2014).
56. WHO, *Sixty-seventh World Health Assembly*. Available at: http://www.who.int/mediacentre/events/2014/wha67/en

CONCLUSION

Attributing policy change to one specific organization, intervention, or strategy is often impossible and can be counterproductive[57]. Moreover, the long-term nature of policy or legal change makes it difficult to track the specific antecedents and contributions of actions that set the stage for later potentially more visible work.

Efforts by coalitions, which bring diverse expertise, authority, and perspectives, can provide critical momentum to the development of new norms and can increase pressure on international organizations to change priorities and practices. In this case, the involvement of mainstream human rights organizations in advocacy around access to palliative care lent credibility and specificity to the concept and helped generate a broad acceptance that palliative care is indeed a right.

Our efforts to advance an understanding and acceptance of access to palliative care as an element of the right to health were aided by recognition of the relationship between this right and two fundamental principles long recognized within human rights movements. First, the right to be free of unnecessary suffering is consistent with the principle of dignity, on which human rights are based[58]. Second, the de facto denial of access to pain relief, where it causes severe pain and suffering, can be considered cruel, inhuman, and degrading treatment. Using testimony from individuals and their families in our research provided vivid support for both the loss of dignity among people suffering chronic pain and the inhuman and degrading consequences of the lack of access to pain relief. Frequently, the testimony provided provocative parallels with the testimony of victims of torture[59]. A human rights-based advocacy approach provided new tools and tactics to complement the traditional skill-building provided by palliative care advocates. The result was increased political will to address structural barriers, increased understanding of the technical solutions required, and the protection of the rights of millions of people suffering unnecessary pain worldwide.

57. Alliance for Justice, *build your advocacy grantmaking: Advocacy evaluation tool* (Washington, DC: Alliance for Justice, 2005); I. Gorvin, "Producing the evidence that human rights advocacy works: First steps towards systematized evaluation at Human Rights Watch," *Journal of Human Rights Practice* 1/3 (2009), pp. 477–487.
58. Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948).
59. Amon JJ, Lohman D. Denial of pain treatment and the prohibition of torture, cruel, inhuman or degrading treatment or punishment. *Interights Bulletin* 2011;16(4):172–184; Amon JJ. Abusing patients: Health providers' complicity in torture and cruel, inhuman or degrading treatment" (New York: Human Rights Watch, 2010). Available at http://www.hrw.org/sites/default/files/ related_material/patients_0.pdf

FURTHER RECOMMENDED READING

Brennen F. Palliative Care as an international human right. J Pain Symptom Manage. 2007; 33(5):494-499.

Gwyther L, Brennen F, Harding R. Advancing palliative care as a human right. J Pain Symptom Manage. 2009;38(5):767-774.

Seatzu F, Fanni S. The right to palliative care: a" mirage" in the jurisprudence of the ECTHR and IACTHR? *Cuadernos de derecho transnacional*, 2016;*8*(1):5-16.

11
EVALUATION OF PALLIATIVE CARE PROGRAMS

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KEY POINTS

- Methodological framework for the evaluation of a national/regional palliative care program.
- Evaluation is an essential part of national/regional programs. It gives information about what a program does and how well it does it.
- Steps for evaluation are: planning, conducting, reporting, and communicating the results of the evaluation.

AIMS OF THIS CHAPTER

This chapter aims to present a methodological framework for the evaluation of a national/regional Palliative Care program[1], and to describe some practical examples of evaluation.

BACKGROUND

The WHA Resolution on Palliative Care considers the evaluation of palliative care programs an essential issue to generate experience and evidence that might be shared and disseminated.

The proposed definition of a palliative care program includes the comprehensive and systematic measures adopted to improve palliative care for a defined population or demographic scenario.

The *evaluation* of a palliative care program consists of a set of methodologies and procedures designed and implemented with the aim of providing informa-

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1. A basic needs assessment at population level should be considered a preliminary and important component of the evaluation process. That topic is discussed in chapter three of this book.

tion about the process of development and implementation of the program and its effectiveness. In other words, evaluation is a tool to find out what a program does and how well it does it. In general, evaluation at regional/national levels is a dynamic *process* based on valid and comparable indicators.

In this chapter we suggest a common framework that allows different degrees of evaluation for programs in each region/country, depending on the local skills, resources, and availability of information and at the same time maintains the possibility of comparison between programs.

A palliative care program should include an evaluation method from the beginning. Evaluation gives important decision-making information for continuing, changing, expanding or ending a program and, under certain conditions, may provide useful evidence for benchmarking. This is fundamental for ensuring that effective programs are maintained and resources are not wasted on ineffective programs (CDC 2006)[2].

More specifically, the process of evaluation of a national/regional program is useful because:

- It allows assessment/monitoring over time of progress towards the stated program's goals and the interim goals and targets of the different phases of implementation;
- It provides the opportunity to introduce continuous quality improvement interventions in critical areas;
- It provides the technical basis for any political decision about the development of the program, including the provision of further funding and support;
- It meets the growing demand for accountability by public, private, or non-profit organisations that have funded the program;
- It permits comparisons among groups, particularly among populations with disproportionately high risk factors and vulnerable populations;
- By offering comparisons, it allows countries or regions where progress towards meeting the targets is relatively slow to be identified;
- A more detailed analysis of monitoring data below the regional/national level can then be undertaken in order to identify areas where performance can be improved.
- It allows the comparison of similar initiatives and can provide models for replication.

2. Centers for Disease Control and Prevention (CDC). Office of the Director, Office of Strategy and Innovation, & National Center for Infectious Diseases, Division of Bacterial and Mycotic Diseases. Introduction to program evaluation for public health programs: Evaluating appropriate antibiotic use programs. Atlanta, GA: Centers for Disease Control and Prevention, 2006. Available at http://www.cdc.gov/getsmart/program-planner/Introduction.pdf (Retrieved: 28th May 2016).

The methodology used for evaluation at a national level is rather specific as compared to evaluations of local services or single interventions. Although both use quality indicators, not all the indicators generated at the local level are relevant to the national level and the target for a national evaluation is much broader (CDC 2006). They can be useful for each other. For example the results of an evaluation at a national/regional level can provide useful information for interpreting local programs of evaluation, while evaluation at the micro level can provide useful information about quality issues or specific problems.

Inferences derived from evaluations should be relevant to the decision-making. Therefore it is necessary to include people with authority to make changes if needed. A participatory approach, including decision-makers and implementers of the programs, partners, program beneficiaries, and funders, ensures that evaluations address equity, share knowledge, and strengthen the evaluation capacities of program beneficiaries, implementers, funders, and other stakeholders (WHO, 2006). In addition such evaluation has to be sensitive to human rights, equity, and gender and is inclusive of diverse stakeholder groups in the evaluation process.

PREPARING FOR AND CONDUCTING AN EVALUATION[3]

Figure 1. Structure and steps in the evaluation process (modified from WHO, Evaluation Practice Handbook, 2013)[3]
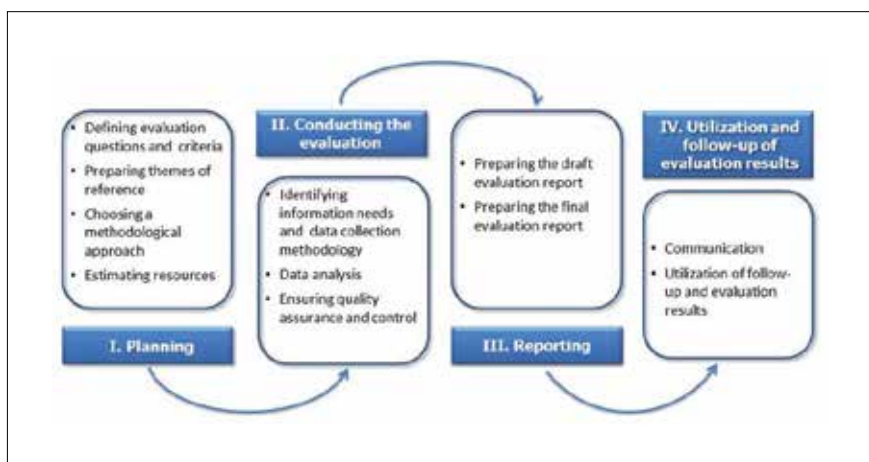
3. This section is taken from WHO (2013) Evaluation Practice Handbook. Retrieved from: http://apps.who.int/iris/bitstream/10665/96311/1/9789241548687_eng.pdf

PLANNING

Evaluation Questions and Criteria

The most crucial part of an evaluation is to identify the key questions that it should address. These questions should consider the organizational context and the life-cycle of the program or project.

For example: descriptive evaluation aims to observe, describe, and measure changes.

Requirements:

- The question must correspond to a real need for information or the identification of a solution.
- The question concerns a need, a result, an impact, or a group of impacts.
- The question concerns only one judgement criterion.

There are three *major risks* in drafting evaluation questions:

- Gathering large quantities of data and producing sometimes technically sophisticated indicators that make little contribution to practice or policy;
- Formulating evaluation questions that are not answerable;
- Defining the overarching concern for utility too narrowly and limiting the user focus to the instrumental use of evaluation by managers, rather than including uses that beneficiaries and civil society groups may make of evaluation in support of public health and accountability.

The following are some core criteria:

- Relevance: The extent to which the objectives of a development intervention are consistent with beneficiaries' requirements, a country's needs, global priorities, and partners' and donors' policies.
- Efficiency: How economic resources and inputs (funds, expertise, time, etc.) are turned into outputs/results. Comparison of the results obtained and the resources spent.
- Effectiveness: The extent to which the objectives of the program or initiative were achieved or are expected to be achieved, taking into account their relative importance.
- Sustainability: Probability of continued long-term benefits. The resilience to risk the net benefit flows over time.
- Impact: Grouping of the positive and negative, primary and secondary long-term effects produced by a development intervention, directly or indirectly, intended or unintended.

The evaluation questions need to be checked for:

- Clarity of the concept,
- Availability of data,
- Access to information sources,
- Usage of the generated recommendations.

Terms of Reference

Once there is agreement on the objectives of the evaluation and the questions that it will need to answer, it is essential to establish the terms of reference. The terms of reference serve as a guide throughout the evaluation and include what is being evaluated and why, who should be involved in the evaluation process, and the expected outputs.

The terms of reference for an evaluation should include detailed information on the following elements:

- Context of the evaluation and framework analysis of the subject under evaluation;
- Purpose and objectives of the evaluation;
- Scope and focus of the evaluation;
- Evaluation criteria (relevance, efficiency, effectiveness, sustainability, and impact);
- Key evaluation questions;
- Users (owners and audience) of the evaluation results;
- Methodology (involvement of stakeholders, approach for data collection, and analysis methods required to answer the evaluation questions);
- Evaluation team (team size, knowledge, skills and required qualifications of evaluators), with specific mention of how conflicts of interests are addressed, and how the independence and objectivity of the team are assured;
- A detailed work plan (timetable, organization and budget);
- Deliverables (including timing of inception/draft/final report, report distribution strategy, follow-up);
- As applicable, composition of the ad hoc evaluation management group (including relevant technical requirements).

Choosing a Methodological Approach

The purpose, scope, and evaluation of questions determine the most appropriate way to inform the selection of an evaluation approach. The evaluation methodology selected should ensure that the most appropriate methods of data collection and analysis are applied in relation to the evaluation objectives and

questions. Evaluation methodologies are derived from research standards and methods.

The evaluation methodology addresses:

- The scope of the evaluation (duration of evaluation period and activities to be covered);
- Data collection techniques at various levels (countries, sectors, themes, cases);
- Data analysis to answer the evaluation questions;
- Quality of the exercised evaluation.

Quantitative evaluations use quantitative indicators of structure, process or outputs, or else outcomes. The indicators are specific and measurable, and can be expressed as percentages, rates, or ratios. They include surveys, research studies, etc. An example of some indicators is shown in table 1.

Table 1. Examples of Key Indicators for National/Regional Palliative Care Programs (Modified from Gómez-Batiste et al, 2011)[4]

Structure	Process	Results
■ Existing formal national or regional plan/program ■ Clear leadership ■ Specialist resources global/population, by type, by setting ■ Directory of services ■ Number of professionals ■ Legislation: general, access to essential medicines, financing. ■ Standards ■ Financing model	■ Number of patients reaching specialist services ■ Training activities ■ Academic and research activities ■ Opioid availability and accessibility global /by settings ■ Actual budget	■ Coverage cancer /non cancer (%) ■ Geographical coverage (%) ■ Opioid consumption ■ Improved quality of life of patients and families ■ Satisfaction (patients and families, stakeholders) ■ Effectiveness in patients ■ Cost ■ Efficiency (global/by services) ■ Publications / research

Qualitative evaluations (table 2) use techniques for obtaining in-depth responses about what people think and how they feel, and enable managers to gain insights into attitudes, beliefs, motives, and behaviours or performance of services. Qualitative methods have their particular strength in proposed solutions and empower participation. They help to identify areas of improvement not described in the quantitative evaluation. They include interviews, SWOT (strengths, weak-

4. Gómez-Batiste X, Stjernsward J, Espinosa J, Martínez-Muñoz, Trelis J, Calle C. How to design and implement Pallitive Care Public Health Programs: Foundation Measures. 2011. Available at: http://ico.gencat.cat/web/.content/minisite/ico/professionals/documents/qualy/arxius/tool__foundation_measures_-_programmes_fv.pdf

nesses, opportunities and threats) analysis, observation, focus groups, nominal expert groups, interviews with patients, families, key stakeholders, or professionals.

Table 2. Examples of Qualitative Methods for Evaluation (Modified from Gómez-Batiste et al, 2011)[5]

Examples	Methods
■ Opinion polls and customer satisfaction ■ Study expectations ■ Studies of complaints and suggestions made by customers ■ Professionals' opinion research	■ SWOT analysis ■ Brainstorming ■ Nominal groups ■ Interview ■ Focal groups

Qualitative and quantitative methods can be used in a manner that is interrelated and complementary. There are many possible methodological combinations mixing quantitative and qualitative methods, which make each evaluation unique.

The expected outcomes (and the types of indicators to be measured) may change over time, from structure to process and finally outcomes (table 3). The appropriateness of the choice between the types of evaluations depends on the aim and the stage of the program.

Formative evaluations (also called process evaluations) are conducted in an early phase of implementation, with the aim of providing useful feedback about the best way to design, develop, and implement the program, selecting the key issues considered essential for success. This approach examines the process of implementing the program and determines whether it is operating as planned. Results are used to fine-tune the program and the procedures of its implementation.

Summative evaluations (also called outcome/impact evaluations) are designed and implemented when a program is running or close to its end. The aim of a summative evaluation is to find out to what extent a program achieves its goals. This evaluation can be quantitative, with the classical quality indicators of structure (number of services, availability of trained physicians, legislation, policies), process (opioid accessibility), and outcomes (coverage for cancer and non-cancer, geographical coverage, opioid consumption), and can include qualitative approaches. This evaluation approach is used to make decisions about the programs evaluated (Habicht 1999)[6].

5. Gómez-Batiste X, Espinosa J, Martínez-Muñoz M. [How to elaborate indicators and standards to evaluate the quality of palliative care in health services] In Spanish: Cómo elaborar indicadores y estándares para la evaluación de calidad de la atención paliativa en servicios de salud. 2011. Available at: http://ico.gencat.cat/web/.content/minisite/ico/professionals/documents/qualy/arxius/tool_como_elaborar_indicadores_y_estandares_calidad_at_pal_ss_vf.pdf
6. Habicht JP, Victora CG, Vaughan JP. Evaluation designs for adequacy, plausibility and probability of public health programme performance and impact. International Journal of Epidemiology. 1999; 28: 10-8.

Table 3. Aims and Methods of Evaluation According to the Stage of the Program

Stage	During program development	Established program	Mature program
Evaluation type	Formative evaluation	Summative evaluation	Impact evaluation
General aim	To improve the program	To determine to what extent the program achieves its goals	
Specific aims	Has the program been implemented as intended? Why not? Can I collect indicators?	Quantitative evaluation of indicators Qualitative assessment	Predicted and unpredicted impacts on the population
Methods	Qualitative and/or quantitative		
Output	Established program, as the result of the evaluation Procedures for collecting indicators	Does the program achieve its goals? Short-medium term effects Strengths and weaknesses	Net effects Long-term effects

Estimating Resources

The following factors need to be considered to estimate the budget for an evaluation:

- The timing of the evaluation, determined by its purpose. An evaluation conducted early in implementation, which focuses on design issues rather than outcomes, tends to be less complex and smaller in scope than a heavier exercise conducted at the end of a program or project cycle that requires more data.
- The scope and the complexity of the evaluation and whether it is a process or outcome/impact evaluation. The time and amount of work needed by the evaluation team to collect and analyse data will affect the cost of the evaluation.
- The availability and accessibility of primary and secondary data and the data collection methods selected. If the data readily available are not sufficient, the evaluators will need to spend time and resources to locate or generate information and the evaluation will be more costly.

When preparing the budget for an evaluation, it is necessary to take into consideration the estimated direct and indirect costs of the evaluation. It has

been estimated that 3 to 5 percent of the program budget should be used for evaluation.

CONDUCTING THE EVALUATION

IDENTIFYING INFORMATION NEEDS AND DATA COLLECTION METHODS

The evaluation will need to select data collection methods that match its purposes. The most commonly used methods are documentary reviews, direct observation, and interviews.

The evaluation team needs to consider the following factors in data collection:

- Methodological rigour;
- Cost–effectiveness;
- Validity, reliability and credibility.

DATA ANALYSIS

Data analysis is a systematic process that involves organizing and classifying the information collected, tabulating it, summarizing it, and comparing the results with other appropriate information to extract useful information that responds to the evaluation questions and fulfils the purposes of the evaluation.

Data synthesis seeks to detect patterns in evidence, either by isolating important findings or by combining sources of information and, finally, the data are translated into usable formats related to each evaluation question.

Steps to data analysis and synthesis are:

- Analysis plan: How the information collected will be organized, classified, interrelated, compared, and displayed relative to the evaluation questions, and any statistical methods that will be used to integrate or present the data.
- Interpreting the findings: Giving meaning to the evaluation findings derived from the analysis.
- Drawing conclusions: A conclusion is a reasoned judgement based on a synthesis of empirical findings or factual statements corresponding to specific circumstances.
- Making recommendations: Recommendations are evidence-based proposals for action aimed at evaluation users and should be based on

conclusions. Recommendations should be formulated in a way that will facilitate the development of a management response. They must be realistic and must reflect an understanding of the evaluation commissioner's organization and potential constraints on follow-up. Each recommendation should clearly identify its target group and stipulate the recommended action and rationale.

- Lessons learned: Lessons learned comprise the new knowledge gained from the particular circumstances (initiative, context outcomes and even evaluation methods) that are applicable to and useful in other similar contexts. Frequently, lessons learned highlight strengths or weaknesses in preparation, design, and implementation that affect performance, outcome, and impact.

ENSURING QUALITY

Quality control is a continuous process that is carried on throughout the evaluation process. It is achieved when the following conditions are met (Danida, 2012)[7]:

- The evaluation plan and the terms of reference are coherent, to ensure a clear logic between rationale, purpose, objectives, and resources available for a planned evaluation.
- The principles of independence and impartiality of the evaluation team are adhered to, from selection to completion.
- The inception report is coherent, and the approach and methodology meet professional quality standards.
- The fieldwork applies robust methodologies, i.e., it uses methods that best answer the evaluation questions in order to ensure the validity and reliability of the findings and conclusions.

REPORTING

Preparing the draft evaluation report

A written report is the principal output of the evaluation process. The draft evaluation report should be logically structured and should contain:

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7. Danida (2012). Danida evaluation guidelines. Copenhagen, Ministry of Foreign Affairs of Denmark. Retrieved from website: http://www.netpublikationer.dk/um/11121/index.htm

- Executive Summary
- Introduction/Background
- Methods
- (Evidence-based) Findings
- Conclusions
- Lessons learned
- Recommendations
- Annexes

The draft report is the last opportunity to provide feedback to the evaluation team before the final report is published. The quality of the draft evaluation report should be reviewed, i.e., provide comments on factual inaccuracies and, if applicable, verify that the recommendations are feasible.

THE FINAL EVALUATION REPORT

A high-quality final report should:

- Be addressed to the right stakeholders (according to the terms of reference and in agreement with the evaluation commissioner);
- Address all issues raised in the terms of reference;
- Be based on an assessment of needs and demand for the product among targeted users to ensure relevance, effectiveness, usefulness, and value of the product;
- Be designed for a specific audience, taking into account functional needs and technical levels;
- Be relevant to decision-making needs;
- Be timely;
- Be written in clear and easily understandable language;
- Be based on the evaluation information without bias;
- Present data in a clear manner;
- Be developed through a participatory process and validated through a quality review process with relevant stakeholders, to the extent that this is compatible with the methodology outlined in the terms of reference and agreed with the evaluation commissioner;
- Be easily accessible to the target audience through the most effective and efficient means;
- Be consistent in the presentation of products to enhance visibility and learning.

COMMUNICATION, UTILIZATION AND FOLLOW-UP OF EVALUATION RESULTS

COMMUNICATION

A formal or informal debriefing offers the opportunity to ensure that important points not included in the report are captured. It allows clarification or discussion of areas that were not significant enough to be included in the report but should receive further attention in later evaluations.

While the main and most important recipients are the individuals with the power to act on the findings (usually senior management), it is good practice to share the report with the people involved in the evaluation process as feedback on their inputs.

Common dissemination methods include printed reports (for relevant meetings), electronic copies, postings on web sites, and through e-mail messages. The news media can be powerful partners in disseminating findings, recommendations, and lessons learned from the evaluation.

Learning and actively using the knowledge generated from the evaluation are the most important elements of the evaluation exercise. Time and resources required for effective follow-up and learning should be allocated at the outset of the program and project design.

Reports should also be shared with all relevant stakeholders. It is advised that the list of intended recipients of the evaluation report be included in the annexes to the evaluation terms of reference.

UTILIZATION AND FOLLOW-UP OF EVALUATION RESULTS

Evaluation plays a key role as a source of evidence on the achievement of planned outcome and impact (results), supporting program improvement and accountability, and as an agent of change that contributes to building knowledge and organizational learning.

The value of an evaluation, however, is heavily dependent on the use that is ultimately made of its recommendations, which is determined by:

- Its relevance in terms of timing, to ensure that its findings are available to report key decisions;
- Its credibility, which derives from the independence, impartiality, clear methodology, and quality of the report;
- The level of acceptance of its recommendations directly linked to the involvement of internal and external stakeholders and to the quality of the recommendations and feasibility of implementing them;

- The appropriateness of the management response, and the dissemination and use of evaluation findings to enhance organizational knowledge.

The preparation of a management response is not a one-time activity. It should document learning that results from the evaluation exercise, and should feed it into the design of new programs and projects or the definition of future outcomes.

Evaluation commissioners are ultimately responsible for the implementation of the evaluation recommendations. The management response constitutes the baseline for monitoring accepted recommendations and agreed actions, which in turn informs of follow-up reports on the status of the implementation.

EVALUATION OF PALLIATIVE CARE PROGRAMS: SOME METHODOLOGICAL AND PRACTICAL EXAMPLES

In this section, different examples are given that can be used as orientation for the evaluation of a national program.

Table 4 shows an example for evaluation outcomes for different periods in the lifetime of a program, and how the outcomes change according to the development of the program along different benchmarks.

There are few countries with a national program of palliative care, and not all of them include an evaluation.

Table 4. Strategic perspective: short-, mid-, long-term aims, actions and expected outcomes

TIME DIMENSION	0-2 years: foundation and initial references	2-5 years: consolidation of solid references	+ 5 years: spread	+ 10 years: coverage
GENERAL AIMS	Foundation	Extension Other settings All types of patients	Coverage Inserted in mainstream	Total coverage
REASONABLE GENERAL OUTCOMES	Advocacy done National Plan approved Officer at DoH Leaders identified National Board Foundation meeting Initial legislation or ways to access essential medicines	Coverage 25-50% Legislation approved Gradual insertion into all the health plans	Coverage 50% of needs	Total coverage for all patients, all settings

TIME DIMENSION	0-2 years: foundation and initial references	2-5 years: consolidation of solid references	+ 5 years: spread	+ 10 years: coverage
SPECIALIST AND PRIMARY SERVICES	Create and consolidate 5-10 specialist services in different settings (home, hospital, other) Standards Directory of services Feasibility as main criteria	Develop 5-10 services Different models: settings, districts, systems Benchmarking processes	Replication and spread of models in all settings	Consolidation
INTEGRATION IN ALL SETTINGS	4-5 references of conventional services adopting palliative approach 4-5 references of integrated palliative care systems in rural / urban	25-50% of primary care services adopting palliative approach		+ 75% of conventional services adopting palliative care approach
EDUCATION AND TRAINING	Focused on policymakers, leaders and specialist teams Training and support to leaders / pioneers in clinical / managerial / training the trainers Managers and stakeholders Public awareness and education	Extension to other specialities Tutorship / mentorship Medical and nursing speciality or sub-speciality Starting pre-graduate	Gradual extension to all levels of training (pre-post graduate, specialist) of all professionals	Total coverage of all levels of training
ACCESS TO ESSENTIAL MEDICINES	Initial actions focused in starting services Access in specific places	Legislation approved Gradual access in all settings	+ 75% population of all settings with access Funding access	Total access
INDICATORS & EVALUATION OF THE PROGRAM	Structure: team at MoH, services, legislation, Process: According to the actions for 2 years Outcomes: number of patients, services, trained professionals, essential medicines, prescriptions, etc	According to the aims x dimensions Start outcomes evaluation: effectiveness, efficiency, satisfaction Start qualitative assessments to identify areas of improvement	According to the aims x dimensions Regular assessment of outcomes Qualitative assessments to identify areas of improvement	According to the aims x dimensions Qualitative assessments to identify areas of improvement

One example of good practice is Uruguay. The country in 2013 started a national program which includes an evaluation (Table 5) using the indicators developed by the Latin American Association for Palliative Care (ALCP)[8].

At the regional level Catalonia regularly evaluates the regional program[9] using qualitative and quantitative methods.

Finally, a check list is provided as example of self-assessment tool for the components of a program in the initial phases[9], which can be helpful for the orientation during the first steps (Table 6).

Table 6. An example of self-assessment tool of the components of a program in the initial phases

Does the written palliative care plan include?	0	1	2	3
Aims, principles, mission, and vision				
Needs Assessment: cancer and non-cancer				
Goals and measurable short, medium and long-term objectives				
Plan of action to meet the objectives based on evidence, affordability, coverage, and equity				
Integration of activities to existing chronic disease and other related programs (Cancer, Geriatrics, Chronic, Health Plan)				
Opioid availability and accessibility (Decree, Order or Law)				
Standards of specialist services				
Directory of palliative care services				
Definition of the model of care and intervention				
Definition of the model(s) of organisation (in settings or districts)				
Standards of general services (primary care, other)				
Financing model				
Specific budget				

8. De Lima L, Pérez-Castells M, Berenguel M, Monti C, Aguilar A, Ahumada M, Ramírez L, Torres Vigil I, Vargas Y, Herrera E, (2013). Palliative Care Indicators - ALCP. 1st edition. Houston: IAHPC Press. Available at: http://cuidadospaliativos.org/uploads/2013/3/Palliative%20Care%20Indicators%20ALCP%20%28english%29.pdf
9. Gómez-Batiste, X, Stjernsward, J, Espinosa J, Martínez-Muñoz, M, Trelis, J and Calle, C. (2011) How to design and implement Palliative Care Public Health Programmes: Foundation measures. Institut Català d'Oncologia. Available at: http://ico.gencat.cat/web/.content/minisite/ico/professionals/documents/qualy/arxius/tool__foundation_measures_-_programmes_fv.pdf

Does the written palliative care plan include?	0	1	2	3
Law, Decree or Order				
Education and training plan				
Priority research areas to support the implementation of the plan				
Development of an information system for monitoring and evaluating the priorities				
Clear process and outcome indicators for monitoring and evaluation				
Budget / Costing of the action plan and resources needed for its implementation				

0= (not developed at all) - Item is not mentioned or included in the plan

1= (low) - The plan mentions the item, but no details are given

2= (medium) - The plan addresses the item to some extent. "Middle-of-the-road score"

3= (fully developed) - The plan does a good, solid job in addressing the item which is generally adequate or close to ideal

FURTHER RECOMMENDED READING

Campbell SM, Braspenning J, Hutchinson A and Marshall MN. *Research methods used in developing and applying quality indicators in primary care.* 2003, p.816-9.

Campbell M, Fitzpatrick R, Haines A, et al. Framework for design and evaluation. of complex interventions to improve health. BMJ 2000;321(7262):694-696.

Campbell NC, Murray E, Darbyshire J, et al. Designing and evaluating complex interventions to improve health care. BMJ 2007; 334(7591):455-459.

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Harding R, Higginson IJ. Inclusion of end-of-life care in the global agenda. Lancet 2014; 2:375-376.

Australian Evaluation Society, (2010). Guidelines for the ethical conduct of evaluations. Retrieved from website: http://www.aes.asn.au/images/stories/files/About/Documents%20-%20ongoing/AES%20Guidlines10.pdf

SECTION 3
CARE OF PATIENTS AND FAMILIES

1
THE MODEL OF COMPREHENSIVE, PERSON-CENTERED, AND INTEGRATED PALLIATIVE CARE

Xavier Gómez-Batiste, Stephen Connor, Scott Murray, Eric Krakauer, Lukas Radbruch, Emmanuel Luyirika, Suresh Kumar, Kathy Foley

KEY POINTS

- The relief of suffering is the main goal of palliative care.
- The comprehensive and integrated model of palliative care is based on the needs and characteristics of persons with advanced chronic conditions and limited life prognosis.
- Multidimensional needs including physical, emotional, spiritual, family, social, economic, and ethical, in a progressive evolution with frequent crises of needs and enormous demands for care.
- The essential needs of patients (spirituality, dignity, autonomy, relations, hope, and some others) must be addressed.
- The aims consist of preventing and relieving pain and suffering of any kind – physical, psychological, social or spiritual – using best available evidence.
- Complex needs require the intervention of specialized services.
- The model of intervention and follow-up consists of the systematic assessment, planning, and follow-up of all dimensions of needs.
- Change the model from late, reactive, and fragmented to early, planned and integrated.
- Solid personal values and professional competencies are needed to respond to these needs.

AIMS OF THIS CHAPTER

To describe the comprehensive, person-centred and multidimensional model of palliative care and the model of systematic intervention in clinical settings.

This chapter is focused on the general, practical aspects of care for patients and families.

WHY COMPREHENSIVE AND INTEGRATED PALLIATIVE CARE FOR THESE PATIENTS AND THEIR FAMILIES IS NEEDED

Patients with advanced chronic conditions and their families have multidimensional needs including physical, emotional, psychological, spiritual, family, social, economic, and ethical needs in progressive evolution with frequent crises of needs and enormous demands for care. Comprehensive palliative care includes the assessment and response to all of these needs.

THE AIMS AND GOALS OF COMPREHENSIVE AND INTEGRATED PALLIATIVE CARE

GENERAL GOALS

- To accompany and comfort adult and paediatric patients throughout the course of serious chronic, complex, or life-limiting conditions by continually assessing, preventing, and relieving pain and suffering of any kind – physical, psychological, social or spiritual – using best available evidence.
- To thereby provide person-centred and family focused care that optimizes quality of life and maximizes the dignity of patients and their families.
- To integrate with and complement health promotion, disease prevention, early diagnosis, and treatment, and rehabilitation of serious chronic, complex, or life-limiting health problems at all levels of any health system and thereby improve continuity of care, strengthen health systems, and promote universal health coverage.

SPECIFIC AIMS OF COMPREHENSIVE, PERSON-CENTRED PALLIATIVE CARE

- Relief of suffering;
- Health and quality of life;
- Promoting self-strength and adjustment to disease and loss;
- Change the experience of loss and dying as opportunities for growth for patients and families;
- Active promotion of dignity and autonomy;
- Prevention of crises and avoidable distress.

PRINCIPLES OF COMPREHENSIVE, PERSON-CENTRED PALLIATIVE CARE

- Starts with a multidimensional assessment of physical, psychological, social, and spiritual needs, values and preferences of patients and families, followed by a systematic approach to planning care;
- Focuses on the essential needs of patients and families, such as spirituality, dignity, autonomy, hope, and key interpersonal relations;
- Considers the family as the unit of care;
- Uses communication to listen to patients' needs and help them realize their goals of care;
- Uses ethical principles and advance care planning to identify patients' priorities and goals. In the case of children, these include the developmental stage for care at the end of life and shared decision-making throughout the process;
- Uses case management as the method for planned, continuing and integrated care;
- Based on excellence and high ethical commitment;
- Must be practised by an interdisciplinary team with an adequate level of competence according to the patients' complexity;
- Provides family care and personalized bereavement support for adults and children as needed.

THE INSTRUMENTS OF PALLIATIVE CARE FOR PATIENTS AND FAMILIES

- Multidimensional needs assessment
- Control of pain and other symptoms
- Communication
- Ethics
- Changes in the organization

CLINICAL TRAJECTORIES OF TARGET PATIENTS

There are several described trajectories in the evolution of these patients with common characteristics: cancer, organ failures, and frailty (see Figure 1).

Figure 1. Trajectories of illnesses and GPs workload (*Modified from Murray SA et al*)[1]
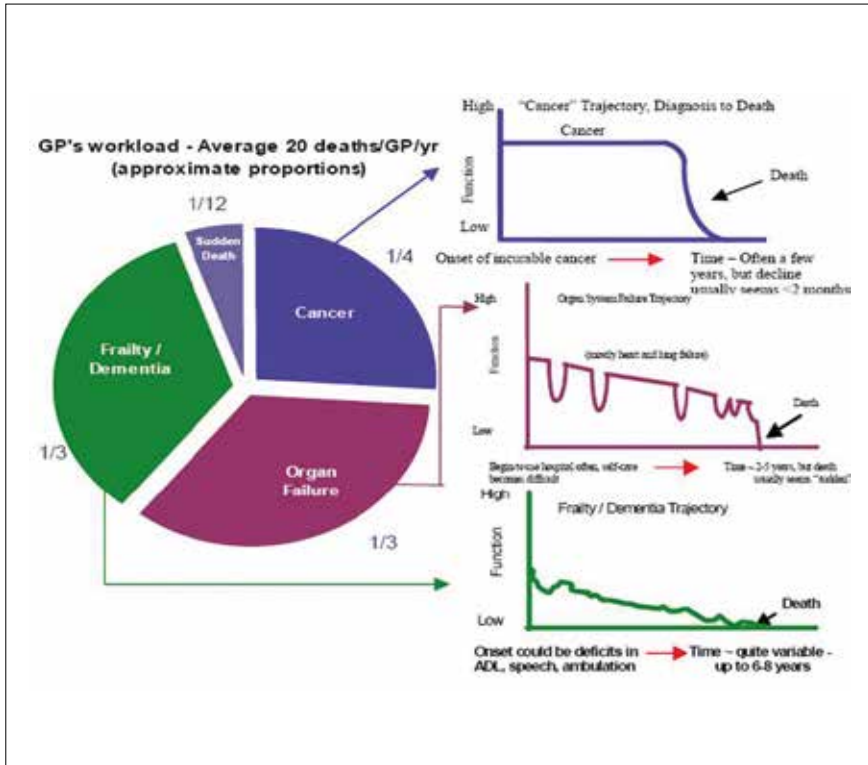
The other aspect to emphasize is the high frequency of crises of various types: physical, psychological, social, spiritual and existential (See Figure 2).

1. Murray SA, Kendall M, Boyd K, et al. Illness trajectories and palliative care. *BMJ* 2005; 330: 1007–1011.

Figure 2. Types of crisis in the evolution of people with chronic advanced/progressive conditions (*From Murray SA et al, 2007*)[2]
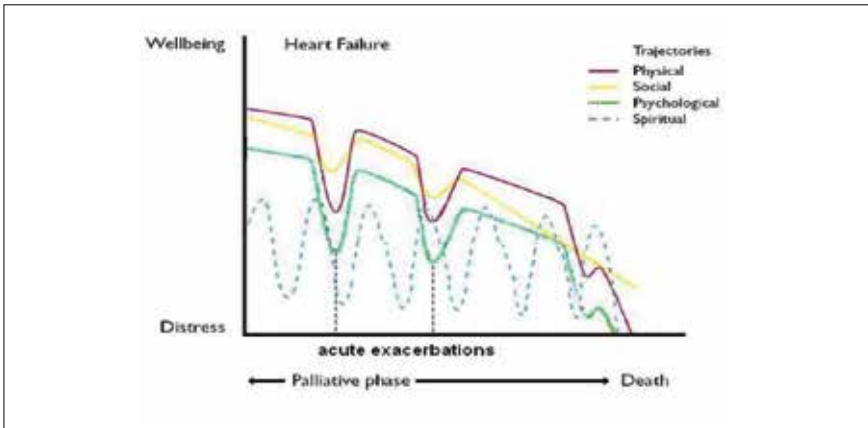
THE MULTIDIMENSIONAL AND ESSENTIAL NEEDS OF PATIENTS AND FAMILIES AND THE PALLIATIVE MODEL OF CARE

THE MULTIDIMENSIONAL NEEDS OF PATIENTS

These were described in the model of "total pain" by Cicely Saunders, and updated more recently as the Canadian model. The multiple dimensions of needs must be identified, assessed, and addressed in a systematic way.

Figure 3. Multidimensional needs of patients and families
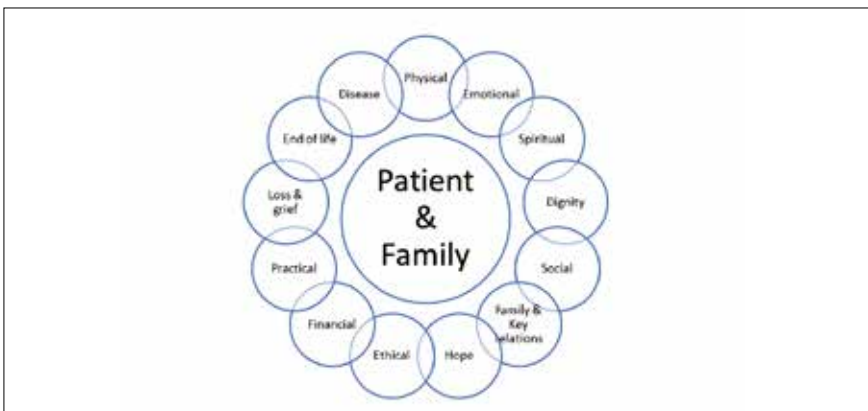
2. Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social psychological and spiritual decline towards the end of life in lung cancer. J Pain Symptom Man 2007; 34:393-402.

THE CLINICAL CHARACTERISTICS OF TARGET PATIENTS

These are composed by the combination of different issues, with various degrees of complexity, and with a progressive course in the context of limited life prognosis:

- Symptoms (different according to causes): multiple, multi-factorial, intense, progressive, changing;
- Variable amount of suffering and existential distress;
- Variable amount of emotional distress, adjustment difficulties, and impact in patients and families;
- Severity and progression of illness;
- Frequent crises in the course of illness;
- Frequent ethical dilemmas in decision-making;
- High need and demand for care.

The most important consequences are:

- Suffering
- High need and demand for care
- High use of resources

CARE OF ESSENTIAL NEEDS OF PATIENTS

Some of the needs have been defined as "essential" because they are related to the most relevant aspects of the human condition, and arise in situations of vulnerability or harm. Some of the needs considered essential are:

- Spirituality (including relation to transcendence, meaning of life, peace, key relations, legacy)
- Dignity (respect)
- Autonomy and Agency (in decision-making about life and treatment choices)
- Love and tenderness (sense of being loved)
- Hope
- Safety

Idenfing and looking after these needs is one of the most appreciated elements of excellent palliative care, and requires specific approaches from caregivers.

NEEDS OF FAMILIES

Cavers' needs are similar to the patient's needs since an advanced chronic condition impacts all members of the family. Families often need to receive care in order to deliver care. The aims of family care can be described as promoting capacity to adjust to the course of illness, increasing capacity of emotional and practical care to patients, and preventing crises and complicated bereavement.

THE MODEL OF INTERVENTION AND FOLLOW UP

- **Systematic assessment, approach and follow-up (see other related chapters)**
  Care for all dimensions of needs, a systematic and dynamic approach for follow-up, including the different phases from assessment to follow up.

Table 1. Methodology of intervention and follow-up of multidimensional needs. Square of Care (*Adapted from Ferris et al)[3]

Phases Dimensions	Assessment of multidimensional needs (tools) Identifying values and preferences	Reviewing disease and treatment Establishing shared goals	Plan and start care procedures Define roles of professionals and teams	Follow-up: standard, preventive crisis, integrated, shared & continuing care Review & Update
Disease management				
Physical Symptoms, (Functional, Cognitive, Nutrition,)				
Emotional / adjustment				
Family				
Social, relations				
Spiritual				
Practical, economical				
Ethical decision-making				
End of Life / last days				

3. Ferris FD et al. A model to guide patient and family care: Based on nationally accepted principles and norms of practice. Journal of Pain and Symptom Management. 2002; (24)2:106-123.

Phases Dimensions	Assessment of multidimensional needs (tools) Identifying values and preferences	Reviewing disease and treatment Establishing shared goals	Plan and start care procedures Define roles of professionals and teams	Follow-up: standard, preventive crisis, integrated, shared & continuing care Review & Update
Grief and loss				
Other needs				

- **Actions for impeccable, comprehensive and integrated care in services**
  To address all needs and existing resources:

  – establish a comprehensive plan based on needs, values and preferences,
  – start advance care planning,
  – review disease and treatment,
  – prevent crises and complications,
  – identify and support caregivers,
  – involve the team in defining referent professionals, and
  – organize case management with continuing and integrated care across all settings involved in care (see table 2).

Table 2. Actions for comprehensive and integrated palliative care

Action	Method
1. Multidimensional assessment: symptoms, emotional, existential-spiritual, adjustment, resources, context	▪ Use validated tools
2. Explore worries, fears, values and preferences of patients and families	▪ Start Advance care planning ▪ Shared decision-making ▪ Start discussion about the future
3. Review state of diseases and conditions	▪ Stage, prognosis, possible complications ▪ Therapeutic Aims ▪ Recommendations to prevent / respond to crisis
4. Review treatment	▪ Update aims & goals of care ▪ Adequacy/effectiveness ▪ De-prescribing if needed ▪ Conciliation between all services
5. Identify, assess, and care for primary caregiver	▪ Assessment ▪ Education and support ▪ Empowerment

Action	Method
6. Involve the team	■ Assessment ■ Plan ■ Definition of roles
7. Define, agree and start a Comprehensive Multidimensional Therapeutic Plan	■ Respecting the preferences of patients ■ Addressing all the needs identified ■ Use the square of care model ■ Involving all team(s)
8. Organize care with all services involved, with special emphasis on the role of specialized Palliative Care Services	■ Case management ■ Shared care and decision-making ■ Therapeutic pathways across settings ■ Manage care and setting transitions ■ Therapeutic Conciliation between services
9. Register and share key information with all involved services	■ In clinical charts ■ In shared information ■ In anticipatory care planning booklet ■ In reports of multi-disciplinary team meetings
10. Evaluate / monitor outcomes	■ Using validated tools ■ Frequent review and update vAfter death clinical audit

THE CHANGE OF THE MODEL OF CHRONIC CARE

The current model of palliative care provision for people with advanced chronic conditions is disease-centred, late, reactive to crisis, fragmented, and based on institutional acute and emergency services. It needs to become person-centred, timely, preventive, planned, and community-care oriented.

THE PERSONAL AND PROFESSIONAL COMPETENCES AND BEHAVIOURS NEEDED TO ASSURE EXCELLENT PALLIATIVE CARE PROVISION

The competencies of professionals must be assured with different levels of training necessary according to the level of care: basic, intermediate, and advanced/specialist for complex conditions.

These should include:

- A basic personal behaviour of education and respect;
- Clinical care competencies, including elements such as needs assessment, disease management, pain and symptom control, defining and implementing a therapeutic plan, use of medicines, specific issues for specific professionals;
- Communication/emotional/counselling skills: communication, emotional support, counselling, specific techniques (active listening, meaning-centred therapy, dignity therapy, spiritual care, mindfulness, others);
- Ethical decision-making: Identifying values and preferences, respecting choices, shared decision-making, advance care planning;
- Integrated care, team approach, case management, and continuity of care: Follow-up, shared care with other services, special attention to crisis prevention, transitions, transfers;
- Competencies to address essential needs (assessment and care): Spirituality, dignity, hope, autonomy, love and tenderness;
- Values, attitude and behaviours, depending on the combination of individual values, personal experience, and knowledge. Some of the necessary behaviours are compassion, empathy, commitment, hospitality, presence, confidence, congruence, and honesty, among others. These behaviours are among the most distinctive components of good palliative care, and are the most appreciated by patients and families;
- Competencies to work in a team, shared decision-making, and networking with other services.

A short **definition of the competencies** could be described with the **4 "Cs":**

- Competent: to assess and treat,
- Committed: to patients and families,
- Conscious: of all dimensions of care,
- Compassionate: to understand and share suffering with patients and families.

TEAM APPROACH

The needs of patients and families suffering from a progressive, life-threatening illness requires the intervention of a competent (according to the diffe-

rent levels of complexity of patients and the setting) interdisciplinary team practising the team approach (shared values and aims, joint assessment and therapeutic aims).

Figure 4. Context and model of personal & professional competencies for palliative care provision (modified from Maté-Méndez J et al, 2013)[4]
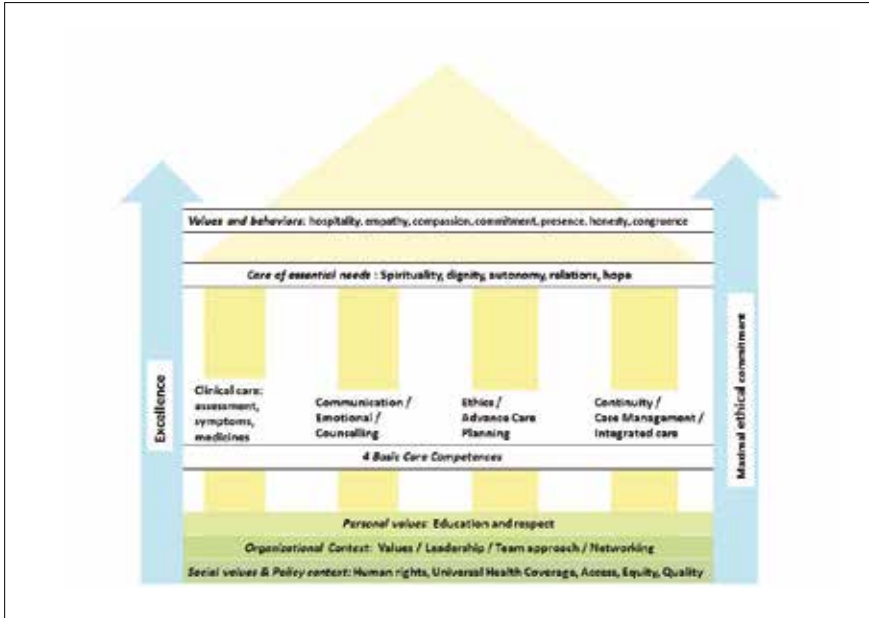
NETWORKING, COOPERATION, AND SHARED CARE CAPACITY

Integrated care across settings requires the capacity to coordinate care, share decisions, facilitate treatments, and cooperate towards integrated pathways. The definition of the roles of the different services in the care and in transitions to different care settings are common challenges. Transitions between services are frequently complex and require specific attention.

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INSTITUTIONAL COMMITMENT

Organizations providing services to any person with palliative care needs must promote and practice the values and behaviours of palliative care and facilitate the selection and training of professionals with those values. Organizational leaders must be committed to palliative care and its values.

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OTHER AVAILABLE RESOURCES

African Palliative Care Association: www.africanpalliativecare.org

Asia Pacific Hospice Palliative Care Network: www.aphn.org

Australian standards: http://palliativecare.org.au/the-national-standards/

Canadian Standards http://www.chpca.net/professionals/norms.aspx

CAPC Quality standards and guidelines www.capc.org/topics/palliative-care-guidelines-quality-standards/

European Association for Palliative Care: www.eapcnet.eu

Hospice UK: www.hospiceUK.org

International Primary Palliative Care Network. http://www.ippcn.org/

International Association for Hospice and Palliative Care: www.hospicecare.com

International Children's Palliative Care Network: www.icpcn.org

Latin American Palliative Care Association: www.cuidadospaliativos.org/

National Hospice and Palliative Care Organization: www.nhpco.org

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White Paper on standards and norms for hospice and palliative care in Europe: part 1&2. Recommendations from the European Association for Palliative Care http://www.eapcnet.eu/

Worldwide Hospice Palliative Care Alliance: www.thewhpca.org

2
IDENTIFYING PALLIATIVE CARE PATIENTS AND ASSESSING THEIR NEEDS

Lukas Radbruch

KEY POINTS

- Assessment of palliative care patients should be comprehensive, multi-dimensional, and interdisciplinary.
- Multidimensional assessment includes physical, psychological, social, and spiritual realms.
- This chapter will provide guidance on assessment for the most common diagnostic groups including:
  - Cancer
  - Dementia
  - HIV/AIDS
  - Other Infectious Diseases
  - Organ Failure
  - Neurological Diseases
  - Childhood Diseases
- Frequently used assessment tools are included.

GENERAL

The most common causes of death globally are heart disease, stroke, chronic respiratory disease, and cancer. Trends in mortality over the last 10 years indicate that Non Communicable Diseases (NCDs) are becoming the most common cause of death, with the exception of Sub Saharan Africa and a few nations in other regions, where communicable diseases are the main causes of death.

The vast majority of the dying patients, but also a considerable percentage of patients living with chronic life-threatening illness will require palliative care. Patients with progressive and life-threatening disease such as advanced cancer or drug-resistant tuberculosis may suffer from a multitude of physical and

psychological symptoms, in addition to the psychosocial and spiritual burden of the illness. Palliative care aims to provide holistic care, and this includes adequate treatment of symptoms and problems.

In general, the most frequent and burdensome symptoms and problems in severely ill or dying patients tend to be the same, regardless of the underlying disease entity. For example, there is consensus that in cancer patients the major physical problems are pain, depression and fatigue, and these are also predominant problems in patients with HIV/AIDS as well as in patients with cardiac or lung failure. Identifying and dealing with pain, dyspnoea, psychological distress and making a care plan were considered the most important components of primary palliative care.

Due to the difficulty of implementing high-quality prospective studies of symptoms and associated distress using validated tools in patients receiving palliative care, only a few studies with prospective high quality methodology have been published. Most of the available evidence of prevalent and distressing symptoms is comprised of retrospective case reviews, expert opinions and case reports. Analysis of available evidence suggested 11 symptoms occurring in the advanced stages and end of life stage for the most common mortality conditions, which are priorities in palliative care:

- Anorexia
- Anxiety
- Constipation
- Delirium
- Depression
- Diarrhoea
- Dyspnoea
- Fatigue
- Nausea and vomiting
- Pain
- Respiratory tract secretions

Symptoms may be defined as a patient's subjective feeling of an abnormal and burdening physical, emotional or cognitive state. This emphasizes that symptoms are assessed by asking the patient what he feels is wrong, not by the description of a pathophysiological deficit. Aberrations of laboratory results, or ECG findings that do not burden the patient often will not require treatment, whereas symptoms should be acknowledged and treatment options should be considered even if there is no pathophysiological explanation for the symptom that the patient reports. Defining a symptom as being physical, emotional, or

mental echoes Cecily Saunders' concept of Total Pain, in which pain includes physical, emotional, psychosocial, and spiritual dimensions.

In addition to physical symptoms patients may be burdened by psychological, social and spiritual problems (tables 1 and 2).

Table 1. Symptom prevalence in different disease entities (percentages of patients)

	Acute stroke[1]	Cancer	Heart failure	Dementia	HIV/AIDS	Children	Intensive care patients at high risk of dying	Last 2 weeks of life[2]
Anxiety	37	40	49	61	22	37	58	18
Appetite loss	28	68	41	86	10-34	33	36	
Breathlessness	28	29	88	57	19	47	44	56
Confusion	28	17	29	87			27	50
Constipation	34[3]	35	42	38		27		27
Cough	23		35		24-32	47		27
Depressiveness	33	34	9	46		17	34	12
Diarrhea			12		5-51	37		10
Swallowing difficulties	26					30		35
Edema			44			50		34
Fatigue	67	67	69	94	55	70	75	48
Itchiness			12		17-18	13		2
Myoclonus								17
Nausea	10	29	48	26	22-50	17		24
Pain	18	56	75	53	24-100	53	40	52
Sleeplessness	40		36			20		11
Tension		45		60		37		
Urinary incontinence			20			40		38
Vomiting	8	19		17	16	40		
Wounds		22		36[4]				23
Weakness	65	85		95				24
Need for help with daily activities	48	73	49[5]	88.8				

	Acute stroke[1]	Cancer	Heart failure	Dementia	HIV/AIDS	Children	Intensive care patients at high risk of dying	Last 2 weeks of life[2]
Overburden of family	12	57		39.1				
Problems with organization of care	8	49		44.3				

1. Percentages of patients with quite a lot / considerable symptom intensity
2. Systematic review including 12 studies (four with cancer, one with heart failure, one with renal failure and six with varions diseases)
3. Bowel problems
4. Nursing problem due to decubitus sore
5. Limitation in physical activity

Table 2. Palliative care needs as identified in a consensus process among palliative care experts

Physical care needs	
Pain	All types
Respiratory problems	Dyspnoea, Cough
Gastrointestinal problems	Constipation, Diarrhoea, Nausea, Vomiting, Dry mouth, Mucositis, Anorexia
Cognitive problems	Delirium, Insomnia, Drowsiness, Sedation
Skin problems	Wounds, ulcers, skin rash, skin lesions
Fatigue	
Sweating	
Psychosocial, emotional, spiritual care needs	
Psychological problems	Psychological distress, Anxiety, Depression
Spiritual needs and existential distress	
Suffering of the relative and/or caregiver	
Family / caregivers grief and bereavement issues	

Care planning and coordination needs	
	Access to medicines
	Care plan
	Advance care planning
	Provision of resources
	Care in last days / weeks of life
	Self-care of health care professionals
Information and communication needs	
	Communication about diagnosis and prognosis
	Information about treatment options
	Information about last days / weeks care issues
	Communication of patient's priorities

Patients also have information and communication needs, and most often they and their caregivers will need help with the organization of care. Family members and caregivers may need support not only with the organization of care, but also with their own emotional burden caused by the patient's illness as well as their burden of care, and they will need bereavement support after the death of the patient. Patients will need to discuss their individual priorities and preferences for the remaining life span. Advance directives as well as enduring power of attorney may be useful instruments for palliative care patients to communicate their priorities and preferences to the health care providers. However, these instruments are only a small part of advance care planning (ACP). ACP is not only a completion of the advance directive or a once-only conversation between patient and health care professional. Ideally ACP should include other members of the health care team (such as asocial worker) and requires ongoing communication with the patient and his family caregivers, as priorities may change and treatments goals may become unrealistic with progression along the disease trajectory.

NEEDS ASSESSMENT

Patients with life-threatening diseases should be screened for symptoms and other problems requiring palliative care (table 3).

Table 3. Clinical assessment for patients entering palliative care

Assessment tool	
Validated tools	African POS ESAS
Screening questions	Well-being Pain Depressiveness Tiredness
History	
Ask patient to describe symptoms	
Pain assessment	P: precipitating and alleviating (palliating factors) Q: quality of pain description e.g., sharp, shooting pain; gnawing pain R: radiation of pain S: site & severity of pain T: time (duration of symptoms) Meaning of pain for patient, patient's morale or mood
Nutritional assessment	Adequate intake of essential food groups Adequate fluid intake
Functional ability	Symptom impact on activities of daily living Time patient spends in bed Assistance patient requires
Examination	
Overall	weight, cachexia, weakness, general colour, lymph nodes, swelling or oedema, tenderness, temperature
Eyes	sunken, red, inflamed
Mouth	redness, white plaque of thrush, leucoplakia, redness of throat, swelling of tonsils, dryness of lips
Skin	dryness, flakiness, swelling, discolouration, ulceration, fungation
Chest	movement of chest, ease and rate of respiration, change in percussion of chest (air, fluid, solidity of lung parenchyma), breath sounds
Heart	feel for apex beat, listen to heart sounds
Abdomen	distention of abdomen, tenderness, masses, enlarged liver or spleen, fluid in abdomen genitals: ulceration, discharge
Nervous system	neck stiffness, weakness or paralysis (unilateral or bilateral), loss of sensation, abnormal sensations
Investigations	
Relevant Special Investigations	Why do I need this test? Is it going to change the management plan? Can we (the health care system or the patient) afford it
First assessment visit may not cover all domains	
Critical domains should be prioritized at the first assessment	

Screening instruments have to be comprehensive but brief in order to be feasible in clinical practice. Short screening instruments that are well validated and have been used in resource-poor as well as in resource-rich settings include for example the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Outcome Score (POS) as adapted by the African Palliative Care Association (African POS).

The ESAS (Figure 1) includes numerical scales for eight symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, shortness of breath) as well as well-being on a range from none to worst possible intensity.

Figure 1. Edmonton Symptom Assessment Scale (ESAS), (http://www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf)

The African POS (Figure 2) includes 7 questions addressed at the patient (pain, other symptoms, feeling worried, able to share feelings, feeling that life is worthwhile, feeling at peace, help and advice for family) as well as 3 questions for the caregivers (information provided, feeling confident, feeling worried), all scored on 6-step categorical scales (for example from not at all to overwhelmingly).

A large range of assessment instruments has been developed for specific areas of palliative care, but often single questions are good surrogates for more elaborate and comprehensive questionnaires. For example, the question "How well are you today" is a good indicator of physical well-being, and "are you feeling depressed" is a valid assessment for depression.

Figure 2. The APCA African Palliative Outcome Score (African POS) (http://www. africanpalliativecare.org/images/stories/pdf/POS_Guidelines.pdf)

PATIENT NO.	POSSIBLE RESPONSES	Visit 1 DATE	Visit 2 DATE	Visit 3 DATE	Visit 4 DATE
ASK THE PATIENT					
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (no pain) - 5 (worst/overwhelming pain)				
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all) - 5 (overwhelmingly)				
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all) - 5 (overwhelming worry)				
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) - 5 (yes, I've talked freely)				
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all) - 5 (Yes, all the time)				
Q6. Over the past 3 days, have you felt at peace?	0 (no, not at all) - 5 (Yes, all the time)				
Q7. Have you had enough help and advice for your family to plan for the future?	0 (not at all) - 5 (as much as wanted)				
ASK THE FAMILY CARER					
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A				
Q9. How confident does the family feel caring for ____ ?	0 (not at all) - 5 (very confident) N/A				
Q10. Has the family been feeling worried about the patient over the last 3 days?	0 (not at all) - 5 (severe worry) N/A				

Assessment of social needs has to be adapted to the setting. In a resource-poor setting access to basic needs such as access to food, clean water, heating or income (every day, some days each week, irregularly, never) may be useful.

For social and family needs, drawing a sociogram may be more useful than long histories or questionnaires (Figure 3), and more information can be added later on as it becomes available.

For spiritual well-being, the question "are you at peace with yourself" is a

good indicator. Another useful short instrument for spiritual needs are the HOPE questions. The acronym stands for:

- H=Sources of hope: what gives you hope or peace in times of illness
- O=Organized religion: are you part of a religious or spiritual community? (Does that help you?)
- P=Personal spirituality and practices: what part of your spiritual beliefs do you find most helpful and meaningful personally?
- E=Effect on medical care and end of life issues: how do your beliefs affect the kind of medical care you would like me to provide?

Figure 3. Genogram of a 57-year old with family structure of an old patient with breast cancer
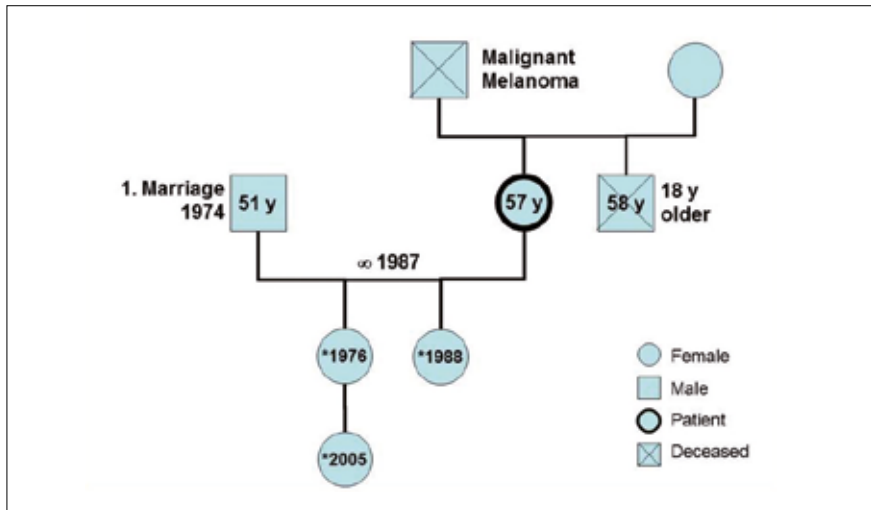
STAGE OF DISEASE

Even if an initial screening does not indicate any palliative care needs, this may change later on in the disease trajectory, when a progressive disease such as heart failure or motor neuron disease progresses, cancer spreads or turns metastatic. Needs may change over time when patient or family resources have been spent, for example if the caregiver falls sick or there is no money left. There are differences in the disease trajectory that explain how early and how long patients will need support during their illness. Prototypes of disease trajectories have been described by Lynne and Teno (Figure 4).

Figure 4. Typical illness trajectories for people with progressive chronic illness. Adapted from Lynn and Adamson and from Murray et al.
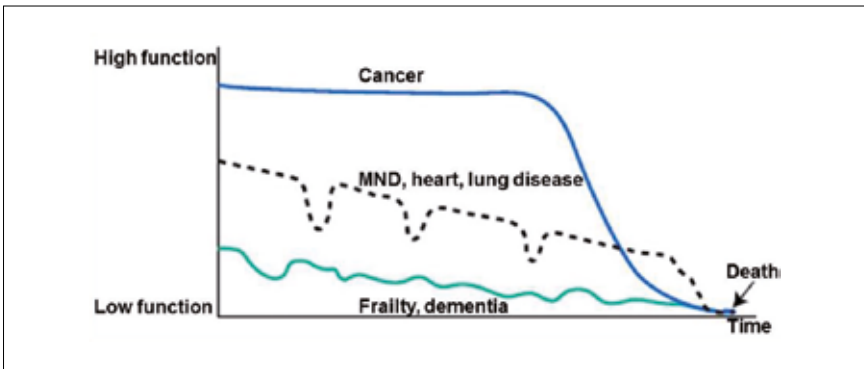
The Australian Palliative Care Phase concept is useful to identify those episodes that include acute changes in conditions and increased palliative care needs (Table 4). The concept defines five phases (stable, unstable, deteriorating, terminal, bereavement). Much emphasis has recently been placed on the early integration of palliative care into the disease trajectory, and it seems clear that early integration can reduce the patient's burden from disease-related symptoms, but also from aggressive treatments. However, it should be understood that patients will have increased palliative care needs in the more advanced phases (deteriorating, terminal), and resource allocation has to consider these increases. As the focus of palliative care is changing towards an approach for life-threating chronic illness, the care of the dying in the last days of life must not be neglected

This is the time when patients and caregivers need most support.

SPECIFIC NEEDS IN SPECIFIC PATIENT GROUPS

Physical, psychosocial and spiritual needs may vary widely between diseases and between phases of disease but also between patients. Needs may be influenced by the individual preferences and priorities of the patient, and palliative care needs have to be assessed for the individual patient.

Discussion of realistic treatment goals and of the individual preferences and priorities should be an ongoing process involving the patient, the professional health care providers and the family caregivers. This discussion has to be adapted to the setting, for example acknowledging the high value of autonomy in Western European and North American culture, and the higher impact of family or clan authority in Asian or African cultures. Advance care planning,

Table 4. Palliative care phases

Start	End
Stable Phase	
Patient problems and symptoms are adequately controlled by established plan of care *and* ■ Further interventions to maintain symptom control and quality of life have been planned *and* ■ Family/carer situation is relatively stable and no new issues are apparent	The needs of the patient and or family/carer increase, requiring changes to the existing plan of care
Unstable Phase	
An urgent change in the plan of care or emergency treatment is required *because* ■ Patient experiences a new problem that was not anticipated in the existing plan of care *and/or* ■ Patient experiences a rapid increase in the severity of a current problem *and/or* ■ Family/carers circumstances change suddenly impacting on patient care	■ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) *and/or* ■ Death is likely within days (i.e. patient is now terminal)
Deteriorating Phase	
The care plan is addressing anticipated needs but requires periodic review *because* Patient's overall functional status is declining and patient experiences a gradual worsening of existing problem *and/or* ■ Patient experiences a new but anticipated problem *and/or* ■ Family/carers experience gradual worsening distress that impacts on the patient care	■ Patient condition plateaus (i.e. patient is now stable) *or* ■ An urgent change in the care plan or emergency treatment *and/or* ■ Family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) *or* ■ Death is likely within days (i.e. patient is now terminal)
Terminal Phase	
Death is likely within days	■ Patient dies *or* ■ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating)
Bereavement Phase – Post death support	
■ The patient has died ■ Bereavement support provided to family/carers is documented in the deceased patient's clinical record	■ Case closure Note that if counselling is provided to a family member or carer, they become a client in their own right

including (but not restricted to) advance directives and enduring power of attorney are useful instruments in the discussion and may help patients to reflect on their priorities.

Though the palliative care needs are similar in most life-threating diseases, there are specific needs and characteristics related to specific diseases such as infectious diseases, cancer, organ failure, neurological diseases, frail elderly patients or children and young adolescents. Characteristics of some patient populations are listed in the following sections.

CANCER

Malignant neoplasms are the second most frequent cause of death globally, with 14.7% of all deaths in 2012. This has changed in the last decade, as death from infectious diseases has been more frequent than cancer deaths since 2002, but both an increase in cancer deaths and a decrease in deaths from infectious diseases has conversed the ranking. Cancer deaths are most often caused by lung cancer, followed by stomach, colon / rectum and liver cancer.

Cancer is not only a major health care problem and a frequent cause of death in Western Europe and Northern America, but is becoming an increasingly significant public health problem in developing countries. For example, in 2012 there were 645,000 new cancer cases and 456,000 cancer-related deaths in Africa, projected to nearly double by 2030. There are specific cancer-related problems in African countries including the high percentage related to infection, late arrival at clinical services and limited access to adequate health care.

Cancer has been the primary target disease of palliative care in Western Europe and North America. Symptoms may be caused by the malignant disease, but cancer-related comorbidities such as herpes zoster or thromboembolism or may be related to the antineoplastic treatment, such as neuropathy or stomatitis caused by chemotherapy, or painful fibrosis by radiotherapy.

Physical symptoms are prevalent in the vast majority of patients with advanced disease, with pain, depression and fatigue being predominant. Depression and fatigue are under-recognised, under-assessed and undertreated. Major depression (requiring anti-depressive medication) must be differentiated from the 'feeling down' sensation that could be considered normal when suffering from life-threatening disease. Fatigue is the most frequent symptom in cancer patients, caused by the disease as well as by its treatment, with a prevalence of 80% or more in patients receiving radiotherapy or chemotherapy. Patients complaining of fatigue often get told that fatigue is unavoidable in cancer and cannot be remedied. However, energy-conserving measures can be offered, even if no medical treatment is available.

Specific symptoms may be related to the cancer pathology, for example with fumigating wounds in patients with malignant melanoma, or gastrointestinal obstruction in patients with colon cancer, or nausea and vomiting in patients with pancreatic cancer.

Cancer treatment has seen major advances in recent years, for example with the advancement of personalized therapies (targeted drugs following individual genetic testing), and new therapies may have only a few side effects. However, other antineoplastic interventions may be very burdensome, sometimes even with a high treatment-related morbidity. Discussion of the potential harm and benefits of the interventions requires close cooperation between oncologist and the palliative care specialist.

Chemotherapy and radiotherapy may be useful not only for life prolongation, but can be used for symptom control as well, for example alleviation of painful bone metastases with radiotherapy.

Agreement on realistic treatment goals requires the patient to be offered full information on diagnosis and prognosis. However, though most patients will receive information on cancer diagnosis some when in the disease trajectory, information on short prognosis is often not offered, and if offered, often is not accepted by the patients.

DEMENTIA

Dementia is a life-limiting disease, although it not always clear whether patients die with dementia or from dementia. Dementia is a major health problem. Worldwide, in 2010 about 35.6 million people were living with dementia, and this number will almost double by 2030. Because no cure is foreseen in the near future, many people will die with or from dementia. Death with or from dementia markedly increases with age: a UK study showed that 6% of people aged 65-69 had dementia at death, increasing to over 58% of those aged 95 and over[3].

The disease trajectory for dementia is different from that for cancer. Even though impairments are progressive, with dementia there may be prolonged "dwindling" and severe disability may persist for years. Survival is variable, and studies have reported means or medians of between about 3 and 10 years. At an individual level, patients may survive to the last phase of dementia with severe physical and cognitive impairment, but may also die earlier from dementia-related health problems such as pneumonia and intake problems or comorbid disease. Prognostication in dementia is difficult.

Patients with dementia will have significant palliative care needs. This includes physical symptoms such as pain, but assessment of symptom is difficult because of the patients' cognitive impairment. Assessment instruments based

on close observation of the patient have been developed and validated, though caregiver or health care staff assessment with the simple instruments described above may provide good proxy ratings that correlate well with self-assessment or observational scores.

In addition to physical symptoms and cognitive problems, behavioural problems or neuropsychiatric symptoms, such as apathy or depression, frequently develop as part of the dementia trajectory. Behavioural problems may be related to other problems, such as cognitive impairment, depression, or pain. It may challenge caregivers, and communicating with patients and families of people with dementia requires special skills. Support for families is needed to help them in their role as proxy decision-makers in more advanced dementia and to deal with a high burden of care and chronic grief caused by the continuing deterioration of the patient.

Anticipating the progression of the disease, advance care planning in dementia should be proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited. At least, the naming of a substitute decision maker at diagnosis is recommended.

HIV/AIDS

UNAIDS has estimated that 35.3 million people were living with HIV/AIDS in 2012. The prevalence is increasing compared to previous years as more people are receiving the life-saving antiretroviral therapy. There were 2.3 million new HIV infections globally, with the number steadily declining in recent years. At the same time, the number of AIDS deaths declined as well, to 1.6 million in 2012.

HIV/AIDS is the most common cause of death by communicable diseases globally, with 1.5 million deaths (2.7% of all deaths) in 2012. There is a particular disease burden in Sub-Saharan Africa, as 72% of these deaths are located in that region (11.5% of all deaths in Sub-Saharan Africa).

Even though these numbers are huge, there has been a major change in the HIV/AIDS epidemic. In recent decades there have been major advances in HIV therapy, and patients living with HIV/AIDS and antiretroviral therapy (ART) today are feeling rather like long-term survivors with a chronic residual condition, but not like death row candidates with a severely limited prognosis. The effects of ART even on advanced disease are spectacular and have even been termed 'Lazarus effect' as patients seem to rise from the dead. In some Western European countries HIV organizations no long want to acknowledge that HIV/AIDS patients may have palliative care needs, although even with modern

treatment options some patients either die from refractory disease or are withdrawn from antiretroviral therapy as they cannot bear the strict compliance required for effective therapy. However, even though globally the percentage of people with HIV/AIDS receiving ART has risen to 37% in 2013 (from 10% in 2006), this still means that the majority of patients in resource-poor settings are not accessing ART. Even with ongoing ART, patients may suffer from multiple symptoms and complications and may require palliative care in addition to the ART.

People living with HIV/AIDS suffer from a multitude of symptoms as the disease progresses, including pain. In an African study patients living with HIV/AIDS reported an average of 18 symptoms each. These may be due to several different causes (examples in Table 5). Symptoms may be related to the direct effects of the virus itself, to comorbidities such as infections or Kaposi sarcoma or to side effects of the antiretroviral medication.

Table 5. Causes of pain and symptoms in HIV/AIDS

Cause	Pain: Example	Symptom: Example
Opportunistic infections or malignancies	Headache with cryptococcal meningitis Visceral abdominal pain with disseminated MAC	■ Sweats and fever in MAC ■ Dyspnoea in *Pneumocystis carinii* pneumonia (PCP)
Direct effects of the human immunodeficiency virus (HIV)	■ Distal sensory polyneuropathy ■ HIV-related myopathy	■ Wasting from HIV enteritis
Medications	■ Dideoxynucleoside-related peripheral neuropathy ■ Zidovudine-related headache	■ Protease-inhibitor-induced nausea and vomiting
Immune reconstitution inflammatory syndrome (IRIS)	■ Headache with cryptococcal meningitis ■ Visceral abdominal pain with disseminated MAC	■ Sweats and fever in MAC ■ Dyspnoea in *Pneumocystis carinii* pneumonia (PCP)
Non-specific manifestations of late stage illness, other non-HIV-related causes	■ Painful pressure sores	■ Fatigue ■ Malaise ■ Depression

In addition to the physical symptom-related suffering, patients are burdened by the social impact of the disease. In many countries HIV/AIDS infection is stigmatising, and even close family members may withdraw from the patient. Fear of stigmatisation causes patients to conceal the diagnosis, sometimes even to their spouse or other close family members. At the same time, open communication about diagnosis and prognosis is not yet the usual procedure in many health care systems, and if communicated at all, it is often to the care givers only

and not to the patients. This does not only impede symptom assessment and treatment, but also raises anxiety and tensions, and increases the danger of further transmission of the disease.

In resource poor settings, patients often suffer from a combination of HIV/AIDS and other infectious diseases such as tuberculosis. More often than not only the less stigmatising diagnosis (such as tuberculosis) and very rarely the prognosis are communicated to the patient and his caregivers.

HIV/AIDS also causes a major economic impact, both on a societal as well as on an individual level. In resource-poor countries, no social security systems are in place, and with progression along the illness trajectory patients who are unable to work will have no income and often suffer from lack of access to food, heating, shelter or even clean water. Patients will completely depend on family and neighbourhood support. In some Sub-Saharan African countries, the impact of the HIV/AIDS epidemic has been so tremendous that the middle generation has been substantially diminished, and the grandparent generation now has a triple burden, as they have to work to generate the income for the whole family, sometimes have to care for their sick children, and have to care for the (bereaved) grandchildren as well.

OTHER INFECTIOUS DISEASES

In addition to infection with HIV/AIDS, other communicable diseases may cause major palliative care needs. This includes multi-drug resistant tuberculosis (MDR-TB) or extensive drug resistant tuberculosis (XDR-TB). In 2010 there were 8.8 million incident cases of TB globally, 1.1 million deaths from TB among HIV-negative people, and 350,000 deaths from HIV-associated TB. A considerable number of patients with TB become drug-resistant. MDR-TB does not respond to standard treatment and requires treatment for at least 20 months with second-line drugs that are less effective and more toxic. Global treatment success rates for MDR-TB are only 53% in countries with a high burden of TB. MDR-TB can be deemed a life-threatening disease from diagnosis.

Several reviews have summarized the disastrous impact of TB on all areas of quality of life, not only with a high burden from physical symptoms but also social and financial strains and emotional stress. There is clear consensus among TB and palliative care experts that palliative care is both appropriate for, and required by, many patients with MDR-TB.

Palliative care needs have also been described in the recent Ebola epidemic in Western Africa. The mortality of Ebola is around 50%, and patients suffer from a range of infection-related physical symptoms including pain, tiredness and weakness. The high contagiousness severely impedes the provision of pallia-

tive care, though recruitment of (now immune) survivors as care givers has been successfully implemented in model projects.

Much less frequently other infectious diseases may induce palliative care needs as well. In a palliative care program in the Philippines, rabies has been described as a repeated reason for referral to a palliative care service. Rabies is not a frequent cause of death (35,000 deaths in 2013), but the most lethal disease with a 100% mortality, and with a high symptom burden on patients for example with muscular pain and hydrophobia (swallowing difficulty, fear of water). Palliative care interventions may relieve suffering in the remaining life span.

NEUROLOGICAL DISEASES

Progressive neurological diseases such as Morbus Parkinson (119,000 deaths) in 2012 or multiple sclerosis (19,000 deaths in 2012) may lead to progressive impairment and symptom burden, and patients may require palliative care support for symptom control or organization of care. Similarly, high symptom burden has been described for patients with acute stroke. Prognosis with acute stroke may vary widely, and rehabilitation will be the primary goal of treatment for most patients. However, for a smaller percentage of patients with major brain damage restitution of cerebral function is very improbable, and goal of treatment should be directed towards palliative care from the onset.

Motor neuron disease (amyotrophic lateral sclerosis) is a comparatively rare but incurable disease, and limited prognosis of 3-5 years from the time of diagnosis and the continuous deterioration throughout the disease trajectory necessitate palliative care support. Patients suffer from progressive paralysis first of the lower limbs, then spreading upwards, causing fatigue and weakness, breathlessness and swallowing difficulties. Artificial ventilation will be required in patients with paralysis of the diaphragm, first only for a few hours during the night, then for increasing periods of time and finally continuously. Symptoms can be alleviated well with symptomatic treatment, for example breathlessness can be treated effectively until the time of death with opioids. Technical support will be required with advanced disease, for example for support in communication special computer systems are available that can be guided by a monitoring camera that is focused on the patient's eyes and follows his line of sight. Patients are often well informed about their disease, and are in favour of advance care planning, though they also often revise the advance care plan they had made earlier. Coordination of care and easing the plight of overburdened family caregivers are important parts of the palliative care support needed in these patients.

ORGAN FAILURE

Cardiovascular diseases are the most frequent cause of death, with 31.4% of all deaths in 2012. This includes a range of diseases from hypertension to myocardial infarction. Chronic heart failure may be related to significant palliative care needs, mostly in patients with impaired functional capacity in class 3 or 4 of the NYHA (New York Heart Association, NYHA class 3= marked limitation of physical activity, less than ordinary activity causes fatigue, palpitation, breathlessness or anginal pain, comfortable at rest; NYHA class 4= inability to carry on any physical activity without discomfort, symptoms present at rest, increased discomfort with any physical activity). Predominant symptoms include breathlessness, pain, fatigue and weakness. Specific problems that have been discussed for patients with implanted internal defibrillators are whether this device has to be turned off in dying patients, as the shocks received from the device may seriously distress the patient and family.

Lung failure, for example from chronic obstructive pulmonary disease (COPD), caused 3.1 million deaths in 2012 (5.6% of all deaths). COPD can be classified with the Global Initiative for Chronic Obstructive Lung Disease (GOLD) score, using the forced expiratory volume (FEV1= the volume in a one-second forced exhalation, measured in litres) and the forced vital capacity (FVC= total exhaled breath, measured in litres). Patients with GOLD stages 3 and 4 will usually have major palliative care needs, including breathless, fatigue and weakness (GOLD stage 3= FEV1/FVC< 0.7 and FEV1 30-49% of normal value; GOLD stage 4= FEV1/FVC< 0.7 and FEV1< 30% of normal value). Other life threatening lung diseases such as pulmonary fibrosis also may cause lung failure.

Kidney failure caused 864,000 deaths in 2012 (1.5% of all deaths). Patients with kidney failure may have a long prognosis with haemodialysis, but may suffer from multiple symptoms such as pain, dyspnoea, nausea, fatigue and weakness, even if haemodialysis is performed regularly. Some patients may decide to withdraw from dialysis at some time and would need information and advance care planning in preparation for the withdrawal and symptom assessment and treatment as well as continuous psychosocial and spiritual support for patient and family following the withdrawal.

CHILDREN

Palliative care needs in children and adolescents are not restricted to cancer, but have to be considered in a wide range of diseases. Four categories have been suggested by the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT):

- Group 1: life-threatening conditions for which curative treatment may be feasible but can fail, where palliative care needs have to be assessed and treated alongside curative treatment and/or if treatment fails, such as cancer,
- Group 2: conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, such as cystic fibrosis,
- Group 3: progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over years, for example muscular dystrophy,
- Group 4: irreversible but non-progressive conditions with complex health care needs leading to complications and likelihood of premature death, such as severe cerebral palsy and multiple disabilities following brain or spinal cord damage.

In addition to the specific physical symptoms related to the disease pathophysiology, children will have emotional and spiritual needs. Parents and other caregivers as well as siblings will be burdened by the disruption of normal family life with the life-threatening disease, in addition to the burden of care. The family is the unit of care, not only the patient himself. Parents may require support if legal, ethical and social problems need to be solved

Children are not just small adults, and children with diseases from any of the four groups will have specific needs that require special consideration for their palliative care. Care needs will depend not only on the disease entity, but also on age and development stage.

With the advances of modern medicine, longer survival is possible with some diseases that would have had a very short prognosis some years ago. Taking cystic fibrosis as an example, this would have led to death from respiratory complications in the first years of life. By now, treatment has improved so much that patients grow up into adulthood. This may cause new problems if patients have to be transferred from paediatric services to adult palliative care services.

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APCA palliative care manual for patients with HIV/AIDS at Global Partners in Care website www.globalpartnersincare.org/clinical-guide-supportive-and-palliative-care-hivaids-sub-saharan-africa

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International Association for Hospice and Palliative Care (IAHPC): Manual for Palliative Care hospicecare.com/about-iahpc/publications/manual-of-palliative-care/

Palliative Care Formulary and other information, including bulletin board www.palliativedrugs.com

Scottish Palliative Care Guidelines www.palliativecareguidelines.scot.nhs.uk/

World Health Organization: Palliative care guideline module for patients with HIV/AIDS http://www.who.int/hiv/pub/imai/primary_palliative/en/

International Children's Palliative Care Network: Resources http://www.icpcn.org

Together for Short Lives. Resources. http://www.togetherforshortlives.org.uk

3
MANAGEMENT OF PAIN AND OTHER SYMPTOMS

Lukas Radbruch

KEY POINTS

- Palliative patients experience a wide range of difficult symptoms that need expert management.
- Pain management is a major symptom that can be managed using palliative assessment principles and treatment by the WHO ladder.
- Symptom management should be patient centred, individualized, and should address any underlying reversible causes.
- Non-pharmacological treatment should be considered.
- This chapter will address the following symptoms:
  - Anxiety
  - Anorexia
  - Breathlessness
  - Confusion/Delirium
  - Constipation
  - Cough
  - Depression
  - Dry Mouth
  - Fatigue/Weakness
  - Itch
  - Nausea & Vomiting
  - Pain
  - Respiratory Secretions
  - Sweating
  - Wounds/Ulcers

Effective and comprehensive symptom management requires a number of basic principles. These include treatment of the underlying cause(s), when possible, in addition to symptomatic pharmacological and non-pharmacological treatments, based on the individual needs and preferences of the patient.

This chapter will provide general guidance and principles for palliative symptom management. WHO approved clinical guidelines on symptom management in palliative care, that will include specific evidence based treatment recommendations, are under development.

TREATING UNDERLYING CAUSES

The underlying mechanism causing the symptom should be identified and treated, if possible. If several factors are involved in the genesis of the symptom, the individual factors should be differentiated and each treated individually. This might include radiotherapy or chemotherapy even in far advanced cancer stages, as reduction of tumour size can alleviate symptoms. This might include optimising organ function in end-stage organ failure. However, this requires careful consideration of the balance between expected benefit and the burden related to the intervention.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Most patients will need symptomatic treatment for symptom relief. Effective symptom control is based on pharmacological symptomatic treatment. The WHO has included a number of medications for the treatment of pain and other common symptoms in palliative care in the model list of essential medicines[1]. Using these essential medicines, for the vast majority of patients burdensome symptoms can be alleviated adequately. In high resource settings, a broader range of medicines is available for symptom management.

Medicines often have to be used off-label, as they have not been registered for treatment of particular symptoms. For example, no opioid has been approved for treatment of breathlessness, though this indication has a strong evidence base and has been included in palliative care guidelines. Off-label use is fully justified in cases where medications have been part of guideline or textbook recommendations in palliative care. Off-label use may also be justified in selec-

1. World Health Organisation. WHO Model List of Essential Medicines - 18th edition, 2013. http://www.who.int/medicines/publications/essentialmedicines/en/ (access date: 4.12.13).

ted cases as an individual treatment test if no other appropriate intervention is available for symptom relief.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Pharmacological treatment should be combined with non-pharmacological treatment. This may be directed against specific symptoms, such as mouth care with fluids or ice cubes, skin care with ointments or washing procedures, lymphatic drainage for oedema, or acupuncture or acupressure at the pericardia meridian for nausea. Non-pharmacological interventions can also have more general effects, such as physical training, which can improve fatigue and weakness, prevent constipation, and in general raise quality of life as the patient's mobility improves or is at least better maintained.

Individual Treatment

Symptom management in palliative care has to be adapted to the individual preferences and needs of the patient. Medicines, routes of administration and dosing intervals, as well as dosages should be selected according to these preferences.

Sometimes small changes make a difference, for example when bitter (tramadol solution) or sweet (lactulose solution) medicines cause nausea or gagging. Fine tuning of the medication, in this case by selecting formulations that the patient prefers may improve compliance with treatment and patient satisfaction considerably.

Treatment should be focused on burdensome symptoms. Abnormal laboratory results, pathological radiology or ultrasound findings or comorbidities should be treated only if they are related to burdensome symptoms or a recognised pathology such as a person with a high likelihood of a pathological fracture. Otherwise side effects from the interventions may cause more impairment than the pathological condition itself.

Patient-Centred Care

Treatment should aim to maintain or improve the quality of life and optimise current levels of function of the patient. The main goal is to enable the patient to live with optimal quality of life and adequate physical and cognitive function until the time of death, preventing loss of control and maintaining autonomy as much as possible. Such autonomy requires focus on maintaining physical mobility for as long as possible.

This means that the patient (and maybe his/her caregivers) have to be involved in the decision-making process and in the treatment plan, as his/her quali-

ty of life will depend primarily on his/her subjective experiences and his/her personal needs and priorities. If the patient is not able to participate, advanced directives may inform decision makers about his/her preferences, and surrogate decision makers (usually close family members or friends) can be involved.

The patient should be informed about available treatment options. Comprehensive information on the illness, the expected disease trajectory and treatment options should be delivered in an empathic way. This will reduce anxiety, as the situation will no longer be unknown. The unknown may induce more anxiety that the reality and patients may live in anticipation of agonies imagined for the future, which are much worse than anything that is likely to occur throughout the disease trajectory.

The person-centred approach also necessitates regular re-assessments of the patient's priorities and needs as he/she progresses along the disease trajectory. In the final days of life, patients may withdraw slowly from life and discontinue some therapies, for example antithrombotic prophylaxis or physiotherapy, may be required.

ANXIETY

Anxiety is defined as the apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria of somatic symptoms of tension. The focus of anticipated danger may be internal or external.

Anxiety is characterized by excessive feelings of fear, apprehension or worry. Anxiety may be associated with symptoms of depression, poor concentration, insomnia, irritability, panic attacks, sweating, tremor and nausea.

Anxiety is frequent in palliative care, and may be deemed an entirely appropriate reaction to severe or life-threatening illness. The disruption of normal life as it has been before, the change of perspective forced upon the patient by the sudden realization that the remaining life span may be considerably shorter than he had assumed until now, in resource-poor settings sometimes connected with the loss of access to basic needs such as income, food, heating or shelter, give reason enough for severe anxiety and worrying. Most patients who have been informed about their diagnosis and prognosis report some anxiety. Patients who have not been informed have less concrete anxieties, but the ongoing deterioration of health and function will cause even more severe anxiety as the disease progresses unless they have their health status discussed.

In addition to the concrete anxieties described above, many patients report free floating anxiety, not related to any disease- or treatment-related issues, which

may burden the patient even more. This kind of anxiety requires symptomatic treatment.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Appropriate information about diagnosis and prognosis and about the available treatment options are paramount to relieve anxieties. As stated above, the unknown often induces more anxiety than the reality.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Benzodiazepines are considered the mainstay of therapy in the management of anxiety in palliative care[2]. However, there are no good quality studies on the role of benzodiazepines (or other drugs) in the treatment of anxiety in palliative care to draw a conclusion about their efficacy[3]. Evidence of use in palliative care is based on expert opinion.

Diazepam and midazolam are included in the WHO essential medicines list. Diazepam is recommended as a first line approach in resource-poor settings.

All benzodiazepines may accumulate if used regularly for a days or weeks, due to the very long half-life of the substances. Side effects include sedation, impaired memory or concentration difficulties. In elderly patients, benzodiazepines may cause paradoxical effects with restlessness and agitation. Sudden discontinuation after long-term treatment may cause withdrawal symptoms such as nausea, headache, anxiety or restlessness.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

A combination of psychotherapeutic and pharmacological approaches has proven to be more effective than administering these treatments separately. Staying with the patient may provide comfort and reduce anxiety. Interventions such as progressive relaxation, hypnosis or imagination may be beneficial but need the patient to be well enough and motivated to participate in the intervention.

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APPETITE LOSS / ANOREXIA

Loss of appetite (anorexia) is a frequent symptom in cancer, but also in other disease entities requiring palliative care such as HIV/AIDS or heart failure. Loss of appetite is often related to other disturbances such as dislike of specific food (for example aversion to meat), change of taste or sense of smelling (for example metallic taste) or to other gastrointestinal symptoms such as nausea. Appetite loss may lead to reduced food intake, weight loss, weakness and reduced performance status. Anorexia is often put together with cachexia, sometimes described as the anorexia-cachexia syndrome (ACS).

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Anorexia may be caused or aggravated by disturbances of the oral or pharyngeal mucosa. Antifungal therapy is required in patients with oral candidiasis (thrush). Mucositis may be alleviated with specific solutions for mouth care (containing local anaesthetics, antibacterial and antifungal substances and other ingredients), and chemotherapy-related mucositis may be prevented or mitigated by granulocyte colony stimulating factor (G-CSF).

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Symptomatic treatment relies mostly on steroids for appetite stimulation. Dexamethasone has been used with effect, starting usually with low dosages, which are then kept for maintenance, compared to other indications where treatment starts with high initial dosages and is down-titrated rapidly after a few days. Dexamethasone is listed in the WHO list of essential medicines in three sections (anti-allergic and anaphylaxis, hormones and anti-hormones and palliative care)[1].

Dexamethasone is a potent synthetic member of the glucocorticoid class of steroid drugs[2]. Dexamethasone acts as an anti-inflammatory and immunosuppressant. When taken orally, it is more potent than the naturally occurring hormone cortisol or than prednisone. The approximate equivalent anti-inflammatory doses 750 microgram dexamethasone ~5mg prednisolone. Dexamethasone has high glucocorticoid activity but insignificant mineralocorticoid effect and is particularly suitable for high dose therapy. Symptomatic hyperglycaemia can occur. Glucocorticoids also have a wide range of psychotropic effects ranging from severe depression to hypomania.

The IAHPC list of essential medicines also lists megestrol acetate in addition to dexamethasone, though this substance will only be available in resource-rich

settings[4]. Megestrol acetate is a progesterone derivate with predominantly pro-gestational and antigonadotropic effects. Symptomatic non-pharmacological treatment.

Non-pharmacological treatment focuses on nutrition counselling. This includes discussion of individual preferences for food and trying to cater for these preferences. Preparing favourite foods and consideration of taste changes (for example switching to vegetarian diet in patients with aversion to meat) may stimulate appetite. Patients often feel burdened by the pressure of family caregivers to eat more, as there is a strong mental connection between food intake and physical well-being in many people. Only if the patient eats enough, can he get well again. However, with advanced diseases such as cancer or cardiac failure, metabolic changes (catabolic state) prevent the appropriate exploitation of additional food taken in by the patient. Adequate information about the nutritional requirements and the reduced need for food in advanced stages of disease may provide considerable relief for the patient, who is not urged to work his way through large meals any more. Cachexia is not reversed by nutritional support alone.

BREATHLESSNESS

Breathlessness (dyspnoea) is the unpleasant sensation of being unable to breathe adequately. Three main components contribute to breathlessness: afferent signals, efferent signals, and central information processing. Dyspnoea results when a mismatch occurs between the need for ventilation (afferent signalling), which is not met by the physical breathing (efferent signalling). The need for ventilation is triggered by the body sensors in the bloodstream when carbon dioxide is increased (as a sign that not enough carbon dioxide is exhaled) in most patients. Only in patients with chronic obstructive pulmonary disease (COPD) carbon dioxide levels may have been elevated for such a long time that the need for ventilation is triggered now by low oxygen partial pressure in the blood.

However, breathlessness is not only a physical symptom, but a complex multidimensional symptom with physical psychological and emotional dimensions. It is a common symptom in palliative care and increases in prevalence and severity as the underlying disease or condition progresses. Anxiety is often a major component of breathlessness and sometimes fear of suffocation

4. De Lima L. International Association for Hospice and Palliative Care list of essential medicines for palliative care. *Ann Oncol* 2007; 18:395-9.

with further progression of the disease is much worse than the breathlessness itself.

Breathlessness is not synonymous with cyanosis, hypoxemia, tachypnoea or respiratory depression. Abnormal values for oxygen saturation, respiratory rate or respiratory volume are not necessarily a symptom that has to be treated, as long as the patient with these findings does not complain of breathlessness.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Breathlessness may be caused or aggravated by a number of factors, either related to the respiratory system, the cardiopulmonary system or other factors including cachexia itself. Mechanical obstruction of lung expansion can be caused by pleural effusions or by ascites, and tapping these fluids can improve ventilation and reduce breathlessness considerably in selected patients. In patients with cancer and recurrent pleural effusions, pleurodesis can be beneficial.

Lack of oxygen carriers may cause breathlessness in anaemic patients, and transfusions may alleviate the symptom in patients with severe anaemia, though in most palliative care patients anaemia is chronic and patients are well adapted to lower hemoglobin levels. Transfusions usually have to be repeated as the anaemia relapses and haemoglobin levels decrease again, and patients may not agree to repeated transfusions because they feel burdened by the procedure. Similarly, improvement of low cardiac function for example with positive inotropic medication such as catecholamines may reduce breathlessness, but can burden the patient with side effects such as tachycardia and may not be indicated in patients who do not want a prolongation of the dying process.

Increases in metabolic rate in septic patients or with other major inflammation may cause dyspnoea, and treatment of the infection will reduce the metabolism and the ventilatory needs.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

In many patients the treatment of the underlying cause of breathlessness has already been optimised, is deemed inappropriate because of the patient's poor clinical state, or (in resource-poor settings) because of the lack of diagnostic and therapeutic resources. Symptomatic pharmacological treatment will be required in these patients. However, other patients will require symptomatic pharmacological treatment until causal therapies become effective or in parallel with causal therapy.

In systematic reviews and meta-analysis, enteral or subcutaneous strong opioids have shown to significantly improve the sensation of breathlessness in

adults with advanced disease[2]. A recent systematic review[5] on four different treatment options (opioids, benzodiazepines, corticosteroids and oxygen) for the relief of breathlessness in palliative care patients, included five systematic reviews and ten randomized controlled trials and found that opioids (oral and parenteral) were the only drug group with evidence for relief of breathlessness.

When administered at appropriate doses, opioids reduce rate of breathing and sensation of dyspnoea, without measurable changes in oxygen saturation or partial pressure of carbon dioxide (pCO2).

Morphine is suggested as the first-line opioid in the treatment of breathlessness. Morphine is included in the WHO essential medicines list as an analgesic, as pre-operative medication and sedation for short-term procedures and for palliative care[1]. Morphine is included in the IAHPC List of Essential Medicines in Palliative Care for the treatment of moderate to severe pain and for the treatment of dyspnoea[6].

Benzodiazepines such as diazepam are useful in relieving anxiety, which often aggravates breathlessness in a vicious circle. Corticosteroids such as dexamethasone may be used to alleviate breathlessness by reduction of peritumoral oedema in patients with lung cancer.

In contrast, bronchodilators such as theophylline are generally not effective in the treatment of breathlessness, as bronchoconstriction is only rarely involved. Most patients with breathlessness will have maximal dilated airways, and application of bronchodilators will only result in burdensome side effects such as tachycardia.

Oxygen application is generally ineffective toi, as breathlessness is related to raised carbon dioxide levels and not to decreased oxygen levels in most patients. The exception is patients with oxygen saturation below 90%, often with central cyanosis, who benefit from oxygen application. Oxygen may burden the patient with the restriction of mobility, dry airways and psychological dependence on the oxygen support.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Pharmacological management should be accompanied by appropriate non-pharmacological measures, including anxiety management and adaptation of the environment. Staying with the patient and not leaving him/her alone may reduce anxiety and lessen panic attacks. "Breathing space" can be provided for example by opening a window or using a fan to provide a flow of cool air.

5. Simon ST, Koskeroglu P, Bausewein C. [Pharmacological therapy of refractory dyspnoea : A systematic literature review]. *Schmerz* 2012; 26:515-22.
6. De Lima L, Doyle D. The International Association for Hospice and Palliative Care list of essential medicines for palliative care. *J Pain Palliat Care Pharmacother* 2007; 21:29-36.

Other non-pharmacological interventions include inhalation, physiotherapy with respiratory exercises, percussion massage, relaxation therapy, or a hand held battery operated fan.

CONFUSION / DELIRIUM

Delirium (acute confusion) is very common in the terminal stages of advanced disease and is associated with a short prognosis. Features suggested being highly specific to acute delirium states are acute onset, fluctuating course, disorganized thinking, inattention, memory impairment and disorientation[7]. Confusion is often used synonymous with delirium, though confusion is a wider term that also includes chronic states such as those seen in patients with dementia.

Delirium may be hyperactive (presenting with agitation, hyperarousal, and restlessness), or hypoactive (presenting with drowsiness, lethargy and reduced levels of arousal), or a mixed pattern in which the symptoms fluctuate between hyperactive and hypoactive.

Subjective assessment of delirium is difficult, as the patient will not be able to self-assess his/her cognitive impairment. Staff or proxy assessment using simple scales (no, slight, moderate, severe confusion) is feasible.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Management of delirium comprises identification and wherever possible treatment of possible underlying causes, including infections, organ failure, fluid, electrolyte or metabolic disturbances such as hypercalcaemia, hypo-or hyper-glycaemia, hypoxia or side effects of medication. Confusion may be aggravated by other factors as well, for example by pain or anxiety, but also by a full bladder. Delirium may be caused by cancer metastases in the brain, and anti-cancer treatment may be indicated. Encephalitis can be caused by HIV, and anti-retro-viral therapy (ART) may be needed.

Sub-acute onset of delirium, sometimes, but not always, in connection with neurological symptoms such as myoclonus may indicate seizures, which are not infrequent in patients with severe life-threatening illness. Indeed, repeated episodes of delirium should always raise a tentative diagnosis of seizures. Antiepileptic medication may prevent future episodes.

7. Ekstrom MP, Abernethy AP, Currow DC. The management of chronic breathlessness in patients with advanced and terminal illness. *BMJ* 2015; 349: g7617.

Delirium is often caused by medicines, for example anti-cholinergic, antidepressants, corticosteroids, neuroleptics or opioids, and the patient's current medicines should be reviewed before symptomatic pharmacological management is initiated.

Delirium can be induced by sudden withdrawal of alcohol or benzodiazepines and careful substitution of the substances will alleviate the withdrawal symptoms including delirium, and a slower stepwise withdrawal will prevent recurrence of the delirium.

Causal treatment may not be indicated in patients with limited prognosis and pharmacological symptomatic therapy has to be initiated without delay.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Haloperidol is considered as first choice therapy in the management of delirium during the terminal phases of disease, although evidence is limited.

A systematic review[8] identified two controlled studies and a survey on the use of neuroleptics for treatment of delirium in palliative care patients. In both controlled studies haloperidol was as effective as chlorpromazine or aripiprazole, but significantly more effective than lorazepam. This study however was unable to demonstrate that any medication changed the natural history of delirium.

A recent study confirmed that Haloperidol as a single drug is successful in reducing hyperactive delirium features in more than 70% of patients[9].

Haloperidol is included in the WHO essential medicines list[1] for management of psychotic disorders in adults and children (complementary) as well as for palliative care. Haloperidol is also included in the IAHPC List of Essential Medicines in Palliative Care[4] for the management of delirium, nausea, vomiting and terminal restlessness. Haloperidol is widely available at low cost.

Levomepromazine (or similar weak neuroleptics) may be used as an alternative if available. As a weak neuroleptic higher dosages are required. Side effects will include sedation and sometimes hypotension, but less severe extrapyramidal symptoms.

In sub-acute delirium, or if neuroleptics alone are not effective, anxiolytics may be added. Midazolam with rapid onset and short rapid effect can be used.

8. Perrar K, Golla;U., Voltz R. Medikamentöse Behandlung des Delirs bei Palliativpatienten - Eine systematische Literaturübersicht. *Schmerz* 2013; online first.
9. Shin SH, Hui D, Chisholm G, Kang JH, Allo J, Williams J, Bruera E. Frequency and Outcome of Neuroleptic Rotation in the Management of Delirium in Patients with Advanced Cancer. *Cancer research and treatment: official journal of Korean Cancer Association* 2014.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Delirium may be triggered by a change of setting, and providing some personal items that the patient feels familiar with (such as some family pictures) may lessen distress in unfamiliar surroundings. Ensuring people who need hearing aids or spectacles have these fitted, having a large clock on the wall, ensuring there is assistance with meals and that the place is quiet and dark at night, and lit during the day have been shown to lessen the impact of delirium.

Communication skills are important. Lengthy discussions or explanations only add to the patient's distress, as he will not be able to understand or accept a change of perspective. Short explanations, if necessary with multiple repetitions, should be provided. Staff should model their language and terminology on the personal biography of the patient. In patients unable to communicate verbally, physical contact can relieve anxieties in confused patients. Basal stimulation is a nursing intervention offering a range of perceptual experiences using all five senses, which has been found helpful in patients with delirium.

Non-pharmacological treatment should be passive rather than active, using massage or music therapy, for example.

CONSTIPATION

Constipation is defined as a condition in which there is difficulty in emptying the bowels, usually associated with hardened faeces[2]. There is a wide range in normal bowel habit (rule of thumb: between three times per day and once every third day) and constipation cannot simply be defined in terms of stool frequency. Self-assessment depends on the subjective feeling of constipation, but this results in higher prevalence, as already 8% of healthy men and 21% of women report feeling constipated.

Severe constipation includes obstipation and faecal impaction, which can progress to bowel obstruction.

In patients with severe illness, a number of factors contribute to constipation. Patients often are bed-bound' fluid intake is reduced, and pharmacological treatment includes a range of substances with constipation as a side effect.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Constipation can be caused by a number of medicines that are frequently used in palliative care. This includes opioids, and often opioid dosages are reduced in order to reduce or prevent opioid-induced constipation. However, the focus on opioid-induced constipation overlooks the fact that a number of other

medicines have constipation as a side effect, including antidepressants, antibiotics or 5-HT3 receptor serotonin agonists such as ondansetron. A thorough review of the medication plan is warranted. Opioid-induced constipation can be treated with specific opioid antagonists such as oral naloxone or subcutaneous methylnaltrexone, if these substances are available.

The gastrointestinal passage may be impaired by primary cancer or metastases in cancer patients, either in the gastrointestinal tract itself, or in the pelvic or retroperitoneal area. Corticosteroid therapy with dexamethasone will reduce tumour-related swelling in these areas and thus restore the passage (at least temporarily). In people with cachexia (and loss of lean body mass), it is likely that they will also have impaired pelvic floor function.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Laxative medicines include bulk forming laxatives, which are not appropriate in palliative care, stimulant laxatives and osmotic laxatives.

A recent systematic review[10] on the laxative treatment for constipation in palliative care patients, identified controlled trials. Four trials evaluated opioid antagonists (methylnaltrexone subcutaneously, oxycodone / naloxone orally), the others tested a broad range of different laxatives.

There is little good quality trial evidence to confirm the effectiveness of laxatives in constipation associated with palliative care. In addition, there is a lack of evidence to recommend the use of one laxative, or combination of laxatives, over another. In the absence of any data showing greater efficacy of one agent over another, the choice of laxative is likely to be determined by factors such as availability of suitable formulations, route of administration, pharmacokinetics and cost-effectiveness.

Use of a stimulant laxative is the most appropriate choice in opioid induced constipation, as constipation due to increased gastrointestinal transit time is an inevitable consequence of opioid use.

Laxatives and stool softeners may be needed at high doses, particularly in opioid induced constipation in palliative care. Where a high dose stimulant laxative is insufficient to manage constipation, a combination of stimulant and osmotic laxative is necessary.

Docusate sodium appears to be better tolerated than to lactulose. It is also cheaper. Docusate sodium is currently included in the WHO essential medicines[2] list for palliative care.

10. Bader S, Weber M, Becker G. [Is the pharmacological treatment of constipation in palliative care evidence based?: A systematic literature review]. *Schmerz* 2012; 26:568-86.

Senna is available in both oral liquid and oral tablet formulations. It is inexpensive and widely used as a stimulant laxative. It is included in the WHO essential medicines[2] list for palliative care and as a laxative.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Non-pharmacological management of constipation with attention to fluid intake, nutrition and mobility is important but may be limited by anorexia and general debilitation in palliative care. Physical activity may help, and physiotherapy should be offered for mobilisation, in addition to more specific interventions such as colon massage. Planning and monitoring fluid intake will be helpful. Ensuring that when a patient feels the urge to defecate, they are able to do so without delay. Having feet on a small step also helps to optimise pelvic floor function.

Non-pharmacological treatment also includes the use of enemas, either with fluids only or with additional laxatives. Faecal impaction in the rectum may require manual debulking.

COUGHING

Cough is a common symptom in cancer as well as in HIV/AIDS or tuberculosis. Coughing may result from pulmonary infection, tumours in the airways, aspiration, unrecognized oesophageal reflux with aspiration, inhaled irritants or drugs such as the angiotensin-converting enzyme inhibitors. Non-productive cough can be caused by bronchospasm related to COPD, smoking, or asthma[11].

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Respiratory infections should be treated with appropriate antibiotics or ART. Cough from bronchospasm often responds to bronchodilators including salbutamol with either inhaled or systemic corticosteroids. In patients moving little air with each breath, systemic corticosteroids and frequent nebulization of bronchodilators may help. If symptoms improve and tidal volumes increase, hand-held metered dose inhalers may be effective. In patients with oesophageal reflux a trial of H2 receptor antagonists or proton pump inhibitors may be appropriate.

11. Gwyther L, Merriman A, Mpanga Sebuyira L, Schietinger H. *A clinical guide to supportive and palliative care for HIV/AIDS in sub-saharan Africa*. Kampala, African Palliative Care Association; 2006.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Symptomatic pharmacological treatment may be required to prevent exhaustion or control an irritating, non-productive cough.

Opioids can be used to suppress cough. Increase doses, as necessary, by carefully titrating effectiveness in cough suppression against side effects. Codeine, but also morphine in low doses are effective antitussives. In patients already receiving opioids for management of pain or breathlessness the opioid dosage may be increased to treat cough.

If available, nebulized lidocaine can sometimes provide rapid relief for an irritating, non-productive cough. A lidocaine solution can be used 3–4 times daily as needed. However, as the sensitivity of the gag reflex is reduced with this anaesthetic agent, patients have to refrain from eating or drinking after treatments for at least an hour.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Spiced drinks with cinnamon, ginger and honey (one teaspoon spice in 150-200 ml boiled water, add honey or sugar to taste) may help to soothe the throat and relieve coughing. Honey with ginger or cinnamon powder (1 teaspoon of spice in 150 ml of honey) can also be used.

DEPRESSION

Depression is characterized by persistent feelings of extreme sadness and low mood associated with loss of interest in activities and inability to experience pleasure[2]. There are often associated biological features of significant changes in appetite and weight, disturbed sleep, fatigue and poor concentration[12].

Diagnosis of major depression in a terminally ill patient often relies more on the psychological or cognitive symptoms (worthlessness, loss of enjoyment, hopelessness, excessive guilt, and suicidal ideation) than the physical/somatic signs (weight loss, sleep disturbance) described in depression in patients who are not terminally ill.

Major depression as a psychiatric disorder has to be differentiated from feelings of sadness that may be entirely appropriate for patients with severe and

12. Rayner L, Price A, Hotopf M, Higginson IJ. The development of evidence-based European guidelines on the management of depression in palliative cancer care. *Eur J Cancer* 2011; 47:702-12.

life-threatening illness. The key indicators of major depression in the terminally ill are persistent feelings of hopelessness and worthless and/or suicidal ideation.

Depression in palliative care is likely to be significantly under-recognized and under-treated as the symptoms overlap with symptoms of the underlying condition. Diagnosing and providing treatment for a major depressive episode in patients with a terminal illness can improve quality of life.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Treatment of pain and other reversible physical symptoms should be instituted before or concurrently with initiation of specific depressive treatment.

Anxiety commonly exists as co-morbidity with depression in palliative care. Management of anxiety is considered in a separate section.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

A systematic review and a meta-analysis[13] assessed twenty-five studies, and reported that both tricyclic antidepressants (TCAs) and selective serotonin reuptake inhibitors (SSRIs), were more effective than a placebo in treating depression. Improvement of depressive symptoms took several weeks of therapy. The therapeutic benefit persisted after eighteen weeks, though side effects such as dry mouth or sexual dysfunction caused patients to stop their medication with prolonged treatment duration. They concluded that there was insufficient evidence to support the use of one antidepressant in preference to another.

A recent systematic review[14] (Ujeyl and Müller-Oerlinghausen 2012) on the treatment of depression in chronic illness identified forty trials (16 studies in neurological patients, twenty-four in general pharmacological conditions, nine in patients at the end of life or in advanced disease stages) and found moderate evidence of efficacy of antidepressants (SSRI: selective serotonin reuptake inhibitors and NSMRI: non-selective monoamine reuptake inhibitors), though the evidence was not conclusive for some diseases and medication classes. Some studies showed superior efficacy of NSMRI than SSRI.

There is less evidence on anti-depressive therapy in palliative care patients,

13. Rayner L, Price A, Evans A, Valsraj K, Higginson IJ, Hotopf M. Antidepressants for depression in physically ill people. *Cochrane Database Syst Rev* 2010: CD007503.

Rayner L, Price A, Evans A, Valsraj K, Hotopf M, Higginson IJ. Antidepressants for the treatment of depression in palliative care: systematic review and meta-analysis. *Palliat Med* 2011; 25: 36-51.

14. Ujeyl M, Muller-Oerlinghausen B. [Antidepressants for treatment of depression in palliative patients : A systematic literature review]. *Schmerz* 2012; 26:523-36.

but moderate evidence of efficacy is supported by expert opinion[12]. No evidence addressed depression management in advanced heart failure or dementia.

Although derived from fewer studies, RCTs consistently support tricyclic antidepressants and selective serotonin reuptake inhibitors for treating depression in cancer when treatment lasts six weeks or longer. Critical gaps include that the evidence base does not address late-stage cancer (for example, terminal care) or delivery system changes.

Amitriptyline is the most widely used tricyclic antidepressant (TCA) and has been proven to be safe and effective in the treatment of depression. Amitriptyline is included in the WHO essential medicines list[1] for the treatment of depression and for palliative care. Amitriptyline is included in the IAHPC List of Essential Medicines in Palliative Care[4] for the treatment of depression.

Fluoxetine is a selective inhibitor of serotonin reuptake (SSRI). Fluoxetine is included in the WHO essential medicines list for the treatment of depressive disorders and for palliative care.

All antidepressants have to be titrated over days or even weeks until the therapeutic effect is adequate. In contrast, side effect that may burden the patient may be described at once. Side effects often include anticholinergic symptoms such as sedation, dry mouth or constipation. A serotonergic syndrome is a rare complication of antidepressant therapy.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Careful assessment is needed to differentiate between depression (requiring pharmacological treatment with antidepressants) and sadness where antidepressant medication often is inappropriate. Psychological approaches, particularly cognitive behavioural therapy are important for all palliative care patients, but particularly for those with depressiveness.

Other interventions such as spiritual support, music or art therapy may be beneficial.

DIARRHOEA

Diarrhoea is defined as having three or more loose or liquid stools per day, or as having more stools than is normal for that person[2].

It is usually a symptom of gastrointestinal infection, which can be caused by a variety of bacterial, viral and parasitic organisms. Infection is spread through contaminated food or drinking-water, or from person to person as a result of

poor hygiene. Severe diarrhoea leads to fluid loss, and may be life-threatening, particularly in young children and people who are malnourished or have impaired immunity. In palliative care it can sometimes be seen in severe constipation as an 'overflow' phenomenon.

Diarrhoea can usually be divided into different types and treatment will vary depending on cause: secretory, osmotic, mechanical, or disordered motility.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Management of diarrhoea comprises identification and, if appropriate, treatment of possible underlying causes. In palliative care, the overuse of laxatives, typically seen when the management of constipation is suddenly "stepped-up", is a common cause. Other causes that may be remedied with specific interventions include partial intestinal obstruction, pancreatic insufficiency, Clostridium infection, chemotherapeutics, and radiation enteritis.

Severe constipation and faecal impaction can also cause diarrhoea as backed-up, liquefied stool may be all that the patient can pass ("overflow diarrhoea").

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

A recent systematic review[15] on loperamide for treatment of diarrhoea in palliative care patients identified seven controlled trials in patients with HIV/AIDS or cancer. Loperamide was superior compared to placebo and to acetorphan, at though the comparison with octreotide was less conclusive. Considering the low level of evidence from clinical trials, the recommendation for treatment of diarrhoea is based on expert opinion.

Loperamide, a synthetic piperidine derivative, is an opioid drug effective against diarrhoea resulting from gastroenteritis or inflammatory bowel disease. Loperamide reduces peristalsis in the gut, increases water reabsorption, and promotes faecal continence.

AIDS-related diarrhoea is a common cause of morbidity and mortality in HIV positive individuals, especially in the sub-Saharan Africa. Loperamide is readily available and has been found to be useful in this condition. Loperamide may be less effective in patients with extensive colorectal resections. In these patients octreotide may be more effective.

Loperamide is included in the WHO essential medicines list[1] for palliative care.

15. Pastrana T, Meissner W. [Treatment of diarrhea with loperamide in palliative medicine. A systematic review]. *Schmerz* 2013; 27:182-9.

If loperamide is not available in resource-poor settings, opioids such as morphine or codeine can be used as alternatives for the treatment of diarrhoea, using the side effect of constipation.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Adequate hydration needs to be part of the treatment for diarrhoea, including the use of rehydration salts.

DRY MOUTH

Numerous conditions contribute to a sore, dry mouth (xerostomia) in patients with cancer or HIV/AIDS, including candidiasis, apthous ulcers (stomatitis), herpes simplex, HIV infection itself or cancer in the oropharyngeal area[11]. A dry mouth is also often simply caused by mouth breathing. Other causes include drugs such as chemotherapy or anti-retrovirals (e.g. indinavir), previous radiotherapy involving salivary glands, antihistamines, anticonvulsants, antidepressants, and anticholinergic drugs, which reduce salivary flow. Dehydration, reduced mastication, anxiety, and depression all reduce salivary flow. Oxygen therapy aggravates a dry mouth.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Infections such as candidiasis and herpes simplex should be treated. The medication plan of the patient should be reviewed and the indication should be reviewed of all medicines that may be the cause of dry mouth, and dose reduction or switching to another substance has to be considered.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

A mouthwash solution should be applied after each meal and at night in addition to teeth brushing, not as a substitute. Mouthwashes containing alcohol should be avoided as they dry out the mouth.

Antimicrobial mouthwashes such as 0.2% chlorhexidine gluconate mouthwash or 1% povidone iodine mouthwash (which has been known to stain the teeth) can be used as an alternative to prevent superinfection. Chlorhexidine gluconate should not be used at the same time as nystatin or amphotericin B.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENTS

Patients and caregivers should be informed about general principles of mouth care. This includes taking regular sips of water to keep up fluid intake. Lips should be kept clean, soft, lubricated, and intact as far as possible, for example with regular application of petroleum jelly or moisturising lotion to the lips. Teeth should be brushed with a chew stick or a small, soft toothbrush (a baby's toothbrush is ideal) after each meal and at night. If available, fluoride toothpaste should be used. If brushing is not possible due to pain or bleeding, a soft sponge, cotton buds, or a gloved finger wrapped with gauze or a soft cloth can be used as alternatives. Mouth, cheeks, palate, gums, tongue, and teeth should be checked regularly to identify and manage problems early. Dentures should be cared for adequately.

Hydration alone will not result in any relief of xerostomia and simple palliative measures are usually more than adequate. Artificial saliva products are costly, but 'homemade' saliva can be produced at low cost, for example as a solution of methylcellulose with lemon essence in water (if methylcellulose is available).

Sips of cold water or ice cubes to suck on can be offered repeatedly. Fresh or frozen pineapple chunks can be used to chew or suck, though this should be avoided if there are open sores in the mouth. Sugar-free gum, Vitamin C tablets, sugar-free lemon-flavoured sweets, or sour sweets can be used as well. Mouthwash solutions can be offered two-hourly. If the patient is too ill for this, water an be applied in the mouth with a spray bottle or using a sponge stick. Lubricating jelly can be applied to the tongue and oral cavity to keep the mouth moist and lubricated in patients with advanced disease. The room air can be humidified if the air is very dry.

Before patients eat, the inside of the mouth should be lubricated with a little butter, margarine, or salad oil. Soft or liquid foods should be prepared that are easy to chew and swallow.

FATIGUE / TIREDNESS /ENERGY LOSS /WEAKNESS

Fatigue is defined as a subjective feeling of tiredness, weakness or lack of energy[16]. The pathophysiology is not fully understood but in most palliative care patients will be multifactorial, including disease- and treatment-related causes. A physical and cognitive dimension seems to be acknowledged by all authors.

16. Radbruch L, Strasser F, Elsner F, Goncalves JF, Loge J, Kaasa S, Nauck F, Stone P. Fatigue in palliative care patients - an EAPC approach. *Palliat Med* 2008; 22:13-32.

Weakness seems to be useful as a paraphrase for the physical dimension and tiredness for the cognitive dimension.

Cancer-related fatigue (CRF) is defined as a common, persistent, and subjective sense of tiredness related to cancer and/or its treatments that interferes with usual functioning. Qualitative differences between fatigue in cancer patients and in healthy controls have been proposed. However, these differences seem to be only an expression of the overwhelming intensity of cancer-related fatigue.

CRF is usually multi factorial; it may be caused by tumour-related and/or treatment-related factors such as decreases in the availability of metabolic substrates, hormonal changes, increase in pro-inflammatory cytokines, cachexia, neurophysiological changes in skeletal muscle, muscle wasting, decreased ventilatory ability, anaemia, and altered sleep patterns.

Fatigue is one of the most frequent symptoms in palliative care patients, impairing quality of life considerably. Fatigue is reported by not only a majority of patients with advanced cancer, but also many cancer survivors, patients with heart failure, COPD, in amyotrophic lateral sclerosis or with HIV/AIDS.

Fatigue in cancer and non-cancer palliative care patients is under-recognized, under-assessed and under-treated. Screening for fatigue should include questions on weakness and tiredness such as 'Do you feel unusually tired or weak?' or 'How weak are you?' / 'How tired are you?' Multidimensional specific questionnaires should be used for research projects on fatigue.

In the final days of life, fatigue may shield the patient from suffering and treatment of fatigue may be detrimental. Identification of the time point where treatment of fatigue no longer is indicated is important to alleviate distress at the end of life.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Primary cancer-related fatigue is related to the tumour itself. This may either be through peripheral mechanisms such as energy depletion or by central mechanisms such as dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis or serotonin metabolism. These mechanisms may ultimately be related to high levels of cytokines. Cancer-related concurrent syndromes and comorbidities such as anaemia, cachexia, fever, infections or metabolic disorders as well as sedative drugs for symptom control can produce secondary fatigue.

Anaemia clearly is a cause of fatigue in cancer patients as well as in other palliative care patients. Erythropoietin secretion is diminished in cancer-related anaemia, and treatment with erythropoietin in patients with low levels can result in alleviation of fatigue, though usually life expectancy is too short in palliative care patients to pursue this option.

Other metabolic disorders such as hypothyroidism, hypogonadism, dehydration or electrolyte disturbances such as hypercalcaemia, hepatic, cardiac or renal failure, sleep disorders, anxiety or emotional stress may contribute to cancer-related fatigue. Dysregulation of growth hormone or hypothyroidism have also been implicated in the pathophysiology of fatigue with HIV. Treatment of these causes may alleviate fatigue considerably.

Depression has been linked with fatigue and fatigue is one of the main symptoms of major depression. Fatigue can also be aggravated by other cancer- or treatment-related symptoms. In a group of breast cancer survivors, fatigue was significantly correlated with dyspnoea, insufficient sleep and depression, with these three variables accounting for a total of 46% of variance in fatigue.

Many drugs with sedative properties regularly used in palliative care such as opioid analgesics, benzodiazepines, anti-depressants or anti-convulsants can add to the fatigue load.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Very few studies have been conducted to evaluate the effectiveness of corticosteroids in fatigue in adults. A recent systematic review published in November 2012[17] on treatment with corticosteroids and androgens for the relief of fatigue in palliative care patients included eleven controlled studies as well as four uncontrolled studies, two case series and two surveys with glucocorticoids (all in cancer patients). Glucocorticoids improved quality of life but results for changes of fatigue and weakness were inconsistent. Tiredness and energy were not improved.

Dexamethasone is included in the WHO essential medicines list[18] as antiallergic, as a hormone (complementary), as an antiemetic and for palliative care.

Other options for treatment of fatigue (in resource-rich settings) include megestrol acetate, amantadine and stimulants such as methylphenidate and modafinil.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Non-pharmacological support includes light aerobic training as well as energy-conserving or restorating therapies. Physical training has to be adapted

17. Thiem A, Rolke R, Radbruch L. [Glucocorticoids and androgens for treatment of tiredness and weakness in palliative care patients: A systematic review]. *Schmerz* 2012; 26:550-67.
18. Peuckmann V, Elsner F, Krumm N, Trottenberg P, Radbruch L. Pharmacological treatments for fatigue associated with palliative care. *Cochrane Database Syst Rev* 2010; 11:CD006788.

to the performance status of the patient, and in patients with low performance status transfer from bed to chair may be strenuous enough.

Energy conservation includes the use of a fatigue diary to document the activities as well as fatigue severity across the day. Using the diary, mismatches between fatigue level and planned activities can be identified, and energy expenditure planning and a discussion on prioritization of the activities can be initiated: which tasks does the patient want to do himself, and which can be delegated to a caregiver?

This is supported by energy restoration, which includes counselling on coping strategies, relaxation therapy, massages or performing enjoyable activities.

ITCHING

Itching is not as frequent as other symptoms, but may be extremely aggravating for palliative care patients. The urge to scratch has been described as much worse than severe pain. Itching may be related to organ dysfunction (liver, kidney), metabolic disorders (diabetes mellitus), allergic reactions to medicines or other substances or to other factors such as dry skin. Itching can also be related to cancer or to HIV/AIDS itself with the papular pruritic eruption of HIV.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Severe itching requires examination of the skin and laboratory evaluation. Accumulation of bile acids in liver dysfunction can be treated with the anion-exchanger cholestyramine 4 – 16 g/d. Chronic renal insufficiency often leads to severe itching, though the pathophysiology is unknown. Haemodialysis may be required to reduce the level of uraemia. As itching often is related to allergic reactions to medicines in palliative care patients, the medication plan should be revised carefully, and potential sources of pruritus should be discontinued if possible.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

For itching, symptomatic pharmacological treatment can use either topical or systemic application[19]. Local anaesthetics such as lidocaine or a mixture of

19. Weisshaar E, Szepietowski JC, Darsow U, Misery L, Wallengren J, Mettang T, Gieler U, Lotti T,

prilocaine and lidocaine may be effective, though usually only with short-term effect. Glucocorticoids such as hydrocortisone 1% may suppress itching related to inflammatory processes; with severe inflammation more potent steroids such as betamethasone valerate 0.1% may be beneficial.

Topical relief for itching may also be provided with Unguentum emulsificans aquosum (UEA) with 1% menthol or calamine lotion.

For systemic application antihistamines may be tested but often are not effective and may be associated with severe sedation as side effect. Glucosteroids such as dexamethasone may be used with good effect. Gabapentin and pregabalin have been used with good effect in several clinical trials for relief of itching, as well as antidepressants such as mirtazapine, doxepin, sertraline and paroxetine.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Non-pharmacological interventions include moisturiser and mild non-alkaline soap (or aqueous cream as a soap substitute) to reduce dryness of the skin[11]. Friction should be minimized during cleansing and drying to avoid mechanical irritation, using soft sponges, wash-cloths and towels and dabbing the skin dry rather than rubbing. Emulsifying ointment or moringa oil may be applied twice daily after washing. Emollient ointments containing urea may give relief and can be applied over large areas of skin. If ineffective, lactic acid, urea (10%), sodium lactate moisturisers or salicylic acid (20%) may relieve itching. Ointments should be kept cool or refrigerated. Fingernails should be kept short, restrictive or non-absorbent clothing avoided. Patients should drink enough fluids, but should avoid alcohol.

Factors that foster dryness of the skin should be avoided, such as dry climate, heat (for example sauna, sitting near fire or heater), alcoholic compresses, ice packs or frequent washing. Patients should not bathe or shower more than once a day. Room air can be humidified by boiling water. Contact with irritant substances (for example compresses with rivanol, chamomile, tea-tree oil) should be avoided.

Patient education about the vicious circle of itching – scratching – itching may be important, and interventions such as relaxation techniques or autogenic training may be beneficial.

Lambert J, Maisel P, Streit M, Greaves MW, Carmichael AJ, Tschachler E, Ring J, Stander S. European guideline on chronic pruritus. *Acta dermato-venereologica* 2012; 92:563-81.

NAUSEA AND VOMITING

Nausea is an unpleasant sensation often accompanied by the urge to vomit.[2] Vomiting is the forceful expulsion of gastric contents through the mouth. Although nausea and vomiting often occur together they are in fact separate symptoms. Patients may be burdened more by an ongoing feeling of nausea than by vomiting that is only unpleasant for a restricted period of time, but leaves a feeling of relief after the act. Caregivers and staff may be more impressed by vomiting and may tend to under-assess nausea.

A number of neural pathways and receptors play a role in the pathophysiology of nausea and vomiting, including histamine, serotonin, dopamine, and cannabinoid and neurokinin receptors.

Nausea and vomiting are often treatment-related in patients with cancer, as most chemotherapy is highly emetogenic. Appropriate management of chemotherapy-induced nausea and vomiting depends on the chemotherapy regime.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Gastrointestinal obstruction may cause vomiting from overflow of gastrointestinal content. There is often only little nausea reported by these patients. Restoration of the passage, either by surgical or endoscopic procedures or by corticosteroid treatment can relieve the symptoms, though often only for a restricted period of time until tumour growth leads to obstruction again. Inhibition of secretion in the gastrointestinal tract (for example with hyoscine butylbromide or H_2 antagonists) also reduces nausea and vomiting effectively. In patients with gastrointestinal obstruction vomiting usually occurs sometime after food intake, with considerable output (up to projectile vomiting) and with little nausea.

Nausea and vomiting may be caused by metabolic or toxic factors that may require treatment. Electrolyte imbalances (hypercalcaemia) should be corrected. Infection may require antibiotic therapy. Raised intracranial pressure from metastases or meningitis can be reduced. In patients with toxic or metabolic causes there is usually severe nausea, often with gagging, but only little vomiting.

For patients with chemotherapy- or radiation therapy-related nausea, 5HT3 antagonists such as ondansetron might be preferable.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Symptomatic management of nausea and vomiting should not be deferred until the underlying cause of the nausea and vomiting has been identified and appropriately treated, but should be initiated without delay.

Pharmacological management based on knowledge of the most important pathophysiological mechanisms for emetogenesis and the relevant neurotransmitters is suggested for optimum management of nausea and vomiting but the evidence to support this approach has been questioned. Unfortunately it is not always possible to identify the precise mechanism(s) underlying the presence of nausea and vomiting. A pragmatic approach addressing the most likely mechanism is indicated, differentiating, for example, between toxic or metabolic nausea and retention vomiting.

Anti-emetics should be prescribed regularly and as required. If a single first-line antiemetic does not relieve nausea and vomiting the antiemetic regime should be reviewed to ensure that the likely pathophysiological mechanisms underlying nausea and vomiting are being targeted, the patient is receiving the medication and that it is being absorbed and that the dose is appropriate. If necessary a second antiemetic with a complementary mechanism of action may be added. Combinations of anti-emetics with antagonistic actions should be avoided. Alternatively the first-line antiemetic can be changed to a single second line antiemetic with a more appropriate or broader spectrum of action.

Where the enteral route is unavailable or absorption is not reliable an alternative route of administration, either rectal or subcutaneous (or intravenous if long term central venous access is available) is required. Antiemetic administration via subcutaneous bolus injections or continuous subcutaneous (or intravenous if long term central venous access is available) infusion is the route of choice where the enteral and rectal routes are unavailable and regular dosing is required.

Drug classes appropriate for pharmacological management of nausea or vomiting include neuroleptics (such as haloperidol, levomepromazine, chlorpromazine or prochlorperazine), antiemetic antihistamines (such as cyclizine, promethazine), 5HT3 antagonists (such as ondansetron), corticosteroids (such as dexamethasone) and prokinetic antiemetics (such as metoclopramide or domperidone).

Most of the evidence base for pharmacological treatment of nausea and vomiting in palliative and terminal care is weak. Two recent reviews[20] (Benze et al. 2012a, 2012b) on antiemetic therapy in palliative care patients indicate moderate evidence of the effectiveness of metoclopramide for the treatment of nausea and vomiting. The moderate to weak evidence from clinical trials is

20. Benze G, Alt-Epping B, Geyer A, Nauck F. [Treatment of nausea and vomiting with prokinetics. Benze G, Geyer A, Alt-Epping B, Nauck F. [Treatment of nausea and vomiting with 5HT3 receptor antagonists, steroids, antihistamines, anticholinergics, somatostatinantagonists, benzodiazepines and cannabinoids in palliative care patients: A systematic review]. *Schmerz* 2012; 26:481-99.

supported by clinical expertise. Expert opinion strongly supports the use of metoclopramide in palliative care patients with nausea or vomiting. However, in the absence of any data showing greater efficacy of one agent over another, the choice of antiemetics is likely to be determined by other factors such as availability of suitable formulations and cost effectiveness.

Metoclopramide is recommended for the first-line management of nausea and vomiting associated with delayed gastric emptying. In palliative care, the most common cause for vomiting is gastric stasis which responds well to metoclopramide. Regurgitation suggests gut hypo-motility which responds to a gastro-kinetic antiemetic such as metoclopramide.

Metoclopramide is included in the WHO essential medicines list[1] as an antiemetic as well as for palliative care.

Availability of a combination of antiemetics with different mechanisms of action is recommended to ensure appropriate first and second-line management for each underlying pathophysiological mechanism.

Neuroleptics were more effective than metoclopramide in some trials, but side effects have to be considered. Haloperidol is used for treatment of nausea in lower doses than for treatment of delirium.

Haloperidol has an oral bioavailability of 60-70%. The onset of action is within 10-15 minutes after subcutaneous application, but more than an hour with oral application. The duration of action is up to 24 hours. The use of haloperidol carries the risk of extrapyramidal side-effects, but less sedation compared with other neuroleptics.

Haloperidol is included in the WHO essential medicines list[1] for management of psychotic disorders in adults and children (complementary) as well as for palliative care.

Cyclizine is the preferred antihistamine in palliative care as less sedation is reported with its use. It has an oral bioavailability of 75% and a half-life of 20 hours. Its main indications are postoperative nausea and vomiting and motion sickness, but it is also found useful for other types of nausea in palliative care.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Pharmacological management is the mainstay of treatment of nausea and vomiting, however non-pharmacological measures including avoidance of precipitants.

In addition, cognitive behavioural therapy, nutritional counselling, and relaxation therapy may be beneficial. Patients with advanced cancer may be burdened by the constant pressure of caregivers and health care staff to eat more, and in these patients a change in the goal of treatment is required, informing patient

and caregivers that it is less important to maintain caloric intake, as the metabolic changes in advanced cancer prevent adequate use of additional food.

PAIN

Pain is an unpleasant sensor and emotional experience associated with actual or potential tissue damage or described in terms of such damage.

Pain is multidimensional, having physical, psychological, social and spiritual aspects that all have to be addressed. The pathophysiology allows differentiation in nociceptive pain (related to compression or destruction of soft tissues, bones or viscera) and neuropathic pain (related to compression or destruction of nerve tissues (including peripheral nerves, nerve plexus or the central nervous system). Nociceptive pain can be further differentiated in bone pain (usually clearly located and movement-related, described as sharp pain), soft tissue pain (increased by touch, sharp or burning) and visceral pain (dull, aching, and diffuse). Neuropathic pain is sometimes described either as burning or tingling, or as shooting, lancinating or electrifying pain, often radiating into the distribution area of peripheral nerves or dermatomes (in case of spinal cord lesions).

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

In cancer patients, reduction of the tumour size may reduce cancer-related compression of tissues as well as cytokine output, and thus may relieve symptoms such as pain. In addition, specific cancer treatments may have an analgesic effect. Cancer patients with bone metastases will benefit from radiotherapy, though the effect often only appears after 1-2 weeks of radiotherapy.

Similarly, painful expansion of visceral hollow organs may be relieved by reducing the tension with restoration of the passage, for example with stenting or with artificial stoma. Painful distension of the liver capsule in patients with liver cancer or metastases can be remedied with dexamethasone, which reduces the peritumorous oedema and thus the swelling causing the distension. Mucositis in cancer patients, not infrequent after radiotherapy of the head and neck region or chemotherapy, can be treated with granulocyte colony stimulating factor (G-CSF), though most patients will require local application of solutions containing local anaesthetics as well.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Analgesic treatment should be applied orally, with around the clock continuous application and should follow the step-ladder approach of the World Health Organization[21]. This approach has been developed for cancer pain, but is applicable for palliative care patients with other diseases as well. Classes of drug that are used for the management of pain include non-steroidal anti-inflammatory medicines (such as ibuprofen) or other non-opioids (such as paracetamol) on step 1 of the analgesic ladder, weak opioids (in combination with step 1 analgesics) on step 2 and strong opioids (in combination with step 1 analgesics) on step 3.

Opioids in many countries of the world are underutilized often due to lack of knowledge and skills needed to properly evaluate, assess and treat pain and the fear of physicians, patients and their families of opioid addiction and tolerance. Additionally, strict regulations and control of these agents in many countries create difficulties in the prescription and dispensing processes.

Paracetamol or non-steroidal anti-inflammatory drugs (NSAID) are used for mild pain on step 1 of the analgesic ladder. Paracetamol is used frequently as a non-opioid analgesic in palliative care, though its analgesic efficacy is low.

Ibuprofen is a NSAID used for pain relief, fever reduction, and swelling. Ibuprofen has an antiplatelet effect, though relatively mild and somewhat short-lived compared with aspirin or prescription antiplatelet drugs. Ibuprofen also acts as a vasoconstrictor.

Non-steroidal anti-inflammatory drugs (NSAIDs) have theoretical advantage in bone or soft tissue pain due to their peripheral anti-inflammatory effect[2]. Their efficacy in reducing pain and opioid doses has been demonstrated although not specifically in patients with bone metastases or mucositis.

Ibuprofen is included in the WHO essential medicines[1] list as an analgesic and anti-migraine agent and for palliative care. Ibuprofen has proven efficacy as an analgesic and has minimal adverse effects when administered at the recommended dosages.

Opioids such as codeine and tramadol have been traditionally used for mild to moderate cancer pain on step 2 of the analgesic ladder. A systematic review showed that codeine and tramadol are effective compared with placebo[22].

21. World Health Organisation. *Cancer pain relief: with a guide to opioid availability*. 2. ed. Genf, World Health Organisation; 1996.
22. Caraceni A, Hanks G, Kaasa S, Bennett MI, Brunelli C, Cherny N, Dale O, De Conno F, Fallon M, Hanna M, Haugen DF, Juhl G, King S, Klepstad P, Laugsand EA, Maltoni M, Mercadante S, Nabal M, Pigni A, Radbruch L, Reid C, Sjogren P, Stone PC, Tassinari D, Zeppetella G. Use of opioid analgesics in the treatment of cancer pain: evidence-based recommendations from the EAPC. *Lancet Oncol* 2012; 13:e58-e68.

For patients with mild to moderate pain or whose pain is not adequately controlled by paracetamol or a non-steroidal anti-inflammatory drug (NSAID) given regularly by mouth, the addition of a step II opioid (codeine or tramadol) given orally might achieve good pain relief without troublesome adverse effects. Alternatively, low doses of a step III opioid (such as morphine < 30 mg/day) may be used instead of codeine or tramadol[22].

For patients with moderate to severe pain, opioids such as morphine are indicated on the third step of the analgesic ladder. Morphine is the prototypic opioid analgesic, and for twenty-five years oral morphine has been deemed the drug of first choice for treating moderate to severe cancer pain. Morphine is available in wide range of application forms. Costs are low for oral application forms such as tablets or solution. Many novel formulations of old opioids, such as oxycodone, hydromorphone, and fentanyl, have been developed and the availability of different opioids across the world has improved.

Several systematic reviews support the use of oral morphine, oxycodone or hydromorphone for cancer pain[22]. No differences between analgesic efficacy and tolerability were found between these opioids. In consequence, morphine, oxycodone, and hydromorphone given by the oral route can be used as the first choice step 3 opioid for moderate to severe cancer pain[22]. However, morphine is the most widely available strong opioid and given its proven efficacy, its use is recommended in moderate to severe pain in palliative care. This is particularly true for developing countries, but also applies for many settings in developed countries (such as community care). Oxycodone or hydromorphone should only be used as first choice opioids if both immediate and slow release application forms are available.

Morphine is included in the WHO essential medicines list[1] as an analgesic, as pre-operative medication and sedation for short-term procedures and as analgesic for palliative care.

Opioids on step 3 of the analgesic ladder have to be titrated upwards until the desired effect is achieved for the individual patient. Immediate release and slow-release oral formulations can be used for dose titration. The titration schedules for both types of formulation should be supplemented with oral immediate-release opioids given as needed[22].

Transdermal fentanyl and buprenorphine are alternatives to morphine, and may even be the preferred step III opioid for some patients. For patients unable to swallow, there are effective, non-invasive means of opioid delivery. However, higher costs prevent their use in many resource-poor settings[22].

Methadone has a complex pharmacokinetic profile with an unpredictably long half-life. It could be used as a step III opioid of first or later choice for moderate to severe cancer pain, but should only be used by experienced professionals[22].

No matter which opioid has been selected, it is recommended that patients receiving step III opioids who do not achieve adequate analgesia and have side effects that are severe, unmanageable, or both, might benefit from switching to an alternative opioid[22].

For patients unable to use the oral route, the subcutaneous route is simple and effective for the administration of morphine, diamorphine, and hydromorphone. Intravenous infusion should be considered when subcutaneous administration is contraindicated, for example because of peripheral oedema, coagulation disorders, poor peripheral circulation, and need for high volumes and doses. Intravenous administration should be used for opioid titration when rapid pain control is needed[22]. The relative analgesic potency (parenteral: oral) is the same for both routes and is between 3:1 and 2:1; and, although rectal opioids are effective, appropriate formulations are often not readily available and for many patients are not acceptable, and this route of administration should be used only as a last resort.

As most patients suffer from episodic pain in addition to the continuous background pain, breakthrough pain (e.g., incident pain) can be effectively managed with oral, immediate-release opioids. In some cases buccal or intranasal fentanyl preparations are preferable to immediate-release oral opioids because of more rapid onset of action and shorter duration of effect. However, these formulations are not available in resource-poor settings because of high costs[22]. Pain exacerbations resulting from uncontrolled background pain should be treated with an appropriate titration of around-the-clock opioid therapy[22].

The most common side effects of opioids are constipation, nausea and sedation. While nausea and sedation are reported in the first days following initiation or dose increases in most patients, constipation remains a problem in most patients. Laxatives should be prescribed routinely for patients receiving opioid therapy. No evidence suggests that one laxative agent should be recommended over others. Methylnaltrexone administered by subcutaneous injection may be considered in the treatment of opioid-related constipation where opioids appear to be the only cause of changed bowel function when traditional laxatives are not effective, though high costs prevent its availability in resource-poor settings[22].

In addition to opioids and non-opioid analgesics, other medicines may be used as co-analgesics in palliative care. These include antidepressants such as amitriptyline that relieve pain via activation of descending inhibitory neural pathways, or anticonvulsants such as carbamazepine or gabapentin that reduce neural activity or transmission of pain signals in the central nervous system.

Figure 1. Analgesic step ladder of the World Health Organization[21]

		Opioid for moderate to severe pain
	Opioid for mild to moderate pain	Nono-pioid analgesics (and non-pharmacological interventions)
Nono-pioid analgesics (and non-pharmacological interventions)	Nono-pioid analgesics (and non-pharmacological interventions)	Nono-pioid analgesics (and non-pharmacological interventions)
Step 1	Step 2	Step 3

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Pain is nearly always accompanied by anxiety, and sometimes a vicious circle develops with pain leading to anxiety aggravating pain and so on. Relief of tension and anxiety will support pharmacological pain relief. Progressive relaxation as well as other relaxation therapies, but also other methods such as hypnosis or visualisation have been used with good success in palliative care. Music therapy and art therapy are additional interventions that may be beneficial.

Some patients will report pain relief from warm or cold application, using cooling pads or heat packs. Patients reporting painful muscle cramps or muscle sores from being bedridden may benefit from physiotherapy or massage, and visceral cramps may be treated with massage or warm applications as well. Pain in the muscles may also be relieved by transdermal electric nerve stimulation (TENS).

RESPIRATORY TRACT SECRETIONS

Excessive respiratory tract secretions (also referred to as death rattle), is used to describe a rattling noise produced by accumulated secretions in the airway which oscillate in time with inspiration and expiration. This generally occurs in patients who are extremely weak and close to death[23].

Excessive respiratory tract secretions are associated with decreased consciousness and associated depression of reflexes (cough and swallow) at end of life. The patient is unlikely to be aware of, or distressed by, accumulated respi-

23. Radbruch L, Glaeske G, Grond S, Munchberg F, Scherbaum N, Storz E, Tholen K, Zagermann-Muncke P, Zieglgansberger W, Hoffmann-Menzel H, Greve H, Cremer-Schaeffer P. Topical review on the abuse and misuse potential of tramadol and tilidine in Germany. *Subst Abus* 2013; 34:313-20.

ratory secretions. Management of this symptom is therefore primarily for the benefit of those present in the last hours and days.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Respiratory tract infection can be treated, for example with antibiotics, but the potential benefits have to be balanced carefully against the side effects of the treatment in the terminal phase of life.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Antimuscarinic medicines such as hyoscine hydrobromide, hyoscine butylbromide and glycopyrronium may reduce the production of saliva and drying of respiratory secretions, but there is no substantial evidence from systematic review, that any intervention is superior to placebo in the treatment of this symptom. A recent systematic review[24] found no difference between hyoscine hydrobromide, hyoscine butylbromide and glycopyrronium. Expert opinion strongly supports the use of these medications in palliative care patients in the terminal stage with respiratory secretions.

There is considerable experience in the use of antimuscarinic drugs in the management of excess salivation and drooling in patients with neurological disabilities.

Antimuscarinic medicines are less likely to be effective when secretions are the result of lung abnormalities (e.g. bronchial secretions) or reflux of gastric contents.

Because it does not cross the blood-brain barrier, hyoscine butylbromide may be preferred over other agents.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

Non-pharmacological management includes positioning (and in some cases oropharyngeal suction) to reduce accumulation of secretions. Raising the upper body by 30 degrees reduces secretions in the upper respiratory tract which will then seep further down in the respiratory tract. Alternatively, the patient could be put on his/her side in a slightly head-down position, so that secretions can flow out of the mouth.

24. Pastrana T, Reineke-Bracke H, Elsner F. [Recommendations for death rattle]. *Schmerz* 2012; 26:600-7.

SWEATING

Sweating may be another unpleasant symptom accompanying late-stage HIV or cancer.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Sweating, often in combination with fever may be caused by opportunistic infections such as malaria or tuberculosis.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Where sweating is troublesome and otherwise difficult to control, anticholinergic agents such as hyoscine hydrobromide may be tried, especially when sweating is unrelated to fever. As an alternative glycopyrrolate, an anticholinergic medication with minimal central nervous involvement, can also be tried.

If sweats cause electrolyte and fluid loss rehydration may be indicated, but the benefits and burdens of aggressive rehydration in the face of short prognosis have to be weighted.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

In patients with fever, cooling measures include fans and moist cool cloths to maintain body temperature in a comfortable range. Increased fluid intake may be needed to maintain hydration.

Sage has been used to reduce sweating, either by drinking sage tea or by washing the patient with sage infusions.

WOUNDS / ULCERS

Skin tumours that cannot be excised may lead to a very unpleasant smell, which may be distressing to palliative care patients and their caregivers[11]. Such tumours include advanced Kaposi's sarcoma, squamous carcinoma, and lymphoma, all of which are common in people with advanced HIV/AIDS. Similarly skin cancer, metastases, but also fistulas caused by spreading cancer growth for example in the pelvic region also may lead to ulcerated enlarging growths and are often complicated by pain, bleeding, unpleasant odour, and secondary infection.

TREATMENT OF ANY UNDERLYING REVERSIBLE CAUSES

Surgical procedures for wound debridement or excising fistulas may be needed as a pre-requisite for adequate symptom management. Though radiotherapy usually leads to delayed wound healing in the area that has received the radiation, in patients with skin cancer radiotherapy can have good effects with less debris in the wound and improved healing. However, the potential benefits and burdens of such an intervention have to be weighed in these patients with short prognosis.

SYMPTOMATIC PHARMACOLOGICAL TREATMENT

Topical treatment should be initiated with metronidazole, which removes the smell, dries up the discharge, provides haemostasis and clears the infection caused by anaerobic organisms.

Metronidazole belongs to the nitro-imodazoles and is a pro-drug. Anaerobic and microaerophilic pathogens such as trichomonads, entamoeba histolytica, giardia lamblia or anaerobic bacteria will activate the drug. Treatment of anaerobic bacteria will eliminate the production of volative fatty acids by these bacteria that cause malodour in infected wounds. Metronidazole is absorbed completely after oral intake. Bioavailability is lower for rectal (60-80%) or vaginal application (20-50%).

Crushed metronidazole tablets should be placed on the fungating area, or metronidazole tablets or pessaries inserted into the sinus or orifice of the smelly wound. The number of tablets depends on the size of the wound. Alternatively, the wound can be cleansed regularly with metronidazole solution or dressings containing metronidazole can be applied.

Infections with mixed aerobic and anaerobic pathogens require treatment with metronidazole in combination with a ß-lactam antibiotic or an aminoglycoside.

In addition to topical treatment, metronidazole can also be given orally.

Chlorophyll is a green pigment used by plants for energy generation via photosynthesis. Commercial formulations usually do not use natural chlorophyll, but chlorophyllin, a semi-synthetic derivate. Unlike natural chlorophyll, chlorophyllin is water-soluble. The antimicrobial activity of chlorophyllin is thought to be due to its antioxidant activity.

Bioavailability of chlorophyll after oral intake seems to be non-existent. In clinical practice chlorophyllin is used topically. Topical application of chlorophyll solution 2.5% is recommended.

Systemic application is indicated only for internal deodorization. Oral intake of 100 – 300 mg chlorophyllin per day have been recommended to reduce odour

from colostomies or ileostomies or to reduce faecal odour due to incontinence. After oral application green discoloration of urine or feces has been reported. Diarrhoea is reported occasionally.

Charcoal can be used to bind smells, for example by filling up compresses with crushed charcoal tablets and using these compresses for wound dressing. Care should be taken that the charcoal does not come into direct contact with the wound.

SYMPTOMATIC NON-PHARMACOLOGICAL TREATMENT

The wound should be cleaned thoroughly to remove the smell. As this procedure might be very painful, adequate analgesia should be provided with fast acting morphine administered 30 minutes before the procedure is started. Salt water can be used for cleaning.

Wound dressings should be permeable for air if possible. Ripe paw fruit can be used for sloughing. Airtight dressings using, for example, plastic wrapping may be required if bad smells cannot be contained with other remedies.

It is helpful to place peppermint or some other fragrant plants in the room to mask the smell, or to apply aromatherapy with fragrant oils. Burning coffee as well as putting a basket with charcoal under the bed can help to bind smell.

4
PSYCHOLOGICAL AND SOCIAL ISSUES

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KEY POINTS

- Psychosocial care involves attention to the psychological, emotional, social and financial well-being of patients and family members.
- Psychosocial care can be delivered by all health and social care workers by skilled communication and compassionate listening.
- Being able to optimally communicate is a basic and essential skill or competence for all people working with patients and family members in palliative care.
- Psychosocial needs should be regularly assessed and, when needs are identified, appropriate referrals made.
- Complex needs require assessment and interventions from specialists in psychological, psychiatric and social care, where available.
- Patients and family members need support to face the losses associated with advanced illness, dying and in bereavement.

AIMS OF THIS CHAPTER

This chapter introduces concepts of communication and psychological support and also explains the types of psychological and psychiatric assessments and interventions that some patients may benefit from. In the following section, attention is turned to introducing the principles of social care. Patients and family caregivers may need support in facing loss and preparing for bereavement and, following the death, in dealing with grief and mourning. Finally, we show how palliative care can be understood as social action within communities. The chapter ends by offering some recommendations on how to implement psychosocial palliative care.

INTRODUCTION

During the last century, the circumstances in which people die have changed substantially. Over the last fifty years, palliative care has emerged as an approach to managing difficult symptoms, psychological and social distress, and spiritual and existential challenges. This chapter focuses on psychosocial aspects of palliative care.

What do we mean by psychosocial care in palliative care? Definitions vary but all focus on the psychological and emotional well-being of patients and their family caregivers, which includes enhancing well-being, maintaining self-esteem, enabling an understanding of the condition and its likely consequences, and maintaining and enhancing intrinsic social functioning and relationships. Psychosocial care is delivered through skilled communication, empathetic listening, and psychosocial support after careful assessment of patient and family needs. Psychosocial care is not an optional extra when health care workers have enough time or sufficient motivation to engage with their patients. Instead, it should be regarded as integral to all aspects of palliative care wherever, and whenever, they are delivered.

All health and social care workers have a role in contributing to psychosocial care by compassionate communication and by recognizing that patients and their families have psychological and social needs[1]. This requires an ability to ask people how they *feel* in both a physical and emotional sense, paying close attention to both their verbal and non-verbal responses. Regular assessment of psychological and social needs will enable concerns to be raised and indicates to patients that staff are interested in all aspects of their lives, not just their disease. For patients who present with complex or long-standing psychological or social problems, referral to specialist workers such as psychologists, social workers, or counsellors might be desirable, although it is acknowledged that these professionals may not be readily available in all settings.

Dying and death are not only biological processes wherein the human body ceases to function, but also a social process of letting go of treasured relationships and roles by the dying person and by family, friends and staff around them. Every person's death will be different, reflecting who they are, their medical conditions, their social circumstances and family supports, their cultural milieu, and their values and preferences about care. For the purposes of this chapter, we define dying as the time when people become aware of death as a possible out-

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1. National Institute for Health and Clinical Excellence (2004). Improving supportive and Palliative Care for Adults with Cancer. The Manual. London: NICE. Available at: http://www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf Last retrieved: March 10, 2015.

come and the periods immediately before and after the physical death of a person, so it may be extended over many months or even years, rather than just the final days and hours of life.

Arguably, there is more research evidence in psychological care but there is emerging attention to social care.

COMMUNICATION

TALKING AND LISTENING

Being able to optimally communicate is a basic and essential skill or competence for all people working with patients and family members in palliative care, not only for specialists working in specialist palliative care services but also for all physicians and other health care professionals from all disciplines as part of their basic palliative care skills. Good communication is the cornerstone of high quality palliative care, using empathy, compassion, and listening skills, ensuring that information is integrated comprehensively and coping is optimized[2].

Communication in palliative care can include several domains covering the whole illness trajectory from diagnosis (or even earlier) to the terminal phase. It is important for patients as well as their families or close caregivers, and is relevant in all settings of care. It encompasses talking and listening skills in several domains[2]:

- the delivery of bad news concerning diagnosis or prognosis, and communication of risks;
- information gathering and exploration of physical, psychosocial, and existential/spiritual needs, and of preferences/wishes;
- providing advice, discussing difficult decisions, sharing decision-making and goals of care discussions including advance care planning;
- relationship building and responding to difficult emotions;
- doing so in a culturally sensitive way.

Moreover, communication involves dyadic exchanges between professionals (doctors, nurses and other health or social care professionals) and patients or family members/caregivers, but also includes the difficult exchanges (verbal and in writing) between different professionals from the same or other disciplines.

2. Kissane DW, Bultz BD, Butow PM, Finlay IG. *Handbook of Communication in Oncology and Palliative Care.* Oxford University Press, 2010.

SKILLS AND TRAINING

If communication is to be effective, the education of health care professionals is necessary. Communication skills can be improved by training. They do not improve with experience "on the job" alone, but evidence-based training programs can effectively improve communication skills. This was recently confirmed by a Cochrane review on communication skills training in cancer[3].

Several models of communication have been described in the literature over recent years and used as conceptual frameworks for communication skills training, e.g., the Bayer Institute for Health care Communication E4 Model, the Calgary-Cambridge Observation Guide, the Comskil model, Oncotalk[3]. It is, however unclear which programs are most likely to work, what are the most effective components of an effective communication skills training, or how long communication skills training is needed to ensure a sustainable effect. Nevertheless, important characteristics of effective teaching seem to include having engaged experienced trainers, teachers, facilitators, and role models, and applying learner-centred, experiential, adult education methods, preferably in small groups using role-play and stimulating self-reflection[2].

For optimal communication skills in palliative care to be integrated into the basic skills set of any physician, nurse or other health care provider, it will be necessary to integrate these competencies more explicitly into the core curricula of these disciplines, not just as a separate course, but fully integrated into all years and levels of education. Following undergraduate education, postgraduate continuing education should also include communication in palliative care as a basic generic competence. Didactical techniques should reach far beyond the usual presentations or lectures that are still part of education in many countries and have proven not to influence professional behaviour, and include interaction and self-directed reflective and life-long learning.

PSYCHOLOGICAL SUPPORT

People approach challenges in life with a wide range of responses, which are linked to their inherent and learned psychological strengths and vulnerabilities. These challenges occur in contexts and environments that may offer more, or

3. Moore PM, Mercado RS, Artigues GM, Lawrie TA. Communication skills training for health care professionals working with people who have cancer. *Cochrane Database of Systematic Reviews* 2013, Issue 3. Ar No : CD003751. DOI :10.1002/14651858.CD003751.pub3.

less, support. Emotional suffering is common among patients adjusting to advanced chronic life-limiting conditions, and psychological distress is natural when an individual is confronted with the knowledge of impending death[4]. The end of life often involves a great deal of psychological pain in regard to loss and grief, anxiety about dying, worries about dependency, and what will happen to the family members after the loss, as well as feelings of powerlessness and hopelessness about the future and other aspects. These reactions can adversely affect treatment compliance and the experience of pain and quality of life and even steal away the sense of meaning and purpose and undermine the ability to connect with loved ones. Psychological support is an integral part of palliative and end-of-life care provision in order to alleviate these painful reactions.

Psychological distress and emotional suffering can range from sadness and a sense of vulnerability to severe symptoms of distress that interfere with quality of life and daily functioning. Psychological distress is likely to be multifactorial and vary according to disease progression, the number of physical symptoms, and the number of limitations the individual experiences. Personal vulnerabilities and previous mental health problems are also likely to play an important role in the severity of psychological distress, as well as lack of emotional support from one's personal network. The individual's coping strategies, i.e. active and targeted attempts to cope with the disease and its impact on the person and on daily life, also play an important role in adjusting to the challenges of terminal illness. Yet, coping strategies are receptive to suggestions and interventions and this has been known to enhance adjustment.

ASSESSMENT

To alleviate psychological distress, it is generally recommended that comprehensive assessments of psychological support needs are provided on a regular basis throughout key points in the disease trajectory[4]. For instance, when moving from curative-focused treatment to palliative care. Assessment can be based on a dialogue with the patient about psychological distress. Patients with significant levels of psychological distress should be assessed with a diagnostic instrument to test whether they meet the diagnostic levels of a psychiatric illness such as adjustment disorder, anxiety and depression, and should be referred to a mental health professional for clinical assessment, medical treatment, and psychotherapy[1].

4. Vachon MLS (2010). The emotional problems of the patient in palliative medicine. In: *Oxford Textbook of Palliative Medicine*, 4th Ed. Geoffrey Hanks, Nathan I. Cherny, Nicholas A. Christakis et al. (eds.) Oxford University Press, New York.

INTERVENTION

The appropriate psychological intervention will depend on the nature and severity of the person's psychological distress, his or her previous history with psychological problems, the availability of social support and disease prognosis[5]. In practice, assessment and communication about psychological distress is in danger of being overlooked and under-prioritized by health care professionals. But psychological well-being is likely to be enhanced if professionals are adequately trained and supervised in communication about emotional suffering and how to alleviate psychological distress[1].

It has been shown that supportive and compassionate communication with the dying person about psychological symptoms increases adjustment and can prevent further suffering[6]. All staff in palliative and end-of-life care should be able to offer patients general emotional support based on skilled communication, effective provision of information, compassion, and respect[1]. Psychological support entails listening to the patient and his/her worries and emotional distress, normalizing reactions, and offering supportive and appreciative communication. Furthermore, alleviating distress can involve specific psychological techniques to facilitate coping and problem solving. Challenges and worries are identified to work towards goal-oriented possible solutions. Professionals can even offer suggestions of coping strategies for the most common symptoms. The new strategies are tested in daily life and evaluated and adjusted in a follow-up session to optimize coping and well-being. Some illnesses may result in difficulties such as dementia. In these cases, it is important to develop new understandings and ways to communicate that do not rely solely on verbal exchange.

PSYCHOLOGICAL AND PSYCHIATRIC INTERVENTIONS

People with life-limiting conditions are at greater risk of psychological distress. Distress in these circumstances derives from dire prognostic expectations, underlying medical complications and various emotional and existential challenges related to death and dying. Quality comprehensive palliative care requires that health care professionals be familiar with and attentive to these issues.

5. Breitbart W, Chochinov HM & Passik SD. Psychiatric symptoms in palliative medicine. In: Hanks G, Cherny N, Christakis N, Fallon M, Kaasa S & Portenoy R (2010). *Oxford Textbook of Palliative Medicine* (4th edition). New York: Oxford University Press.
6. Adams MP & Urban CQ (2013). *Pharmacology, Connections to Nursing Practice*. Upper Saddle River, New Jersey: Pearson.

That includes the ability to recognize common manifestations of distress, and to apply effective psychological and psychiatric interventions.

Anxiety, generally described as a feeling of tension, fear, or helplessness, is common amongst patients nearing death. While sadness is a normal part of the grief experience people go through as they anticipate the end of life, some develop more severe depression associated with low mood, loss of interest, hopelessness, and suicidal ideation. Persistently significant anxiety and depression may lead to a desire for hastened death and undermine quality of life; therefore, early detection and management are essential. While symptoms of depression can sometimes replicate coexisting somatic symptoms, diagnostic accuracy can be enhanced by combining careful clinical assessment with screening tools and applying diagnostic criteria. Decisions regarding treatment for anxiety and depression should be based on combined consideration of meeting diagnostic criteria, clinical judgment, and the severity, frequency, and number of symptoms[5].

Depression and anxiety may be treated with pharmacotherapy, counselling and psychotherapy, complementary therapies, or a combination of these. However, it is important for health care professionals to recognize that treating patients as whole persons, providing reassurance, being present and supportive, addressing patients' concerns and offering choices are absolutely critical. Whatever the nature of the patient's distress, this supportive, compassionate approach is the mainstay of effective, quality palliative care, as explained above.

Pharmacological therapy is an important option, especially in the treatment of moderate and severe levels of psychological distress. Refer to general psychiatric guidelines for treatment of common disorders such as anxiety and depression. For patients with mild or moderate psychological distress, those having concern about coping or with insufficient social support, counselling can be a good choice. There are various models of counselling, which can be offered individually or within groups. Short-term interventions such as problem-solving therapy, supportive psychotherapy or cognitive-behavioural therapy are preferable in palliative care, due to the patient's poor health status and limited prognosis. Other models of counselling can be useful, but further evidence to support their application is needed.

COUNSELLING

Before initiating counselling, a thorough clinical assessment should be done, including a psychosocial history, mental state examination, and exploration of the cause of or predisposition to distress. Delivery of counselling, including the number, frequency, and duration of sessions, location and format of treatment, should be flexible, depending on the stage of illness and medical status. To

ensure the effectiveness of any counselling, common therapeutic factors should be remembered. These include establishing a strong and trusting relationship, active listening, encouraging the sharing of emotions, venting of concerns, a respectful and non-judgmental manner, and providing support.

Individual psychotherapeutic interventions are optimally initiated in patients with no cognitive impairment or severe physical distress[7]. Interventions such as relaxation therapy, guided imagery and hypnosis and cognitive behavioural therapy can be used to reduce physical and psychological distress. Goal-setting, problem-solving, and supportive therapy are helpful in promoting active coping and decision-making. Meaning-centred therapy, narrative therapy and dignity therapy can bolster patients' sense of meaning and purpose at the end of life. Undertaking individual psychotherapy should always be done with sensitivity to the individual's background, values, religion, culture, and ethnicity[8].

Group interventions for terminally ill patients are usually focused on social support, emotional ventilation, education, cognitive restructuring, and stress reduction[8]. Examples of group interventions include supportive-expressive group psychotherapy, psycho-educational group therapy, meaning-centred group psychotherapy, and cognitive-existential group psychotherapy. To ensure the effectiveness of group interventions, therapists need to be well-trained, with broad knowledge and sufficient skills so that the benefits of treatment can be maximized and negative outcomes avoided. Complementary therapies are sometimes used in palliative care to mitigate distress, either in conjunction with other therapeutic approaches or as stand-alone interventions. These may include massage, progressive muscle relaxation, guided imagery, meditation, music therapy, and aromatherapy. While an evidence base for some of these approaches is still limited, they can be beneficial for selective patients and should be applied and evaluated on a case-by-case basis.

In summary, management of anxiety and depression, along with other psychosocial distress, is essential in the delivery of optimal, quality palliative care. Therapeutic approaches may include pharmacological therapy, counselling, psychotherapy, and complementary therapy. Whatever approach is taken, it should be tailored to the specific needs and preferences of the patient and family, and delivered by well-trained, competent health care professionals. Compassionate responses to distress are a critical element of palliative care, ensuring that patients achieve optimal symptom relief and the best quality of life possible.

7. Rodin G. Individual psychotherapy for the patient with advanced disease. In: Chochinov HM & Breitbart W (2009). *Handbook of Psychiatry in Palliative Medicine*. New York: Oxford University Press.

8. Spiegel D & Leszcz M. Group psychotherapy and the terminally ill. In: Chochinov HM & Breitbart W (2009). *Handbook of psychiatry in palliative medicine*. New York: Oxford University Press.

SOCIAL SUPPORT

Comprehensive assessment of social support needs is a cornerstone of holistic palliative and end-of-life care provision. Some core principles underpin the approach that workers should adopt in engaging with this task. These include an understanding that needs are contextualized and specific to the individual concerned within their particular family and social network. A second principle is that of self-determination. It is essential to acknowledge that the individuals will know best what their needs are and, in many cases, what solutions will work in their unique circumstance. Assessment needs to be flexible and responsive to changes in the sick person's needs and circumstances[9].

People with progressive, life-limiting illness, wherever they may be, lose social capital. They may be unable to work, and roles within family and social networks shift and change as the illness takes hold. Workers need to enable the sick person to adjust to changes in their social positioning and to find new roles and activities that sustain or improve quality of life. Part of this task might include finding ways to help people reconnect with social networks when these have been disrupted by illness processes. Another focus for workers should be to enhance and build on the capacity for resilience that is recognized as a feature of the lives of many people facing adversity. Resilience, in this sense, can be considered at the levels of individual, family, and community.

It is important to realize that in working to improve social support, other people connected to the sick person: family, friends, neighbours, faith leaders, community elders - and others - need to be considered. The central task here is to galvanize those elements of the social network which may have fallen away in the face of serious and progressive illness. Fear and uncertainty are common reactions and these need to be countered in sensitive but bold ways by workers seeking to help. In places where resources are limited, more formalized community networks have had very positive effects in reducing isolation and responding to need[10].

It should be remembered that a person with incurable illness may nonetheless have many months or even years to live. Illness, in itself, does not mean that a person becomes wholly unproductive and dependent within their family and community. Where possible, workers should engage local enterprises and employers to consider how they might provide useful and purpo-

9. Hughes S, Firth P & Oliviere D. Core competencies in palliative care social work in Europe: an EAPC White Paper – part 2. *Eur J Palliat Care.* 2015;22 (1):38-44.
10. Kumar S K. Kerala, India: A Regional Community-Based Palliative Care Model. *J Pain Symptom Manag.* 2007;33 (5):623-627.

seful occupational activity within the constraints of episodic and progressive illness.

For those no longer able to financially support themselves and their families, workers need to be thoroughly familiar with statutory, charitable, and other sources of funding and how to access these. Illness leads to increased costs just at the time when income may drop or cease. Providing some financial security - where this is possible - is a vital component of holistic care provision. Removing or ameliorating financial worry enables people with progressive illness to focus on relationships, on quality life experiences, and on adjusting to and preparing for the future.

Providing comprehensive social support to someone facing increasing illness and the prospect of death is as important as other aspects of physical, psychological, and spiritual care. It has a ripple effect in family and community networks, can significantly enhance these relationships, and facilitate better adjustment for bereaved family and friends when death ultimately occurs.

FAMILY CAREGIVERS

ASSESSMENT

Support for family caregivers is a core aspect of palliative care provision. Family caregivers can be defined as the relative, friend or partner who has a significant relationship and provides assistance (physical, social, and/or psychological) to a person with a life-threatening, non-curative illness[11].

There are multiple reasons why family caregivers should have their needs assessed and be offered psychosocial support. A summary of these reasons is outlined in Figure 1.

It is vital (and indeed policy in many countries) that the family caregiver's needs are assessed and an appropriate care plan developed and reviewed. Here are some recommended strategies for assessment and care planning:

- Ask the patient to identify the primary family caregiver. Where only one family caregiver is identified, ask the patient if there is another key person who may be willing to be approached and act as an additional family caregiver. Discuss the patient's preferences for the involvement of the family caregiver in medical and care planning discussions and note this

11. Hudson, P., et al. (2012). Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *J Palliat Med.* 2012;15(6):696-702. (DOI: 10.1089/jpm. 2011.0466).

in the medical record/care plan. Family trees and genograms can be effective methods of capturing a patient's close relationships, extended family and networks of support.

Figure 1. Reasons why family caregivers should be offered support

(1) Family caregivers typically have unmet needs and problems. Caregivers:
- Are prone to physical and psychological morbidity. Approximately 50% of caregivers are below population norms on physical health, and rates of potential depression and anxiety of between 30- 50% have been reported.
- Are responsible for numerous tasks, such as symptom management.
- Are financially disadvantaged.
- Become socially isolated.
- Report unmet needs (typically aligned with lack of information about the caregiver role).
- Have needs equal to and/or greater than the needs of patients.

(2) Confounding factors impact upon the caregiving role:
- Caregivers may have very limited first-hand exposure to death and dying.
- Caregivers are often excluded from information and care planning and consequently feel under-prepared for their role.

(3) Caregivers have the potential for positive outcomes and gains. Caregivers:
- Have the potential (with suitable support) to gain positive outcomes from the role.
- Are pivotal to achieving 'successful' home care (in the setting where most people prefer to die).
- Make a remarkable economic contribution to health care.
- May significantly enhance the well-being of patients when they are well supported.

Adapted from Hudson & Payne, 2012[1]

1. Hudson, P & Payne, S Family Caregivers and palliative care: Current status and agenda for the future. *J Palliat Med.* 2011;14(7):864-9.

- Confirm with the family caregiver(s) that they understand the patient has nominated them for this role. Explain the typical role and responsibilities of 'family caregiver' and discuss any concerns that the family caregiver may have in accepting this role (including possible conflicts with other family members).
- Explain to the family caregiver(s) what services and resources can be provided by the palliative care service (and more broadly) so that realistic expectations are established.
- Seek permission from the family caregiver to conduct a holistic needs assessment. Offer to meet with the family caregiver(s) alone to undertake this, as many family caregivers do not feel comfortable raising their concerns in front of the person they are caring for. Such discussions can provide an opportunity to ask important questions like, 'How are things for you at the moment?' 'What are your main concerns?' and 'What would be most helpful to you?'

- Based on discussion with the family caregiver(s), determine the current state of and risk for poor psychological health and/or prolonged grief and plan relevant intervention(s).

ROLES AND RELATIONSHIPS

Some families may have less-than-optimal relationships; consequently barriers to effective communication within the family and with health and social care professionals may arise. Patients' needs and expectations may not be congruent with family caregiver(s). This makes it difficult for health and social care professionals to determine whose needs take priority. Cultural and spiritual aspects also need to be considered.

Some family caregivers take on the role not because they want to but because they feel obliged to do so. Family caregiver roles may also vary. For example in some situations a family caregiver may act as the main 'hands on' support person as well as spokesperson for the family and main point of contact for health professionals. In other situations these roles may be shared amongst other family members and may change.

INTERVENTIONS

Once the caregivers' needs are assessed, develop a plan of action to provide optimal support. This plan of action should be a part of the overall Interdisciplinary Team Plan of Care. Support for family caregivers may incorporate practical, educational, psychological, spiritual, financial or social strategies (based on unmet needs) and a desire by the caregiver(s) for assistance, with the intention of enhancing the caregiver's capacity to undertake their role, respond to its challenges and maintain their own health (before and after their relative/friend's death).

A 'one size fits all' approach to family caregiver support is not appropriate. However common expectations that caregivers have include:

1. Information about what to expect as a caregiver (in written format as well as verbally);
2. The patient's symptoms controlled;
3. Assistance to prepare for death;
4. Patient will die and be cared for in a place of their choice;
5. Treatment decisions respected;
6. Cared for compassionately as unique individuals; and
7. Bereavement support.

Recent reviews of interventions and guidelines for family caregivers have highlighted the following as potentially useful examples of strategies for caregiver support:

- Provision of psycho-educational support (individual or group) to prepare family caregivers for their role;
- Establishment of advance care directives;
- Access to 24/7 advice;
- Conducting a family meeting to confirm goals of care and site of care options;
- Assisting the family caregiver(s) in how to recognize signs that death may be imminent and the potential implications for the patient's care requirements;
- Enhancing problem-solving through specific sessions;
- Individual and family counselling as well as caregiver support groups;
- As soon as practical after the patient's death, a member of the interdisciplinary team should contact the family caregiver(s) to offer condolences and respond to queries;
- Develop a preliminary bereavement care plan based on the needs of the family caregiver(s), pre-death risk assessment, and the circumstances of the death (e.g. unexpected or traumatic).

BEREAVEMENT SUPPORT

Bereavement is a painful and challenging part of human experience, requiring immense adjustment for individuals and families. Bereavement can have psychological, emotional, practical, physical, and spiritual dimensions and is a process engaged in over time. 'Stage' models of grief (which suggest specific steps or phases) are no longer recommended, with the emphasis instead on the dynamic processes of grief. Most people, with the help and support of others, go on to develop a new life and a new reality without the person who has died. Smaller proportions of people (around 10%) may experience debilitating symptoms of grief which persist over time – a diagnostic condition labelled 'complicated' or 'prolonged' grief.

Bereavement care, arguably an important part of all health care, is a central and explicit aspect of palliative care. Palliative care extends to those who are important to the patient by assuring the family that everything that can be done is being done and by considering family welfare as explained above.

The excellent symptom control, holistic care and communication that make

up palliative care can be viewed as having a beneficial impact on relatives', friends' and partners' futures and in this way making up the first layer of bereavement care. Basic or 'universal' bereavement care can also be provided in normal interactions with friends or others concerned and takes the shape of practical help, a listening ear, and accurate information about loss.

Some bereaved people may require extra support because they are deemed to be more at risk, or identify themselves as being less well resourced. Access to group support, community befriending services, and one-to-one support sessions meet these needs. Finally, the small proportion of people who develop complicated or prolonged grief must have access to specialist psychotherapeutic grief therapies, which have been demonstrated as effective.

Figure 2 summarizes the approaches to bereavement care in palliative care using the language of public health approaches (as opposed to disease models). It also links to the evidence-based guidance from the UK National Institute for Clinical Excellence[12] for bereavement care in palliative and supportive care. A set of bereavement support standards developed in Australia provides further guidance on detailed service.[12]

Figure 2. A framework for bereavement care in palliative care (adapted from Aoun et al.[1])

Level public health	NICE Level/ component	Type of support	Provided by	Target population and level of need
Universal or Primary	1	Information about bereavement and relevant supports	Family and friends (information supplied by health and social care professionals)	All bereaved (normal grief) Low level of need
Selective or Secondary	2	Non-specialist support	Trained volunteers, mutual-help groups, community supports	Those at-risk of developing complex needs Medium level of need
Indicative or Tertiary	3	Professional specialist interventions	Mental health services, bereavement services, or psychotherapy	Those with complex needs High level of need

1. Aoun, S. M., L. J. Breen, et al. A public health approach to bereavement support services in palliative care. Aust N Z J Public Health 2012;36(1):14-6.

12. Hall C, Hudson P, Boughey A (2012), *Bereavement support standards for specialist palliative care services*. Department of Health, State Government of Victoria, Melbourne.

Making decisions about the type of care required by bereaved people is an important feature of palliative care teams' activity. In practice this involves information from a number of sources, a formal risk assessment or bereavement needs assessment form and the opinion of members of the team, remembering that the family members' themselves form part of that team. The range of instruments used for assessing bereavement need have been reviewed by Agnew et al[13].

INTERNATIONAL EXAMPLES

Apart from the hospice model of management of volunteers, two models of community engagement are described in this short description of community engagement.

South Africa - The Integrated Community-based Home Care model[14] provides palliative care in a person's home through the use of trained community care workers supervised by a professional nurse with a strong network of community organizations including the local clinic and district hospital. This model empowers family members and neighbours to cope in caring for patients at home, relieving the health system of the burden of care.

India - The Kerala Neighbourhood Network in Palliative Care (NNPC)[15] is a community-led initiative that recognizes the need for a different model of care when caring for people with chronic and incurable diseases different as opposed to acute illnesses[16]. There is both coverage – good access to palliative care in the home - and quality. Doctors and nurses provide clinical care and trained volunteers provide psychosocial support. Community ownership also applies to funding with people in the community donating few rupees at a time and collection boxes sited in shops and bus stations. There is good media and political support for the program. The NNPC has received attention from palliative care services in the UK and the model has been adapted to the first world setting at Weston Hospice care in Somerset, UK[17].

13. Agnew, A., R. Manktelow, et al. Bereavement needs assessment in specialist palliative care: a review of the literature. 2010; *Palliat Med* 24(1): 46-59.

14. Defilippi, Kathleen M., and Sue Cameron. "Promoting the integration of quality palliative care—the South African mentorship program." *J Pain Symptom Manage* 2007;33(5):552-557.

15. Kumar S K Kerala, India: A Regional Community-Based Palliative Care Model. *J Pain Symptom Manage* 2007;33 (5) 623-627.

16. Sallnow, Libby, Suresh Kumar, and Mathews Numpeli. "Home-based palliative care in Kerala, India: the Neighbourhood Network in Palliative Care." *Prog Palliat Care* 2010;18(1):14-17.

17. Abel, Julian, et al. Compassionate community networks: supporting home dying. *BMJ Support & Palliat Care* 2011;1(2):129-133.

CONCLUSIONS

The chapter ends by summarizing a few key points for health and social care professionals in delivering psychosocial care.

PSYCHOLOGICAL AND EMOTIONAL CARE

Patients and family members face a range of issues that are not only related to illness and approaching death. All health professionals can offer patients an opportunity to express their concerns. Staff should also learn how to assess their patients' strengths and coping styles, their previous experiences, life goals, and concurrent stress. There are simple-to-use, standardized measures that can be used to screen patients, but they should always be followed by more detailed clinical assessments and open conversations. If psychological distress is identified, the patient should be referred to appropriate types of support and offered intervention. It should not be assumed that depression, anxiety, or overwhelming sadness is a normal part of dying and that nothing can be done to improve the remaining quality of life. Towards the end of life, most patients are very aware they are near to death; for the majority this may be welcomed and they may want to talk about death and dying. In such circumstances it is often the staff who need the courage not to cut short these conversations. A few people will be frightened; the challenge then is for you to try and help the person express their fears and offer support.

SOCIAL CARE

Early on, social care may involve exploring the relationships that are important to the patient; a genogram might be a helpful way to record this information. In addition, the roles that are important to the patient such as being a parent, a spouse, a care-provider of another, and a worker earning income to support the family can be acknowledged. It is helpful to consider how transitions in these roles can be managed, the impact of role changes on family income, stability, and support for dependents like children or older parents. The degree of social care available from other family members, the community, or statutory sources will vary by country, region, and political and economic environment. Some people may be very isolated because they are refugees, or socially marginalized, and therefore lack the normal family support systems. During the dying phase, the patient may pay less attention to things around them. However, family, grandchildren, and very close friends remain important. Relatives can be helped to be made aware that their family member is dying, so an opportunity is given to say 'goodbye', if this is culturally appropriate.

Some families feel awkward, and do not know what to say or how to visit if the patient is in hospital. Sitting and chatting with them at the bedside, giving them permission to just sit and read a newspaper, or listening to the radio or television while holding their family member's hand, may enable them to visit for longer. It has even been observed that a dying person will sometimes wait for the arrival of a specific person before 'letting go'. A time of 'waiting' can be difficult for all people involved including the family, especially if goodbyes have been said and there is certain expectancy about the death. However, such a time can be used to involve and get to know the family and to remember about times passed and significant events together. If a patient does not have any family or friends available, nurses can provide reassurance and support by remaining near them, using touch such as stroking or holding their hand, even when they appear to be unconscious.

FURTHER RECOMMENDED READING

Hudson P and Payne S (ed.) *Family Carers in Palliative Care.* Oxford University Press, Oxford, 2008.

Lloyd Williams M (ed.) *Psychosocial issues in Palliative Care*. 2nd edition. Oxford University Press: Oxford, 2008,

5
SPIRITUAL CARE AS AN ESSENTIAL COMPONENT OF PALLIATIVE CARE

Christina Puchalski, Robert Vitillo, Najmeh Jafari, Richard Bauer, Shane Sinclair

KEY POINTS

- Spiritual care is an essential of palliative care utilizing an inclusive and broad consensus –based definition.
- Several international consensus conferences have developed recommendations for the integration of spiritual care into palliative care in diverse health settings.
- Spiritual screening or history should be a routine part of a comprehensive clinical assessment, including the diagnosis and identification of spiritual distress and suffering, and spiritual resources of strength, and that screening should be integrated into the whole person assessment and treatment or care plan.
- Provision of spiritual care is the responsibility of all members of the clinical team; the team should also include professional, board-certified spiritual care providers.
- Several tools for spiritual assessment are being tested; currently work is being done on the development of evidence-based tools and interventions in spiritual care in palliative care.
- Spiritual care models, tools and training programs should be developed in ways that include the religious, philosophical, existential, and cultural aspects of the target population.
- Models and training programs should be developed for diverse health settings including hospitals, hospices, primary palliative care and community.

INTRODUCTION

Cicely Saunders, the founder of the modern hospice and palliative care movement, described the concept of *total pain* as physical, emotional, spiritual and social pain, a concept which she promoted throughout her lifetime[1]. More recent work has identified spiritual distress as a clinical diagnosis and spirituality as an inner resource of strength for patients, both of which should be included in the treatment plan[2]. Thus, the World Health Assembly's identification of spiritual care as an equal and full component of palliative care is a most welcome development in the field of spirituality and health.

Empirical evidence, patient and family experience and theoretical frameworks support the critical role spirituality plays in the care of patients, particularly those with chronic and complex illness. In addition, there is increasing evidence that interventions addressing patient spiritual issues can improve pain management[3] and improve patients' and family spiritual well-being and hence quality of life[4].

Several consensus conferences have concluded that suffering, psychosocial and spiritual pain must be attended with the same intensity as relief of physical pain[5]. These conclusions were based on evidence that spiritual care is a fundamental component of quality health care and that this aspect of care is most effective when it is recognized and reflected in the attitudes and actions of both patients and health care providers.

DEFINITION OF SPIRITUALITY

There are many definitions of spirituality considered by health-related disciplines. In a clinical context, however, several consensus-derived definitions have been developed by experts at national, regional, and global conferences[6].

1. Clark D. Total pain: The work of Cicely Saunders and the hospice movement. *American Pain Society Bulletin*. 2000;10(4):13-15.
2. Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *J Palliat Med*. 2009;12(10):885-904.
   Jacobsen PB, Ransom S. Implementation of NCCN distress management guidelines by member institutions. *J Natl Compr Canc Netw*. 2007;5(1):99-103.
3. Siddall PJ, Lovell M, MacLeod R. Spirituality: What is its role in pain medicine? *Pain Medicine*. 2014.
4. Sun V, Kim JY, Irish TL, et al. Palliative care and spiritual well-being in lung cancer patients and family caregivers. *Psycho-Oncology*. 2015.
5. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: Reaching national and international consensus. *J Palliat Med*. 2014;17(6):642-56.
6. Nolan S, Saltmarsh P, Leget C. Spiritual care in palliative care: Working towards an EAPC task force. *EJPC*. 2011;18(2):86-89.

All of these were centered on finding meaning, purpose, and connectedness. An additional definition was further developed at a global conference, with participation from all regions of the world. It was expressed as follows:

- Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices[5].

The key characteristic of the latter definition is that it is broad and inclusive of the many relationships and aspects of spirituality that can be found in different cultures and societies. Additionally, it is centred on the clinical application of spirituality. Moreover, it is based on the presumption that everyone has spirituality, an inner life, that involves searching for meaning and purpose and connectedness to the significant or sacred, and that search can be impacted by illness, death and dying. This definition was designed in a way to help clinicians understand that spirituality encompasses all forms of beliefs and meaning in the lives of all engaged in the clinical process, patients, family members, and health care professionals.

The European Association for Palliative Care (EAPC) cited the multi-dimensional nature of spirituality and listed the following dimensions of the spiritual field:

- Existential questions (concerning, for example, identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy);
- Value-based considerations and attitudes (that is, the things most important to each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself);
- Religious considerations and foundations (faith, beliefs and practices, one's relationship with God or the ultimate)[6].

PALLIATIVE CARE GUIDELINES AND PREFERRED PRACTICES

In the United States of America, the first clinical practice guidelines for palliative care were developed and continue to be used as a standard by specialist-level palliative care for a wide range of treatments. The guidelines address eight domains

of care: structure and processes; physical aspects; psychological and psychiatric aspects; social aspects; spiritual, religious, and existential aspects; cultural aspects; imminent death; and ethical and legal aspects. This is significant since spiritual, religious, and existential aspects constitute a required domain of care equal to the other domains. These practices are evidence-based or have been endorsed through expert opinion and apply to both hospice and palliative care.

The updated 2013 National Consensus Project Guidelines[7], utilizing work from prior Consensus Conferences, identified the following Preferred Practices:

- Develop and document a plan, based on *assessment of religious, spiritual, and existential concerns* using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan;
- Provide information about the availability of spiritual care services and make *spiritual care available* either through organizational spiritual counselling or through the patient's own clergy relationships;
- Specialized palliative and hospice care teams should include *spiritual care professionals appropriately trained and certified* in palliative care;
- Specialized palliative and hospice spiritual care professionals should build *partnerships* with community clergy, and provide education and counselling related to end-of-life care.

Another model of palliative care was introduced by *La Caixa* Foundation in collaboration of the World Health Organization (WHO) in Spain. The proposed model "Comprehensive Care for Patients with Advanced Illnesses and their Families," consists of implementing Psycho-social Support Teams (PSTs), with the aim of improving the psychosocial care of terminally ill patients (and their families) with a special focus on spiritual aspects. The support of the health care professionals in existing palliative care services is also addressed. The preliminary evaluation results of this model showed that PST is effective in improving the psychosocial and spiritual aspects of care of patients in palliative care settings, and their families[8].

In another effort, the Spanish Association for Palliative Care (SECPAL) formed a Task Force on Spiritual Care (Grupo de Espiritualidad de la SECPAL [GES]), to design a conceptual framework for addressing the spiritual needs of

7. National Consensus Project for Quality Palliative Care. *Clinical practice guidelines for quality palliative care.* National Consensus Project for Quality Palliative Care; 2013.
8. Gómez-Batiste X, Buisan M, Gonzalez MP, Velasco D, de Pascual V et al. The "La Caixa" Foundation and WHO Collaborating Center Spanish national program for enhancing psychosocial and spiritual palliative care for patients with advanced diseases and their families: preliminary findings. Palliat Support Care 2011; 9:239-49.

patients in palliative care settings. This working group has developed strategies to recognize, share, and assess the spiritual needs of palliative care patients, including: 1) developing a spiritual care guideline for the Spanish context; 2) implementing nationwide residential training workshops on spiritual care for clinicians; and 3) developing and validating of GES questionnaire for the assessment and spiritual care of palliative care patients[9].

In India, palliative care professionals are developing guidelines for implementing the inter-professional spiritual care in palliative care and developing educational programs to include all clinicians addressing spirituality with patients, training spiritual care professionals, and addressing models of self-care for clinicians.

The International Work Group on Death, Dying, and Bereavement has also published guidance on spiritual care and existential questions[10]. According to this guideline, most spiritual/existential questions are concerned with the concept of "meaning of life" in the context of an inevitable death. Examples of these questions include:

- Who am I?
- Why do I have to die now?
- What am I doing here?
- What is the meaning of life?
- Why is life so unfair?
- Why do I have to go on living?
- Where do I fit in the world?
- Why does God allow this?
- Is there a meaning in suffering?
- Why do I have to suffer?
- What is the meaning of my life now?
- What has been important to me in my life?
- Is there life after death?
- Will I see my loved ones again?
- Have I made a difference?

9. Benito E, Oliver A, Galiana L, et al. Development and validation of a new tool for the assessment and spiritual care of palliative care patients. *J Pain Symptom Manage*. 2014;47 (6):1008-1018.e1. doi: 10.1016/j.jpainsymman.2013.06.018.
10. Cockburn MM. Assumptions and Principles of Spiritual Care. Death Stud 1990;14:75-81.

SPIRITUAL CARE IN LIMITED RESOURCE SETTINGS

The recommendations in this chapter are focused mainly on palliative care in high resource settings. For limited resource settings they may be aspirational. Delivery of supportive care, including spiritual care, is often a low priority in low- and middle-income settings, and is also dependent on resources available. In 2013, the Breast Health Global Initiative developed key recommendations for breast cancer supportive care program implementation in low – and middle-resource settings[11].

This panel recommended the provision of spiritual care at the basic level of resource allocation. Based on these recommendations, spiritual consideration (through patient-provider dialogue and other appropriate means) and referral to community-based spiritual support should be considered as a fundamental service necessary for any breast health care system to function. They also recommended clinic – or hospital – associated spiritual support, and hospital or hospice spiritual reflection and meditation space at enhanced levels.

MODELS OF SPIRITUAL CARE

Many health systems are based on a biomedical model that treats health as absence of disease and sees the goal of care as cure of the illness. While strong in its emphasis of disease identification and treatment, the model lacked the integration of the whole person-mind, body and spirit. In fact, the Constitution of the World Health Organization refers to health as:

> … a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition[12].

Based on the bio-psychosocial-spiritual model, and models of patient-centred care, a national consensus conference in the USA[2] developed an inter-profes-

11. Cleary J, Ddungu H, Distelhorst SR, et al. Supportive and palliative care for metastatic breast cancer: Resource allocations in low-and middle-income countries. A breast health global initiative 2013 consensus statement. *The Breast*. 2013;22(5):616-627.
12. International Health Conference. Constitution of the World Health Organization. 1946. *Bull World Health Organ*. 2002;80(12):983-984.

sional model of spiritual care. This is a relational model in which the patient and clinician work together in a process of collaborative dialogue, treatment and ongoing evaluation and follow-up. Spiritual issues are categorized as spiritual distress and spiritual resources of strength using the definition referenced above. The model is described for both in- and out-patient settings. It defines certified trained chaplains as the spiritual care experts, with other clinicians serving as spiritual care generalists. Unlike previously described models of health described above, this model includes the potential for clinicians and patients/ families to be transformed or changed through interaction with one another, thus endorsing spiritual or inner life development as part of professional development. The aim of this model is to create a whole-person model of care within the existing biomedical framework as well as to expand it in order to include the humanistic and spiritual aspects of all persons involved in health care-patient, family, clinicians including chaplains and community-based clinical, religious and culturally-based professionals. The model is based on honouring the dignity of all persons and on providing compassionate care through the full integration of spirituality into health systems. The model also calls on the need for interdisciplinary care to help meet all the needs of patients and families.

INTER-PROFESSIONAL APPROACH

## STORIES OF SPIRITUAL CARE MODELS FROM ALL AROUND THE WORLD

The Medical Faculty Associate- George Washington University Outpatient Supportive and Palliative Care Clinic (MFA-GWU SAPC): Example from USA

By Christina Puchalski, MD, Najmeh Jafari, MD, Susan Dohham, BCC, Jen Bires, MSW, Katalin Roth, MD, Vanessa Torres, MDGeorge Washington University Medical Faculty Associates Washington, DC

The SAPC is an interdisciplinary outpatient supportive and palliative care clinic in oncology. The SAPC comprehensively integrates the expertise of a team of health care professionals from different disciplines (e.g. physicians, nurses, chaplains, social workers, art therapists) to address the complex needs of patients. Patients with complex diagnosis and/or symptom management and psychosocial or spiritual distress are referred to the clinic. Using the standard palliative care implemen-

tation model developed by consensus in US and globally (figure 1)[2]. The interdisciplinary team completes a comprehensive assessment including: diagnoses and prognosis; functional status; co-morbid medical and psychiatric disorders; physical and psychological symptoms; social, cultural, and spiritual strengths, values, practices, and concerns; advance care planning concerns; and preferences. Patients are interviewed with the interdisciplinary team and are included with family in the development of treatment plans in a collaborative whole person model of care. Based on this assessment, individualized palliative care services are delivered according to each patient's specific needs. Furthermore, the clinic offers training for clinicians in generalist spiritual care; the chaplain on team provides specialist spiritual care. Data demonstrates improved quality of life, symptom control and improved spiritual wellbeing.

Figure 1. Outpatient Spiritual Care Implementation Model
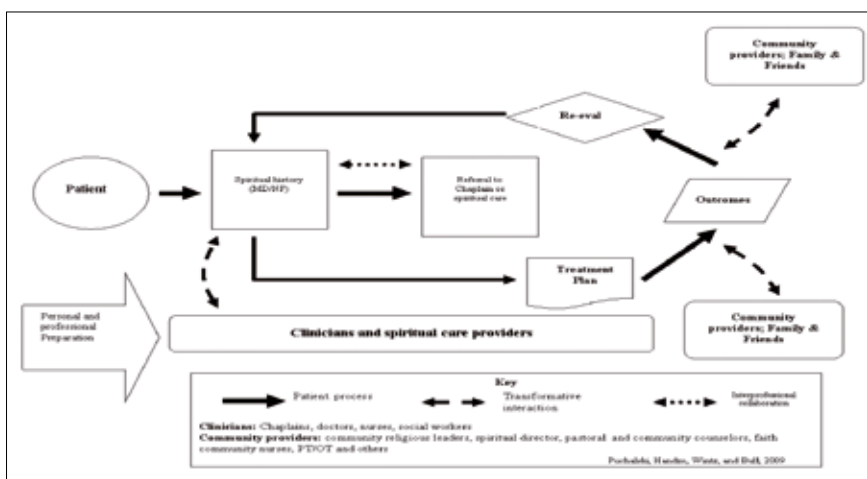
Spirituality in New Zealand hospices

By: Roderick MacLeod, MMedEd, Ph.D. Conjoint Professor in Palliative Care Medicine, Northern Clinical School University of Sidney

One model for understanding Māori health is the concept of 'te whare tapa whā' – the four cornerstones (or sides) of Māori health. These are represented as four equal sides of a house such that if one is weak or damaged in some way a person or family (whanau) may become unbalanced and unwell.

Quite understandably, for many Māori people, modern health services lack recognition of taha wairua (the spiritual dimension). In a traditional Māori approach, the inclusion of the wairua, the role of the whānau (family) and the balance of the hinengaro (mind) are as important as the tinana (physical) manifestations of illness.

The spiritual essence of a person is seen as their life force. This determines who and what we are as people, and where we are going. It is essential therefore when trying to understand physical illness that we examine that wairua or spirit, to determine whether damage here could be a contributing factor.

To address this, Hospice New Zealand, the peak body representing hospices throughout New Zealand worked with Māori to develop the Fundamentals of Spiritual Care. The program consists of a facilitator's guide with a range of teaching ideas and resources for four two-hour face-to-face sessions. Clear objectives for each session are provided to maintain some standards of facilitated learning throughout the country. Evaluations so far have been generally positive.

Pastoral care in South Africa

By: Dr Liz Gwyther
Chief Executive Officer of Hospice Palliative Care Association of South Africa
Chair of the Worldwide Hospice Palliative Care Alliance

The Hospice Palliative Care Association (HPCA) of South Africa's pastoral care course was developed by hospice spiritual care workers in collaboration with prison chaplains in its partnership with the Department of Correctional Services.

The hospice chaplain from St Luke's hospice led on the development of the programme. St Luke's have a strong inter-faith spiritual counsellors group which focus on understanding the patient and family's understanding and experience of spirituality, engaging in faith discussions if led by the patient, to interventions based on religion but also including listening and counselling for patients in their own exploration of meaning regarding their illness, death and dying, as well as the life they have lived and the celebration of their life.

St Luke's hospice chaplain is part of the faculty developing a training course for lecturers at medical and nursing schools to provide understanding of, and materials for, the teaching of palliative medicine in their institutions.

Providing spiritual care at the end of life and helping patients to die well: The African experience in Uganda

By: Eve Namisango
Research Manager at the African Palliative Care Association, Kampala, Uganda.

As we get closer to dying, God, or the external world for those who do not believe in God, speaks to our spirits to come home. So good deaths are important and should be given due attention. As one faces the end of one's life, the greatest gift a person can have is an opportunity to be prepared in body and soul.

For a dying person, the first thing one should do is improve their comfort level. As the body declines, the spiritual domain gains precedence, so spiritual care will give comfort whether one believes in God or not. The dying also have many questions. So they should be listened to and an effort made to answer these questions. Give these people time, be with them, and give them comfort.

It is very important to understand and respect patients' preferences in coping with spiritual distress and departure. Some people want to see relatives and friends around, giving them comfort and strength. Others do not wish them to suffer the pain of watching them die. Forgiveness is another issue that one has to address in providing spiritual care at the end of life. As such, it is important to address the 'forgiveness need' among the dying, to help them forgive and feel forgiven. Where the dying person believes in God, prayer will heal their mind and souls, give them joy and help them to meet the creator when they are ready, happy and prepared.

INTERDISCIPLINARY TEAM CONSIDERATIONS AND TRAINING

The 2014 World Health Assembly resolution, recognized "the existence of diverse cost–effective and efficient palliative care models," acknowledged "that palliative care uses an interdisciplinary approach to address the needs of patients and their families" and noted "that the delivery of quality palliative care is most likely to be realized where strong networks exist between professional palliative care providers, support care providers (including spiritual support and counselling, as needed), volunteers and affected families, as well as between the community and providers of care for acute illness and the elderly."

Members of the interdisciplinary team can include physicians, nurses, social workers, psychologists, & spiritual care professionals along with volunteers and various types of community health workers.

Spiritual care professionals include: Certified chaplains, clergy, community clergy, religious leaders, community elders, spiritual directors, pastoral counsellors, parish nurses, lay religious professionals, culturally-based healers, and other spiritual care providers of diverse religious, spiritual and culturally diverse backgrounds, including humanists, and non-religious leaders.

Palliative care provision needs to involve different professionals working with an interdisciplinary methodology, sharing the assessment of needs, the design of a therapeutic plan, the follow-up, and specific professional interventions. According to the level of complexity and existing resources, the components of the team can be either full-or part-time.

Within an interdisciplinary team-based approach, the key features of collaboration should include: respect for the other team members and understanding the limits of one's own expertise and when to refer to team members with greater expertise in their respective domain of care. All team members adhere to their own professional standards, and many of those standards refer to the entire team, for example, confidentiality. Finally, with regard to spiritual care, there is a need for specific skill training for the generalist spiritual care professional, i.e. physicians, nurses, etc. In countries that do not have trained chaplains, training needs to be developed for spiritual/cultural leaders engaged in providing spiritual care in the health care setting.

While we have described the role and functioning of the professional team, we also should keep in mind that patients and family members are members of the palliative care team. Also that these volunteers, community health workers, and other lay caregivers are important in providing spiritual support and need training. Training programs should be directed for all members of the interdisciplinary teams and in different settings such as hospital, primary care and community.

Interdisciplinary Palliative Care in Germany

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In Germany, spiritual care is mainly provided by chaplains. To accompany the seriously ill and dying has always been an inherent part of pastoral care provided in the main Christian Churches. Nowadays, hospital chaplains are specially trained for delivering spiritual care in the context of death and dying.

In our Clinic for Palliative Care at the University Medical Centre in Freiburg spiritual care has been a crucial discipline of palliative care since the beginning of the idea to implement a palliative care unit. Consequently, hospital chaplains of both religious denominations, Protestants and Roman Catholics, have been part of our palliative care task force founded to develop a concept for a palliative care. Now, our hospital chaplains add to the multi-professional team, take part in our daily multi-professional team conference and have a hand in our team events like retreats or commemorations for our deceased patients. They are also engaged in research and in teaching medical students and doctors. In the clinical setting, they visit every patient irrespective of his denomination. Nevertheless, in our clinic spiritual care is recognized as the task of all occupation groups and our hospital chaplains are glad to support the team members in the process.

ELNEC Project

By: Betty Ferrell, PhD, FAAN
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ELNEC Project

Over the past 15 years we have had the opportunity to teach professionals around the world through our End of Life Nursing Education Consortium (ELNEC) project (www.aacn.nche.edu/elnec) ELNEC has now reached 85 countries and been translated into 8 languages and has prepared over 19,500 professionals to be Trainers

and to share the education with others. Our courses have been held on 6 continents reaching many developing countries and across extremely diverse cultures and spiritual perspectives. We have done extensive teaching in Eastern Europe, interacting with many countries moving from being former Russian states to independent countries and in Asian countries who have in recent decades seem tremendous cultural shifts in now being offered greater religious freedoms. We have also done work in African countries and other cultures where cultural values and beliefs, traditions, healing practices and many rich traditions inform spiritual beliefs in times of illness. Across each of these very diverse countries and populations, spirituality has been a key component of all we teach in palliative care. Whether discussing pain and symptom management, communication issues, care in the final hours of life, or ethical concerns we hear from our international colleagues about the importance of seeing the end of life not as medical failure but as a sacred time of life.

While there are great differences across countries there are vast similarities. Professionals need support in becoming skilled in communication about spirituality and in the ability to do spiritual screening and assessment.

They seek to understand the diversity of beliefs in the people they serve and to honour and respect their spirituality. As I have taught in many of these countries, I often ask participants to describe what happens at the time of death in their countries. I invite them to tell stories of where people die, who is present, how do they are for the boy, how does their family mourn and how they are buried. In telling these stories we hear the deep spirituality of life. We often include rituals in our training such as a blessing of the hands as a way of honouring the spirituality of these caregivers. In every country, we learn much our own spirituality and the shared need to include spirituality in health care.

Palliative Care Team at Santa Monica-UCLA Medical Center

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I'm happy to describe what we're doing at Santa Monica-UCLA Medical Center. Our Palliative Care team consists of the attending MD, the fellow MD, the CNS, the CSW, a dedicated staff chaplain (half-time), a dedicated chaplain resident (full-time), and an administrative assistant. Chaplains are fully integrated and essential team members. Key components of our program include:

- Entire team meets weekly to discuss all patients;
- The team rounds together daily, as able;
- The team uses an acuity level designation from PCQN;
- The team uses the PCQN documentation format to track Palliative Care team interventions and results;
- Chaplains provide spiritual assessments and psycho-spiritual interventions, and co-develop care plans;
- Chaplains initiate and facilitate care conferences with patients, families, and all pertinent disciplines;
- Chaplains provide didactic and reflective education throughout hospital to nursing and medical staff on relationship-based care, cultural humility and sensitivity, and transformative engagement;
- Attending MD and Staff Chaplain co-present at conferences and nursing staff meetings on effective interdisciplinary communication;
- Staff chaplain facilitates Schwartz Center Rounds, a forum for multidisciplinary caregivers to discuss the challenges.

ASSESSMENT OF PATIENTS AND FAMILIES

The interdisciplinary model of spiritual care describes clinical spiritual issues in terms of spiritual distress and spiritual resources of strength. Examples are listed in tables 1 and 2 below.

Communication with patients includes listening to spiritual themes within the patient narrative and/or responding to patients' statements about spiritual, religious or existential issues. But more formal standardized parts of the clinical encounter include conducting spiritual screening and spiritual history by clinicians or a full spiritual assessment by trained chaplains.

Spiritual screening involves a rapid determination of whether the patient is in spiritual complex crisis and thus requires referral to a trained chaplain for an in-depth spiritual assessment and spiritual intervention. Screening is usually done by a clinician, often a nurse, who does the overall intake of a patient. Spiritual screening models are brief and employ one or two questions asked in a context of a general health screening. Examples of such questions include "Is spirituality or religion important in your life" and "How are these resources working for you at this time?" A yes/no answer to these questions would suggest whether referral to a trained chaplain or other spiritual skilled professional is necessary.

SPIRITUAL HISTORY

A spiritual history is integrated into the overall patient history and conducted by a member of the team. The clinician then can make referrals to specialists, including trained chaplains. This history is done in the context of the comprehensive history and examination. The goal of the spiritual history is to invite patients to share information about their spirituality. The patients themselves, however, define what spirituality means to them and explain how spirituality might have an impact on their decisions concerning health care. The information from the spiritual history helps the clinician to identify spiritual distress and/or spiritual resources of strength. The information obtained from the spiritual history is then documented in the patient history section of the chart and is included in the overall assessment and plan for the patient. Examples of clinical spiritual history tools include FICA[13], HOPE, SPIRIT, SECPAL Tool[9], and Domains

13. Borneman T, Ferrell B, Puchalski CM. Evaluation of the FICA tool for spiritual assessment. *J Pain Symptom Manage*. 2010;40(2):163-173.

of Spirituality (used by social workers). Clinicians follow up on spiritual distress or issues just as they do with any other physical and/or psychosocial issues or diagnosis obtained through history and examination.

SPIRITUAL ASSESSMENT

Formal spiritual assessment, conducted by a trained professional or chaplain, refers to a more in-depth process of active listening to the patients' and/or family members' story and discernment of spiritual needs and resources of the patient/family. The chaplain's summary is documented in the patient chart, and includes a spiritual care plan with expected outcomes, which is then communicated to the rest of the team. Chaplains follow up with the patient and evaluate outcomes and spiritual care plan similar to the functioning of other members within the clinical team.

Table 1. Spiritual Diagnosis

Diagnoses (Primary)	Key feature from history	Example Statements
Existential Concerns	Lack of meaning Questions meaning about one's own existence Concern about afterlife Questions the meaning of suffering Seeks spiritual assistance	"My life is meaningless." "I feel useless."
Abandonment by God or others	Lack of love, loneliness Not being remembered No sense of Relatedness	"God has abandoned me." "No one comes by anymore."
Anger at God or others	Displaces anger toward religious representatives Inability to forgive	"Why would God take my child… it's not fair."
Concerns about relationship with deity	Desires closeness to God, deepening relationship	"I want to have a deeper relationship with God."
Conflicted or challenged belief systems	Verbalizes inner conflicts or questions about beliefs or faith Conflicts between religious beliefs and recommended treatments Questions moral or ethical implications of therapeutic regimen Expresses concern with life/death or belief system	"I am not sure if God is with me anymore."

Diagnoses (Primary)	Key feature from history	Example Statements
Despair/ Hopelessness	Hopelessness about future health, life Despair as absolute hopelessness No hope for value in life	"Life is being cut short." "There is nothing left for me to live for."
Grief/loss	The feeling and process associated with the loss of a person, health, relationship	"I miss my loved one so much." "I wish I could run again."
Guilt/shame	Feeling that one has done something wrong or evil Feeling that one is bad or evil	"I do not deserve to die pain-free."
Reconciliation	Need for forgiveness or reconciliation from self or others	"I need to be forgiven for what I did." "I would like my wife to forgive me."
Isolation	Separated from religious community or other	"Since moving to assisted living I am not able to go to my church anymore."
Religious-specific	Ritual needs Unable to perform usual religious practices	"I just can't pray anymore."
Religious/Spiritual Struggle	Loss of faith or meaning Religious or spiritual beliefs or community not helping with coping	"What if all that I believe is not true."

TREATMENT PLANNING – FORMULATION OF A WHOLE PERSON ASSESSMENT AND TREATMENT PLAN

Spiritual distress should be treated with the same level of intensity and priority as psychosocial and physical distress or pain. Thus spiritual distress is identified in the formal assessment of the patient and appropriate treatment should be proposed. Treatment can include referral to the trained chaplain or other spiritual care professional, referral to other treatment options such as dignity-centred care[14], meaning oriented therapy[15], legacy building, guided-vi-

14. Chochinov HM, Kristjanson LJ, Breitbart W, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomised controlled trial. *The lancet oncology*. 2011;12(8):753-762.
15. Breitbart W, Rosenfeld B, Gibson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial. *Psychooncology*. 2010;19(1):21-28.

sualization, mindfulness meditation[16], yoga and other mind-body interventions[17], art therapy[18], journaling among others. Some of these are resources that already may be used by patients and that are identified by them as helpful. These might include a relationship with a specific person, spiritual, religious or cultural rituals or readings or practices. Religious- or culturally-specific interventions, such as scriptural reading or prayer, should not be recommended by the clinician unless patients have already identified them as helpful.

Treatment plans are formulated within the framework of the bio-psychosocial and spiritual model. An example is shown in table 2 below. The spiritual care plan is incorporated into and becomes part of the Interdisciplinary Plan of Care.

As with the biomedical treatment plan, formulation of the spiritual treatment plans is based on issues and goals determining and implementing appropriate spiritual interventions.

Table 2. Examples of Spiritual Health Interventions

Therapeutic Communication Techniques	■ Compassionate presence ■ Reflective listening, query about important life events ■ Support patient's sources of spiritual strength ■ Open-ended questions to illicit feelings ■ Inquiry about spiritual beliefs, values and practices ■ Life review, listening to the patient's story ■ Continued presence and follow-up
Therapy	■ Referral to spiritual care provider as indicated ■ Guided visualization ■ Progressive relaxation ■ Breathing practice or contemplation ■ Meaning-oriented therapy ■ Use of story telling ■ Dignity-conserving therapy
Self-Care	■ Massage ■ Reconciliation with self or others ■ Spiritual support groups ■ Meditation ■ Sacred/spiritual readings or rituals ■ Yoga, Tai Chi ■ Exercise ■ Art therapy (music, art, dance) ■ Journaling

16. Marchand WR. Mindfulness-based stress reduction, mindfulness-based cognitive therapy, and zen meditation for depression, anxiety, pain, and psychological distress. *J Psychiatr Pract*. 2012;18 (4):233-252.

17. Jafari N, Farajzadegan Z, Zamani A, et al. Spiritual therapy to improve the spiritual well-being of iranian women with breast cancer: A randomized controlled trial. *Evidence-Based Complementary and Alternative Medicine*. 2013;2013:1-9.

18. Lin M, Moh S, Kuo Y, et al. Art therapy for terminal cancer patients in a hospice palliative care unit in Taiwan. *Palliative and Supportive Care*. 2012;10 (01):51-57.

Regarding spiritual distress, the physician or other health professional may elect to provide compassionate listening and presence as an intervention, and the distress then may be resolved, as patients find solutions for themselves in the context of the compassionate relationship. But if the patients' spiritual distress does not resolve a referral to a trained chaplain (where available), other spiritual caregivers maybe required to help clarify and treat the spiritual distress.

Spiritual care also should extend to bereavement care. Moreover, following the death of the patient, health care settings should have procedures to facilitate contact with family or loved ones. This may include sending condolence cards, attending funerals, holding memorial services or other rituals.

Stories of Spiritual Assessment and Intervention from all around the World

Incorporating Spiritual History for a Holistic Approach to a Hospice and Palliative Patient Care in the Philippines

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A holistic approach to patient care has been the trademark of family practice improving patient care and increasing patient satisfaction. However, a holistic care is lacking if spirituality is not integrated in patient care.

The Department of Family and Community Medicine in Ospital ng Maynila incorporates spirituality to patients referred for hospice and palliative care. One example is the story of a 71 year old single male cancer patient referred for palliative care by the ENT department. The patient is admitted in the ward under the ENT service. He was very irritable, difficult and indifferent to his attending medical doctors. He complains that they are not taking care of him properly despite the specialty services attending to his biomedical needs. Aside from the biopsychosocial considerations of depression, anxiety or denial of his medical condition, the spiritual history helped reveal the patient was having a spiritual crisis. He is suffering from "hopelessness" believing any medical intervention by doctors and medicines is futile thus his resentment to medical care. The spiritual history aided the family physician address the spiritual issues in the physician's management plan. Incorporating the spiritual history in the medical history helped the physician give a holistic patient care.

Spiritual Support for a Non-religious Patient: A Story from Namibia

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The main hospital in our city that provides care and treatment for folks with cancer does not have a dedicated chaplain. Since I had provided the initial staff training on spiritual care within palliative care, the ward nurse called me one day, concerned about a young patient with an end stage glioblastoma. Although his symptoms and physical pain were being well-controlled, the nurses were concerned about the patient's withdrawal and spiritual well-being. I stopped by and greeted the young man and explained that I provided some chaplaincy services and asked him if he would he like to chat. He politely smiled, but said that he really wasn't religious. This went for several days, often just stopping in his doorway and waving hello. One day, he asked me to come in and he wanted to talk. After a brief FICA, I learned that what was important to this young man, were weekly Sunday morning walks around a small lake with his friends. They would discuss jobs, families, partners and life in general. Yet none of these buddies knew that his condition at significantly deteriorated. He gave me permission to contact them and the next Sunday, his friends walked around the lake, taking a cell-phone video of their conversation. Together, they all came to visit the young man with the video. He died a week later, having experienced support, connectedness, meaning and peace.

Praying in Native Language: Spiritual Intervention for an Immigrant from Angola

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Portland is a hub for immigration, especially from countries in Africa.

I met an Angolan woman on the Labour and Delivery floor of the hospital. Both of us speaking in rusty school-girl French, we managed to have a simple conversation.

The patient was sick, with fever and body pain, and close to her time. She felt frightened and vulnerable, here from Africa only seven days. She had no friends. No home. No church. No English. Not even any belongings—the night she arrived at the shelter, the clothes she'd brought to America for herself and the baby had gone missing.

Our most intimate connection occurred when we prayed. Despite the linguistic and theological distance between us—she a Pentecostal Christian and I a Unitarian Universalist mystic—something shifted when I suggested that we each pray in our native tongue. Our voices overlapped each other's, like a duet—a whispered mix of Portuguese, French and English. We prayed in this manner for a good minute or more, until all was silent, and she drifted off to sleep.

When I returned the next day, we spoke briefly, then gladly took up the prayerful duet where it had left off. Surely we were speaking the same language.

Effects of the Spirituality Promotion Program on Spiritual Wellbeing, Anxiety and Depression of Patients with Cancer

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The purpose of this project was to evaluate the effects of the Spirituality Promotion Program (SPP) on spiritual well-being, anxiety and depression, and pain of patients with cancer. As a result of the study, the Spirituality Promotion Program was effective on alleviation of participants' anxiety, depression, and stress. This research was certainly a challenging task that needed a long time which was more than a year and half, efforts, and patience. However, it was such a great experience to meet patients individually, listen to their personal life of stories, and observe their positive changes. Following is one of the patients' experiences from the Spiritual Intervention Program;

'Colon cancer', these simple words made my vision fuzzy, my body trembling all over, and my mind confused. I felt dejected about life and I was angry after I heard that I was diagnosed with colon cancer. Before I had colon cancer, I had to go to work early in the morning every day and it was certainly continuation of extreme fatigue and stress. I smoked two packs of cigarettes and drank ten cups of instant coffee all day long since early in the morning. Therefore, I had irregular eating habits and lack of sleeps. Now, I began to recite the Holy Name which is "Thank you, Lord" even though I could hardly think and mumble the phase because of treatment medications. I shouted inwardly whenever and wherever I could. As time went by, a change started in my body and my mind; I felt that anxiety, restlessness, and feelings of emptiness were decreased. As days went by, I sometimes wept uncontrollably when I recited the phase. As I repeated the phase of "Thank you, Lord", I actually began to pray for God. Through prayer, I have been experiencing many changes and receiving peace in my mind and blessing at the same time. As I prayed for giving thanks to God and tried to rid myself of greed, I found a peace of mind and I even thanked the Lord for the fact that I got cancer.

Music Therapy and Family Support

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I am called to the home of a woman in her 90's who is reported by her sons to be withdrawn as she declines. They are distressed as miss her and that has been like this since her husband died years earlier, I enter her bedroom and see what appears to be a child's size organ. It is powered by a foot pedal. I approach her bed. Her eyes are closed. I gently sit beside her, introduce myself and my role, and say that I admire her little organ and its beauty. Her eyes open and she looks at me directly.

She says, "Do you play?"

I smile and say, "a little." She asks me to play. I improvise, attuning to her mood, then shifting tempo and melody to more upbeat. She sits up in bed and watches. When am done, she's smiling, says, "My parents got that organ for me. I've played it all my life." This leads to life review, how her family connected through music as telling their story. We framed this as shared legacy of love and purpose, which she could pass on to her sons." She no longer felt alone.

I visited a few times after this and always played that organ. Her sons said noticed a remarkable shift and now closer as they shared music and stories of family playing together. To me, music became prayer and music therapy methods integrated as spiritual intervention.

He came from Singapore for "The Cure". His family relocated near the hospital. They paid out of pocket for his care. Thus began the revolving door of admissions and discharges, chemo and radiation, scans and drains. Until the request came for the Palliative Service to help, as a chaplain with the Service, I met the patient and his family. They were practicing Roman Catholics. The mother had a deep faith the God would heal her son through a miracle. She followed the traditional Asian practice of smiling and nodding appreciation, even as I saw deep despair and fear in her eyes. The palliative staff worked tirelessly to ensure that the patient was comfortable and pain free.

The additional layer of support for the patient and his family allowed for quality time and moments of grace at his end of life. During my last visit, the patient's sister was trimming his moustache with a special scissors, using the skill of a surgeon. It was a beautiful moment of intimacy. His father remained stoic; his mother cried in

my arms. The patient asked for a blessing. He died on a Sunday, the Lord's Day of rest in the Catholic faith. He was 26.

Quiet Room

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For a long time, patients who were dying in our hospital might have to do so in the open ward, in multi-bedded cubicles, with little privacy. But over the past year, a "quiet room" was created in one of our Oncology wards (the one which I mainly cover), to allow patients and families some privacy in the last hours or days of life. This also allows them to practice any rites that they wish to, including, for some Buddhists, the practice of leaving the body undisturbed for eight hours. We've incorporated this into our "Last Hours" care, so that families are routinely offered the use of the Quiet Room and the nurses know to enquire about religious or spiritual needs.

ETHICAL ISSUES IN SPIRITUAL CAREGIVING

The 2014 World Health Assembly declared that palliative care should be made accessible across the life course to all patients who could benefit from it:

"… palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care."

Guidelines have been developed about non-spiritual care professionals such as doctors, nurses and social workers disclosing their own faith or personal beliefs. In general this is discouraged due to the power differential between the

clinician and the patients. It is of primary importance not to cause harm to the patient. If the doctor shares his or her belief the patient may feel obliged to accept what the physician is saying out of fear that their medical care may be compromised. Or if the clinician offers to pray with a patient, that too may appear coercive. Most clinicians are not trained in use of prayer in professional spiritual care so it is best to leave that level of spiritual care to the spiritual care expert. However, patients may desire and request prayer or spiritual rituals with the physician or nurse. The general recommendation is that if the clinician is willing to witness the ritual they can do so by asking the patient to lead the ritual and simply be present at that experience. Or they can ask the spiritual care professional to lead the ritual and be present in that experience. It is best to follow the patient's lead and to be respectful at all times of the patient's belief with the focus on the patient not the clinician[19].

SUMMARY

The WHO palliative care resolution recognizes the ethical obligation of all health care providers to attend to the pain and suffering of all patients with serious and chronic illness. Guidelines and preferred practices have been developed to facilitate the development and improvement of spiritual care within palliative care, establish uniformly accepted definitions of spirituality as an essential domain of palliative care, to foster measurement of quality improvement initiatives in spiritual care within palliative care. Models derived from these guidelines and preferred practices enable clinicians to integrate spirituality, in an ethical and practical manner, within current health systems. The result is an enhanced delivery of compassionate and whole-person palliative care. We recognize that these are models that when implemented in other countries and regions will be modified based on cultural, economic and other considerations. Spiritual care is practised in different ways in different cultures. While some cultures utilize clinical pastoral education trained chaplains, others do not have such professionals. Instead pastoral counsellors, culturally based healers and other providers are used. In many places volunteers serve the role of the spiritual care professional. It will be necessary to look at appropriate training and certification to ensure that spiritual care professionals around the world are trained appropriately, certified and seen as equal members of clinical palliative care

19. Astrow AB, Puchalski CM, Sulmasy DP. Religion, spirituality, and health care: Social, ethical, and practical considerations. *Am J Med*. 2001;110(4):283-287.

teams. Currently work is being done in several countries to develop these guidelines, tools, education programs and demonstration projects in spiritual care within palliative care in diverse health settings.

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6
CLINICAL ETHICAL ISSUES

Stephen Connor

KEY POINTS

- Ethical practice in palliative care is guided by ethical principles.
- Delivering good ethical practice requires well-developed skills in:
  - Communication,
  - Provision of respectful, people-centred care,
  - Supporting dignity, spirituality, hope, and autonomy,
  - With attention to advance care planning,
  - Based on the identification of values, preferences, and goals for care,
  - Leading to shared care decision-making.
- Common ethical issues in decision making include: settings of care, withdrawal or refusal of specific treatments, sedation, resuscitation, desire for hastened death, persons with cognitive deficits, and cultural, regional, and setting issues.

PRINCIPLES OF CLINICAL ETHICS IN THE CARE OF PERSONS WITH ADVANCED CHRONIC CONDITIONS / END OF LIFE

Ethical issues that arise towards the end of life are often fraught with difficulty in an increasingly technological age in which the process of dying may be prolonged. In health care, there is often no "right" or "wrong" decision, but only a consensus view of a clear aim, considered on the basis of ethical principles. The most widely used ethical principles in health issues are:

- **Autonomy** (patients should be informed and involved in decision-making),
- **Beneficence** (do good),
- **Non-maleficence** (do no harm),
- **Justice** (balancing the needs of individuals with those of society).

In practice these issues are difficult to translate, but having an ethical framework will help clinicians and patients to come to decisions that are right for them.

METHODOLOGY AND SKILLS ASPECTS

COMMUNICATION

Open and clear communication is a necessary condition for good ethical palliative care practice. Many challenges arise between patients, their families, and health care professionals, which need to be handled with skill and sensitivity. These challenges include informing the patient and family about diagnosis and prognosis, breaking bad news, making difficult decisions about treatment and discontinuation of treatment, resuscitation, administration of nutrition and hydration, and so forth. Clinicians need to be able to exercise good communication skills, to be capable of empathic responses, and to demonstrate active listening.

A systematic approach to giving bad news can be used to avoid harming the patient and can be summarized as follows[1]:

- Setting the scene (quiet location, phones/pagers off, sitting at eye level). Involve family and other team members as appropriate.
- Elicit the patient's perception. What do you already understand about your situation/diagnosis?
- Ask for the patient's preferences regarding information. "How much do you want to know, a lot of detail, or big picture? If you don't want to know, who should we talk to about decision making?
- Give the information starting with statements like "I wish I had better news." Keep statements simple and clear, without medical jargon. Pause and allow time for patient response and reaction.
- Acknowledge and respond to the patient's emotional reactions. If no reaction, ask what the patient is thinking or feeling now.
- Arrange for follow up. "This is a lot to think about. Let's meet again soon to talk more." "Here are some things we can do moving forward." Never say: "There's nothing more I can do."

1. Baile WF, Buckman R, Lenzi R, et al; SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302-11.

RESPECTFUL, PEOPLE-CENTRED CARE

Putting people at the heart of the health care experience and focusing on a true and lasting integration of services offered to them is urgently needed to meet the challenges faced in today's health systems, however diverse. This strategy presents a compelling vision of a future in which all people have access to health services that are provided in a way that responds to their preferences, are coordinated around their needs, and are safe, effective, timely, efficient and of acceptable quality

ESSENTIAL NEEDS CARE: DIGNITY, SPIRITUALITY, HOPE, AUTONOMY

At the end of life, persons are vulnerable and dependent on others for care. In this condition it is essential that care be delivered safely and sensitively. To maintain dignity when vulnerable depends on a number of factors including ensuring pain control, provision of informal and formal support, minimizing hopelessness and depression, coming to terms with dependency needs, and finding meaning.

ADVANCE CARE PLANNING

Advance care planning involves learning about the types of health care decisions that might need to be made, considering those decisions ahead of time, and then letting others know about your preferences, often by putting them into an *advance directive*. An advance directive is a legal document that goes into effect only if you are incapacitated and unable to speak for yourself. This could be the result of disease or severe injury—no matter how old you are. It helps others know what type of medical care you want. It also allows you to express your values and desires related to end-of-life care. You might think of an advance directive as a living document—one that you can adjust as your situation changes because of new information or a change in your health.

IDENTIFICATION OF VALUES, PREFERENCES, AND GOALS FOR CARE

Clinicians can help define goals of care by asking questions about patients' values and preferences for care. Values can help the person to make decisions about treatment and care options. The following questions can be used to help clarify the patients' values:

"What is most important to you now?"
"What do you enjoy the most now?"

"What concerns you most about your disease?"

"What are you expecting to happen in the coming weeks or months?"

"What have you seen in others you have known with the same disease?"

A values history can be used prospectively to help address future decision-making. Values histories can include two major components (1) identification of values, and (2) preference statements based on patients' values. Values about end-of-life care centre mainly on future life in terms of duration versus quality of life. Having clarity about patient values helps patients and clinicians make future decisions more flexibly.

Clarifying goals for care with the patient involves an on-going discussion of the relative risks, benefits and alternatives to the various treatment options. Initial discussion of goals of care will generate an on-going dialogue about the person's clinical situation and response to treatment.

SHARED CARE AND DECISION-MAKING: PATIENTS, FAMILIES, TEAMS

A fundamental principle of palliative care is that the patient and their family are the unit of care. By family, we mean more than those related by blood or marriage. Included are those close friends and relationships that are part of the affected person's attachment network, those who will participate in helping to care for the patient and those who have meaningful relationships. Shared care means care that is the shared responsibility of a group of professionals along with the patient and family. In palliative care we also call this interdisciplinary care where the patient and family lead the team by setting goals of care that the professionals and volunteers help them to realize. Decision-making about care is done collaboratively as an ongoing process. Whenever possible, care planning is done proactively in order to prevent crises and to promote a sense of control over events or symptoms that can be anticipated for a particular illness or condition. Advance care planning is one of the ways this is accomplished.

DECISION-MAKING AND COMMON ETHICAL ISSUES WITH PERSONS WITH ADVANCED CHRONIC CONDITIONS (1ST TRANSITION): PLACE OF CARE TRANSFERS BETWEEN SERVICES, INFORMATION AND COMMUNICATION ISSUES

PLACE OF CARE

Decision-making about place of care depends on the available options. Most people state that they would prefer to be cared for in their home if they have a life-limiting condition. However, what one calls home varies considerably and can include a homeless shelter, a nursing facility, or a prison. Also where inpatient hospice facilities are accessible some patients may want to avoid burdening family with caregiving and will want to die there. As with other such decisions, helping the person to make this choice, when options are available, will depend on values and goals.

TRANSFERS BETWEEN SETTINGS

Acute care facilities often limit the time patients can remain hospitalized to make use of scarce resources. To ensure safe transitions between settings, palliative care standards usually require that there be a transfer summary and continuity in the care planning between settings.

INFORMATION AND COMMUNICATION

A person with an advanced chronic condition is entitled to all available information about their changing health condition and also should be allowed to decide how much information to be given. Some people prefer to have every detail of the situation while others prefer more general information or even to appoint someone else to be the recipient. Some patients respond to information in symbolic ways without speaking directly about dying or other difficult subjects. These preferences should be respected.

DECISION MAKING IN END-OF-LIFE CARE: WITHDRAWAL OR REFUSAL OF SPECIFIC TREATMENT, NUTRITION AND HYDRATION, SEDATION, DESIRE FOR HASTENED DEATH, RESUSCITATION, ETC.

WITHDRAWAL OR REFUSAL OF SPECIFIC TREATMENT

The right to refuse medical interventions is now well established. The right to access specific medical treatment has more potential areas of conflict. In many countries treatment may only be accessible for those with the resources to pay for it. The right to palliative care has been asserted but less than 10% of the need is being met. In end-of-life care, the most common issue is refusal of treatment. Ethically there is no distinction made between withdrawal and refusal of any medical treatment.

NUTRITION AND HYDRATION

While there has been some debate as to whether the artificial provision of nutrition and hydration is medical treatment or ordinary care, the consensus is that it indeed is a medical treatment and thus subject to the same right to accept or reject. The literature on withholding nutrition and especially hydration has demonstrated that decease in intake is a normal part of the dying process and does not need to result in suffering as long as good mouth care is maintained. Recent literature also has shown that the use of feeding tubes in nursing home patients does not significantly improve survival. Withdrawal or refusal of nutrition and hydration often falls to surrogate decision makers, so it is important to understand the patient's wishes beforehand.

SEDATION

When all attempts to relieve suffering have been unsuccessful, the option to sedate a patient can be considered. Therapeutic (or palliative) sedation in the context of palliative medicine is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family, and health care providers[2].

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2. Cherny NI, Radbrach L, et al. European Association for Palliative Care recommended framework for the use of sedation in palliative care. (2009). *Palliat Med*, 23(7):581-593.

RESUSCITATION AND LIFE SUPPORT

Cardio-pulmonary resuscitation (CPR) was developed to increase survival in acutely ill patients. Patients with advanced, chronic life- limiting conditions rarely benefit from CPR and ongoing life support. The use of CPR in these cases more often results in a prolongation of the dying process if even partially successful and increased suffering from trauma. As with all other medical interventions the patient has a right to request that CPR not be undertaken. Unfortunately, in the absence of an advance directive and do–not-resuscitate order, the default in medical institutions and emergency care is to initiate CPR. In many low- and middle-income countries there may not even be a process for a do-not-resuscitate order. Some recent efforts to proactively deal with this problem include the allow natural death (AND) order and physician orders for life sustaining treatment (POLST), which clarify patients' wishes at the end of life.

DESIRE FOR HASTENED DEATH

Patients may ask their health care providers to hasten their death. In palliative care this is often a cry for help and the best response is to try to understand what is driving the patient to want to prematurely end their life and to remedy the problem. In some cases, it may not be possible to relieve the suffering or the patient may have such a high need for control that they want to determine their time of death. Palliative care providers have the dual ethical obligation to support patient autonomy while at the same time doing no harm. In some jurisdictions it may be legal to provide assistance in hastening death. While it has been the case that assisted suicide and euthanasia are not considered part of palliative care practice, nonetheless it is essential to continue to support and not to abandon patients who intend to hasten their deaths.

DECISION-MAKING IN PATIENTS WITH LIMITED COGNITIVE FUNCTION: DEMENTIA, DEFICITS, ETC.

Patients with cognitive deficits including delirium and dementias pose additional ethical burdens on palliative care providers. Determining when a patient is no longer able to make health care decisions can be challenging as these deficits may develop gradually. Therefore, it is especially important to both document patient wishes regarding the end of life and to ensure that a legal surrogate is appointed to make decisions when the patient is unable to. In most places family members may be required to make decisions for these patients.

CULTURAL, REGIONAL, AND SETTING ISSUES

Ethical issues in palliative care may be strongly influenced by the setting where care is delivered. Local customs and cultural dictates can influence how care is delivered, who and how decisions are made about treatments, and what settings care is provided in. In addition, what happens at the time of death, handling and preparation of the body, rituals performed, funerary practices, and grieving are all heavily influenced by culture and local custom. It is essential that palliative care workers are aware of and sensitive to these norms for all cultures in the areas where palliative care services are provided.

FURTHER RECOMMENDED READING

Gordon JS (author); Schildmann J (Editor). Clinical Ethics Consultation: Theories and Methods, Implementation, Evaluation (Medical Law and Ethics) 1st Edition. 2016. New York: Routledge.

McCarthy J, Donnelly M, Dooley D, Smith D, Campbell L. End of Life Care: Ethics and Law. 2011. Cork University Press.

Youngner SJ, Arnold RM. The Oxford Handbook of Ethics at the End of Life . 2014. Oxford University Press.

SECTION 4

SPECIFIC VULNERABLE POPULATIONS: EXPERIENCES

1
PALLIATIVE CARE APPROACH FOR PEOPLE WITH ADVANCED CHRONIC CONDITIONS IN ALL SETTINGS: THE CATALAN EXPERIENCE

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Xavier Costa, Sebastià Santaeugènia

BACKGROUND

Palliative care has been developed systematically in Catalonia since 1990 as a WHO Demonstration Project, with most of the elements of a comprehensive Public Health Program: aims, values, principles, needs assessment, legislation and funding, implementation of specialist palliative care services, education and training, standards, and evaluation[1].

A high development of palliative care has been achieved since then, with a wide range of services, high geographical coverage, and high coverage for cancer. The implementation of palliative care has shown evidence of effectiveness, efficiency, satisfaction and social impact[2].

After performing a systematic qualitative assessment[3], some areas for improvement were identified in the early 2000's. Those include low coverage for non-cancer patients, late intervention of palliative care services, variability of palliative care approach in conventional services, low development of psychosocial issues, and others such as lack of research, low evaluation, low funding and professionals' support. At the same time, several international initiatives were developing

1. Gómez-Batiste X, Fontanals MD, Roca J, Stjernsward J, Trias X. Palliative care in Catalonia Catalonia WHO Demostration Project for Palliative Care 1990-95. Palliat Med 1992; 6: 321-327.
2. Gómez-Batiste X, Caja C, Espinosa J, Ingrid Bullich, Martínez-Muñoz M, Porta-Sales J, Trelis J, Esperalba J, and Stjernsward J. The Catalonia WHO Demonstration Project for Palliative Care implementation: quantitative and qualitative results at 20 years. J of Pain and Symptom Manage 2012; 43 (4): 783-794.
3. Gómez-Batiste X, Nabal Vicuña M, Trelis Navarro J, Roca Casas J, Porta-Sales J, Paz Ruiz S, Espinosa Rojas J. Evaluación cualitativa del desarrollo del proyecto Demostrativo OMS de Cuidados Paliativos de Cataluña a los 15 años de su implementación y propuestas de mejora. Med Pal 2008; 15(5): 293-300.

tools and policies for the timely identification of people in need of palliative care[4], and new conceptual approaches were elaborated[5].

STRATEGY DEFINITION

A systematic strategy[6] was elaborated to face these challenges, within the context of the WHO Collaborating centre for Palliative Care Public Health Programmes and the Chair of Palliative Care at the University of Vic. This strategy, elaborated from a public health perspective, was based on the following principles: community oriented and population-based approach.

PC services have incorporated conceptual transitions and identified challenges, the most relevant being to extend PC beyond cancer. In the process, there have been several conceptual changes: from terminal illness to advanced chronic conditions and limited-life prognosis illnesses; from mortality to prevalence. In order to distinguish people with advanced chronic conditions from terminal patients, we introduced new terms such as "MACA": "Model of Advance Care Approach".

Additionally, the NECPAL ICO-CCOMS©[7] tool was elaborated to identify patients with palliative care needs early. Based on the Gold Standards Framework, this tool introduced some elements such as the inclusion of the team members' assessment, the emphasis on three declines with a dynamic perspective, the importance of the geriatric syndromes, and the inclusion of psychosocial distress as activators of a "palliative approach".

From the epidemiological perspective, research was oriented to determine the prevalence[8] of MACA patients within a global population. The results of

4. Prognostic Indicator Guidance (PIG). The gold standards framework centre in end of life care CIC, 4th ed. 2011. Available from: http://www.goldstandardsframework.org.uk. Accessed January, 2017.

5. Gómez-Batiste, X, Blay, C, Roca, J, Fontanals, MD. Innovaciones conceptuales e iniciativas de mejora en la atención paliativa del siglo XXI. Med Paliat 2012; 19:3; 85-6.

6. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Espinosa J, Contel JC, Ledesma A. Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. Curr Opin Support Palliat Care 2012, 6:371–378.

7. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, Villanueva A, Espaulella J, Espinosa J, Figuerola M, Constante C. Identifying chronic patients in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. BMJ Support Palliat Care 2013;3:300-308.

8. Gómez-Batiste X, Martinez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, Espaulella J, Espinosa J, Constante C, Mitchell GK. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: a cross-sectional study. Palliat Med 2014; 28(4):302-311.

these studies showed that in high-income countries, around 75% of the population will die due to chronic conditions. The characteristics and distributions of patients by age, gender and clinical condition are summarised as it follows: around 65% were women living in the community and in nursing homes. The mean age of these patients was 81 and mostly all presented multi-morbidity and high prevalence of dementia. Other clinical needs of patients were also found. Such patients presented high prevalence of pain, psychosocial needs, and other issues as multi-pharmacy, multi-morbidity, dementia, etc.[9].

The prevalence in different setting was also analysed. A 35-45% was determined in acute hospitals; 20-25% for GPs and 50-70% in nursing homes.

This epidemiologic approach was a key aspect of success. The principles of timely palliative approach in all settings for all types of patients was adopted by the Catalan Department of Health, and inserted as one of the key components of the Program for Chronic Care[10], which actively promoted the implementation of policies in diverse and specific health care settings including primary care, acute hospitals and nursing homes in order to generate further experience and evidence. Such policies included the training of health care professionals to support the identification of patients, among others.

BARRIERS AND DIFFICULTIES

Several barriers and difficulties were identified during the implementation process. First of all, the concepts of palliative approach for people with advanced chronic conditions and limited life prognosis are innovative and generated misunderstandings and resistances. It is frequent to deny the existence of several and relevant needs in the end-of-life process.

The most important barriers and difficulties consist of the lack of training of many professionals to assess and respond to these needs. Some areas such as multidimensional assessment, communication, advance care planning, clinical management, difficulties in team approach and ethics issues are poorly developed or inserted in the health care system.

Additionally, palliative care services can see this as a threat instead of an

9. Calsina A. Prevalence and clinical characteristics of patients with advanced chronic illness and palliative care needs identified with the NECPAL CCOMS-ICO© tool at a tertiary care hospital. PhD Thesis, University of Vic, 2017.
10. Chronic Care Program. Department of Health, Government of Catalonia. Available at: http://salutweb.gencat.cat/ca/ambits_tematics/linies_dactuacio/model_assistencial/atencio_al_malalt_cronic/ Accessed December 2016.

opportunity, and have difficulty in adapting their services. Conventional existent palliative care services should open their perspective towards a population-based approach, inserting the non-cancer patients in their clinical settings, and changing their late-end stage-dichotomist one-way model of intervention into a flexible, timely, shared and cooperative one. In some cases, services can have difficulty in changing their organisation to be adapted to these needs and specific training is needed to look after non-cancer chronic patients as compared to terminal cancer patients.

Prior to and during the implementation of the MACA Program, an assessment of ethical issues was shared with 5 ethical committees, and the Catalan Bioethics committee. This process identified risks and benefits of the early identification, and it proposed several actions to minimize the risks (mainly training, clear clinical information added to the identification process and shared decision-making patients between patients and professionals)[11].

One of the challenges of the existing tools was to explore their value in the prognostic approach. A cohort study[12] was conducted looking at the prognosis, and a prognostic utility of the NECPAL tool was founded, and acuracy is currently being improved through the addition of some parameters to the original tool.

There is still a great variability in the degree of implementation of the MACA Program. The initial focus on community has produced a different slower implementation in other areas, such as hospitals and nursing homes. As any other relevant change, it requires strong leadership (clinical and organisational), high commitment, resilience, training, and intelligence. Generation of evidence is also a crucial issue to promote acceptation.

PRELIMINARY RESULTS

The most relevant results include the identification of more than 150,000 people with PC needs in primary care services, the general implementation of

11. Gómez-Batiste X, Blay C, Broggi MA, Lasmarías C, Vila L, Amblàs J, Espaulella J, Costa X, Martínez-Muñoz M, Robles B, Quintana S, Bertran J, Torralba F, Benito C, Terribas N, Busquets JM, Constante C. Ethical challenges of early identification of advanced chronic patients in need of palliative care: the Catalan experience. In press, J Palliat Care 2017.
12. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, Espaulella J, Villanueva A, Oller R, Martori JC, Constante C. Utility of the NECPAL CCOMS-ICO tool and the Surprise Question as screening tools for early palliative care and to predict mortality in patients with advanced chronic condition: A cohort study. Palliat Med 2016; First Published November 5, 2016 doi:10.1177/0269216316676647.

several training activities for health care professionals, the active development of projects at a local level, and the generation of evidence[13].

The NECPAL tool and the MACA Program are very well known at all levels of our health care system, and its use is growing exponentially.

TRAINING, EDUCATION AND RESEARCH

Training and education: existing training activities have adapted to the chronic care perspective. For instance, the Master of Palliative Care in Catalonia has introduced contents about clinical, epidemiological, organisational and ethical issues of chronic advanced care approach. As a result, professionals working in primary care, acute or geriatrics services, other hospital services, and nursing homes represent a significant percentage of the students.

Additionally, new training activities have been designed and are being implemented. An online course on advance care planning is currently available for all professionals. Face-to-face sessions and workshops are also being performed to complement the online course.

Added to the published research described previously, 12 PhD theses have been conducted on this topic in the last 5 years, and 8 have already been successfully presented.

A specific survey was practised among patients participating in the "Expert patient's group". Additionally, a project with the concept of "Compassive Communities" is currently being developed and implemented in Vic (Barcelona) ("Vic, Ciutat Cuidadora")[14].

CONCLUSIONS

Palliative care for people with advanced chronic conditions - most of them vulnerable elderly non-cancer patients living in the community – is currently one of the most relevant challenges for the health care systems.

A systematic Policy[15] Public Health-based, Community oriented, and Systems

13. Gómez-Batiste X, Blay C, Martínez-Muñoz M, Lasmarías C, Vila L, Espinosa J, Costa X, Sánchez-Ferrin P, Bullich I, Constante C, Kelley E. The Catalonia WHO Demonstration Project of Palliative Care: results at 25 years (1990-2015). J Pain Symptom Manage 2016 Jul;52(1):92-98.
14. http://www.vicciutatcuidadora.cat/ Accessed March 2017.
15. Gómez-Batiste X, Murray SA, Keri T, Blay C, Boyd K, Moine S, Gignon M, Van den Eynden B, Leysen B, Wens J, Engels Y, Dees M, Costantini M. Comprehensive and integrated palliative care for people with advanced chronic conditions: an update from several European initiatives and recommendations for policy. J Pain Symptom Manage 2017 Mar;53(3):509-517.

practiced, and ranging from tools elaboration, identification, improving quality of care of these patients and changing models of organisation of services to emphasizing training.

2

LOOKING AFTER THE ESSENTIAL NEEDS OF PATIENTS: THE PROGRAM FOR THE COMPREHENSIVE CARE OF PEOPLE WITH ADVANCED CHRONIC CONDITIONS AND THEIR FAMILIES IN SPAIN

Xavier Gómez-Batiste, Dolors Mateo-Ortega, Cristina Lasmarías, Elba Beas, Cristian Tebé, Anna Novellas, Sara Ela, Rosa M. Montoliu-Valls, Jun Lluch

SUMMARY

In the context of development of a Spanish National Strategy for Palliative Care, psychosocial and spiritual care were identified as areas for improvement in the existing model of care and organization. Based on this analysis, we proposed the design, implementation and evaluation of a comprehensive, systematic and nation-wide program in 2008.

The program implemented psychosocial teams (PST) composed mainly of psychologists and social workers, to complement existing health services, focused on the psychosocial and spiritual care of complex patients and families.

The main aims of the program included generating experience and evidence to demonstrate the efficiency and effectiveness of psychosocial care provision through clinical interventions, systematic evaluation of results, the generation of tools and protocols to improve the quality of care. Another objective is to promote the insertion of such teams in the mainstream of the health care system.

The Program has implemented 42 full-time PSTs, in all Spanish regions, which means more than 200 professionals, mainly psychologists and social workers, giving support to existing services in more than 100 hospitals and more than 100 home care support teams. The PSTs have taken care of more than 100,000 patients with advanced chronic conditions and 150,000 relatives. After eight years of implementation, there is evidence that Psychosocial Care Teams provide effective interventions and improve the emotional symptoms and unease of patients already taken care of other palliative care services.

BACKGROUND

The Program of Comprehensive Care for People with Advanced Illnesses[1] was designed according to a qualitative analysis that identified the areas for improvement of the Palliative care model in Spain[2], mainly related to the low development of psychosocial and spiritual areas, in part due to the lack of implementation of psychologists or slow development of care for essential needs of patients and families.

"la Caixa" Banking Foundation has developed the biggest social foundation in Spain, committed to support social initiatives and focusing on vulnerable populations or social development. The WHO Collaborating Centre for Palliative Care Public Health Programs at the Catalan Institute of Oncology aims to promote and improve palliative care with a public health vision. In 2008, both entities established some areas of cooperation, based on the assessment of needs and developing initiatives that might complement the existing palliative system, in the context of the Spanish National Palliative Care Strategy at the Spanish Ministry of Health. The program has thus presence in all Spanish Regions.

AIMS OF THIS CHAPTER

- To implement a comprehensive model of psychosocial and spiritual care;
- To generate experience and evidence about needs assessment, models of care and models of organization;
- To generate clinical and organizational innovation;
- To generate, share and disseminate knowledge.

INITIAL ACTIVITIES

MODEL OF CARE

The definition and piloting of a comprehensive model of care and professional competences for psychosocial spiritual care (figure 1). With an inclusive perspective that brings together the different perspectives and initiatives of

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1. https://obrasociallacaixa.org/es/investigacion-y-salud/atencion-integral-personas-enfermedades-avanzadas/ Accessed March 2017.
2. Gómez-Batiste X., Ferris F., Paz S., Espinosa J., Porta-Sales J., Stjernsward J., Esperalba J. Ensure quality public health programmes. A Spanish model. Eur. J Palliat Care,2008; 15(4): 195-199.

psychosocial spiritual care (table 1), the model was based on previous international and national experiences[3].

Figure 1. Model of essential professional competences
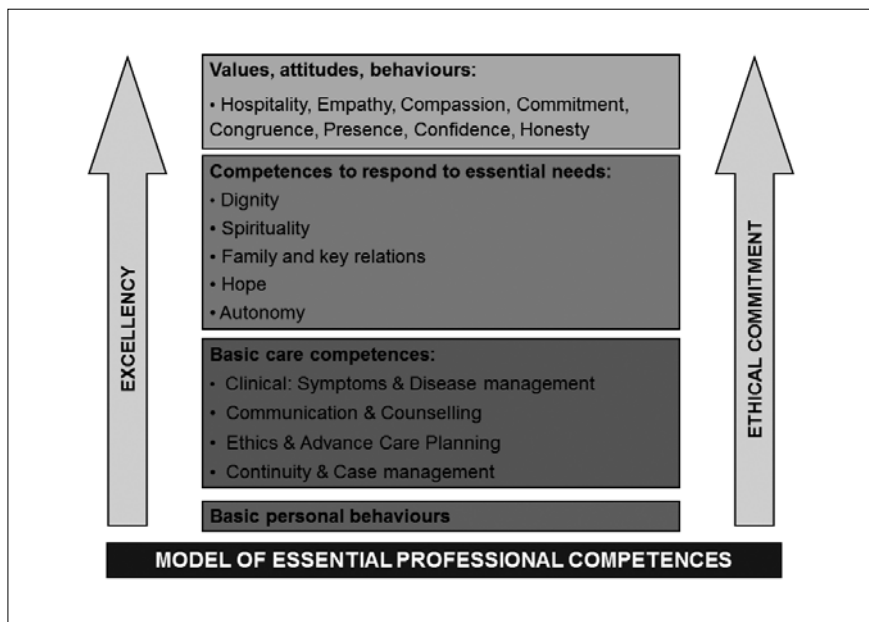
Table 1. Examples of personal attitudes and behaviour on first contact with patient

1.	Introduce yourself, your colleagues (or team members) and your service
2.	Always use formal verbal / non-verbal personal respect
3.	Always ask for permission to start questions or explorations, enter a room, etc. ("Do you mind if…?")
4.	Establish the objective and purpose of the visit-consultation
5.	Guarantee privacy and intimacy, especially for deep conversations or explorations
6.	Start with general, open, non-invasive questions
7.	Always finish by asking if there is any doubt or misunderstanding, or if there is something more that we could do for the patient
8.	Always clarify the decisions adopted and the follow-up proposed

3. Maté-Méndez J, González-Barboteo J, Calsina-Berna A, Mateo-Ortega D, Codorniu-Zamora N, Limonero-García J, Trelis-Navarro J, Serrano-Bermúdez G, Gómez-Batiste X. The Institut Català d'Oncologia (ICO) model of palliative care: An integrated and comprehensive framework to address essential needs of patients with advanced cancer. JPC, 2013; 29(4): 236-242.

MODEL OF ORGANIZATION

The implementation of a new model of organization called "Psychosocial support team". They give support and advice to existing palliative or other care services ("beneficiary services or teams") for the specialized psychosocial and spiritual care of people with specific complex situations, through direct care, joint sessions, training, shared protocols, and specific support for the team. The main activities of these teams are described in table 2.

Table 2: Main activities of the Psychosocial Support Teams

Primary activities	
Support palliative care units	Training sessions, and support for preventive care team
	Case analysis meetings and interventional planning
	Individualized intervention in specific cases
	Informal support actions in specific situations and promotion of mutual support between the PC team and the PST
	Help the PC team in making difficult decisions (primarily ethical)
Provision of patient-centered care	Assessment of discomfort & helping patients and families with adjustment difficulties
	Spiritual care
	Supportive psychotherapy
	Help in resolving practical issues (financial, public assistance programs, wills, paperwork to obtain support with wheelchairs, finding household help outstanding issues
	Short-term individual psychotherapy sessions
	Apply specific psychological techniques (counselling, cognitive behavioral therapy, narrative therapy, life review therapy, redefinition, dignity therapy or legacy , and search for meaning) depending on the needs of each patient
Family-centered care	Assessment of family needs
	Psycho-education regarding the relationship between the patient and family members
	Capacity-building to help caregivers organize care
	Mediation of interpersonal relationship problems
	Provide advice about available community resources
	Psychotherapeutic interventions in cases of distress
Bereavement care	Detect risk factors for complicated grief
	Mental health care for bereavement
	Intervention in complex situations
	Care for most vulnerable family members
	Advice and / or referral to community resources

Primary activities	
Registration platform	Input data (on assessments and interventions) into computerized platform
Administrative	Processing pensions, financial aid, legal documents, etc. Coordination with other centres
Training	Attend courses conducted by the program and other external related to the subject
Knowledge contribution	Contribute knowledge to community entities; courses, conferences, workshops etc.
Volunteer Management	Selection, coordination and monitoring of volunteers

SELECTION AND IMPLEMENTATION OF PROJECTS

A national call for projects was launched in 2008. The providers needed to be NGOs, preferably with experience in managerial issues and palliative care, and having a formal agreement with the beneficiary or receiver organizations, in the context of the national or regional palliative care program. A systematic selection process was performed, and 29 projects were selected among 90 proposals, according to quality criteria defined by an expert's committee. A second launch was performed in 2014, to increase the number of PSTs to 42 (Figure 1).

EDUCATION AND TRAINING

The professionals were provided with necessary training to enable them to perform their task. Such training includes a postgraduate course, seminaries twice a year and continuous support and monitoring to empower the teams to their development and action as referents in their areas.

DOCUMENTATION

The clinical and administrative documentation was created and shared on-line by all teams, with the main mission of generating common clinical perspective and also retrieve information. This has been a good promoter of common work, and also a benchmark between teams for follow-up, and collecting information for the assessment of results.

**Figure 2.** Map of Psychosocial Teams

MAIN RESULTS

During the program's 8 years of existence, more than 100,000 patients and 130,000 relatives have received psychosocial care[4]. The program provides support for more than 18,000 patients and 25,000 relatives every year.

The effectiveness of psychosocial interventions[5] has been assessed by a quasi-experimental survey performed in more than 80,000 patients, and showed significant improvement in the pre-post assessment of the severity of parameters (anxiety, depression, adjustment, distress, mood, peace and forgiveness). These results are sustained in the evolution of the program, achieved mostly in the 2nd – 3rd interventions, and are more intense in patients with highest complexity at the 1st assessment. As an example, figure 3 shows how emotional distress decreased due to the PSTs intervention.

4. Gómez-Batiste X, Mateo-Ortega D, Lasmarías C, Novellas A, Espinosa J, Beas E, Ela S, Barbero J. Enhancing Psychosocial and Spiritual Palliative Care: Four-year results of the Program of comprehensive care for People with Advanced Illnesses and their families in Spain. Palliat Support Care 2017 Feb;15(1):98-109.
5. Mateo-Ortega D, Gómez-Batiste X, Limonero J, Martínez-Muñoz M, Buisan M, de Pascual V. Efectividad de la intervención psicosocial en pacientes con enfermedad avanzada y final de vida. Psiconcología 2013; 10(2-3): 299-316.

Figure 3. Emotional distress in patients: changes from 1st to 5th PST visit
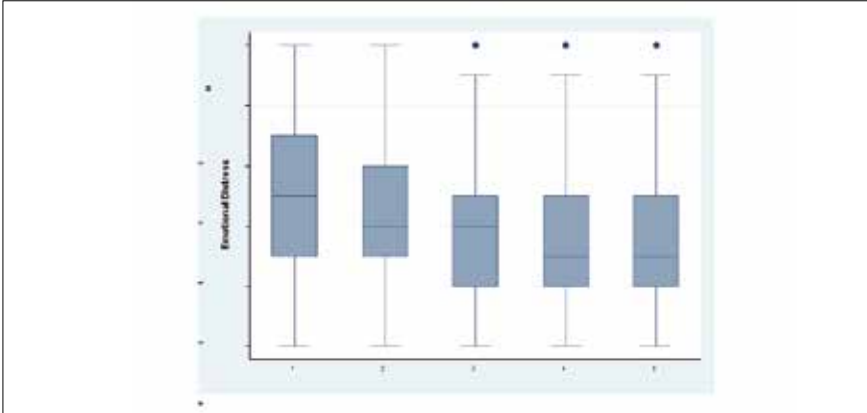
Additionally, satisfaction was checked in patients, relatives and stakeholders by a semi-structured survey. Results showed high satisfaction of patients and relatives, on the one hand. The most appreciated issues were accessibility, availability to talk about concerns, help to deal with difficult issues or decisions, and help to resolve practical questions. On the other hand, there is high satisfaction among leaders and professionals of beneficiary or receiver services as well (figure 4). This was measured by a semi-structured and Likert scale[6].

Figure 4. Survey Professionals of Receptor Services (mean >4.4/5)
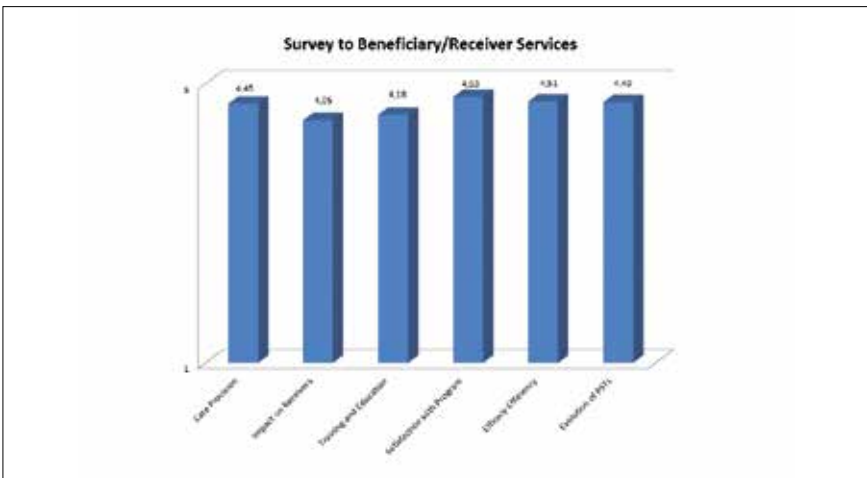
6. Gómez-Batiste X., Buisan M., González M.P., Velasco D., de Pascual V., Espinosa J., Novellas A., Martínez-Muñoz M., Simón M., Calle C., Lanaspa J., Breitbart W. "la Caixa" Banking Foundation and WHO Collaborating Center Spanish National Program for enhancing psychosocial and spiritual palliative care for patients with advanced diseases, and their families: Preliminary findings. Palliat Support Care 2011; 9 (3):239–249.

The program produced valuable information and tools for improving the assessment or training. The main outcomes were:

Manuals and books:

- ***Manual para la atención integral de personas con enfermedades avanzadas***[7]. A complete manual including the conceptual basis and the most common clinical situations with practical recommendations for psychosocial and spiritual care.
- ***Atención religiosa al Final de la Vida***[8]: this book describes the approaches and rites that all religious confessions propose for end of life and death.

Validated tools:

- The *DME* (Detección Malestar Emocional in Spanish / Emotional discomfort diagnosis)[9]: a screening tool for identifying emotional needs of patients
- The *DME-C*[10], a screening tool for identifying emotional needs of carers
- The *ENP*[11], development of a new tool for the assessment of the psychosocial needs of end-of-life patients (PNE) (Evaluación necesidades Psicosociales, (ENP) in Spanish).

7. Barbero Gutiérrez J, Gómez Batiste X, Maté Méndez J, Mateo Ortega D (eds.) Manual para la atención psicosocial y espiritual a personas con enfermedades avanzadas. Intervención psicológica y espiritual. Barcelona: Obra Social La Caixa, 2016; Depósito legal: B 8914-2016.

8. Sobrevia X., Torredeflot F. Atención religiosa al final de la vida. Conocimientos útiles sobre creencias y convicciones. Barcelona 2013.

9. Maté J, Mateo D, Bayés R, Bernaus M, Casas C, González-Barboteo J et al. Elaboración y propuesta de un instrumento para la detección de malestar emocional en enfermos al final de la vida. Psicooncologia 2009;6:507-18.

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CONCLUSIONS

The added values of the Program can be summarized as it follows:

- Focused on the most essential needs of people with advanced chronic conditions and end of life.
- Innovation in the models of care and organization of psychosocial and spiritual care.
- Great quantitative figures: 42 Services, 200.000 people attended, 240 full time specialists, all regions in Spain, critical mass achieved.
- Results in effectiveness, satisfaction of patients, relatives, receptor services, and stakeholders.
- Strong commitment to evaluation.

3
SPECIFIC VULNERABLE POPULATIONS: EXPERIENCES

Joan Marston

THE GLOBAL NEED

Over 21 million children worldwide are living with a condition that would benefit from palliative care; 8.1 million of these require specialized care[1]. According to the World Health Organization (WHO) 98% of these children live in low and middle income countries (LMIC) whilst most development and resources are in high income countries. While there is a steady growth of paediatric hospice and palliative care programs and educational opportunities in all regions of the world, the need is largely unmet.

The International Children's Palliative Care Network (ICPCN) has been mapping the development of palliative care for children since 2011 and this map shows the estimated levels of development in December 2016, the advanced development in high income countries and the huge gaps in development, especially in Africa. Yet it also shows that even in low-income countries such as Malawi and Uganda, palliative care can be provided.

CHARACTERISTICS OF PALLIATIVE CARE FOR INFANTS, CHILDREN AND YOUNG PEOPLE

Palliative care for children is similar to palliative care for adults[2] in that it is holistic, culturally relevant, involves the child patient and family, seeks to relieve suffering and to ensure the best possible quality of life and should be available from the time of diagnosis of a life-limiting condition through death and into bereavement.

1. S Connor; J Downing; J Marston. Estimating the Global Need for Palliative Care for Children: A Cross-Sectional Analysis. JPSM Vol53. No2. February 2017.
2. WHO Definition. www.who.int/cancerpalliative/definition/en/
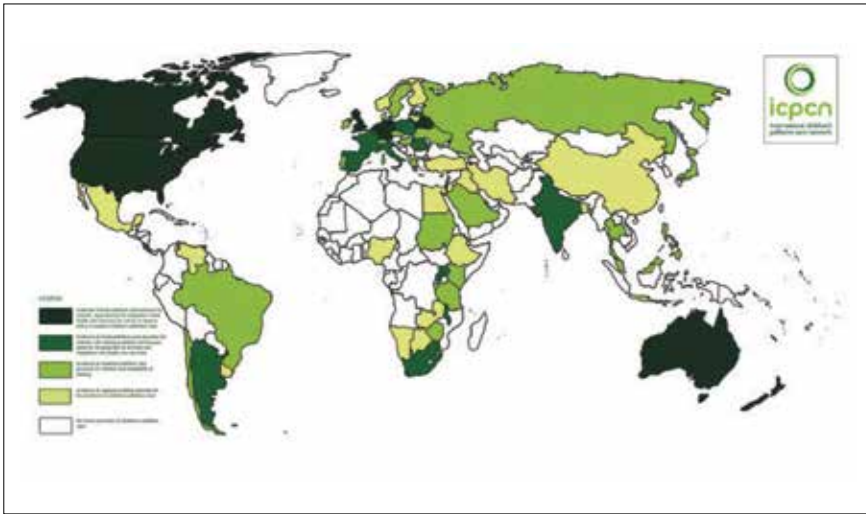
What makes the difference is the child him or herself, as this may be a tiny neonate, a growing infant, a child from toddler to adolescent with all the ages and developmental stages in between, each requiring a different approach, knowledge, and communication and assessment skills. This also means that models for providing palliative care will be different and developed to meet the needs of each stage of childhood and to ensure that the child has opportunities to develop as well as possible through play, stimulation, education and the provision of a suitable child-friendly environment.

Education in paediatric palliative care is essential and programs such as the ICPCN e-Learning modules[3] and EPEC (Education in Palliative and End-of-Life Care) Pediatrics are doing much to provide access to education globally and complement the too-few educational opportunities provided within some countries, even LMIC such as Uganda, Indonesia and India.

Children are seen with a wide variety of conditions, some not seen in adults

The impact of a child with a life-limiting condition on the family can be immense. Siblings are often neglected.

The child's understanding of illness and death changes as they develop.

The impact of poverty, lack of transport and/or funding for transport, poor home environment, lack of health resources, the cultural status of children and women all affect the provision of palliative care.

The multidisciplinary team may include members not seen in adult teams, such as midwives, paediatric nurses, teachers, play therapists, child psychologists and child-life specialists. Chaplains/spiritual care coordinators require an ability to communicate with children, and to identify, understand and meet their

3. www.icpcn.org

spiritual needs. Community caregivers in a number of LMIC provide most basic home palliative care and they require not only basic and ongoing education but also support and supervision from health professionals.

Special groups requiring attention include neonates, adolescents and children with disabilities.

A diagnosis may be made in the antenatal period, when preparation and support of the parents and siblings should begin, with special preparations for the birth and immediate post-natal period to possibly include the opportunity to stimulate memories through photographs, hand and foot prints.

PALLIATIVE CARE FOR CHILDREN WITH HIV: EFFECTIVE PROGRAMS IN SOUTH AFRICA

The development of pediatric palliative care in Africa was mainly in response to the HIV/AIDs epidemic where prior to access to anti-retroviral therapy (ART) mortality was high. With an estimated 800,000 children in South Africa[4] needing palliative care, most children on hospice programs have HIV-related conditions, despite improvements in access to ART.

South Africa has shown that effective palliative care can be provided through different models and there is no "one-size-fits-all". All have the same objective: to improve quality of life. All work closely with the primary health care system and provide training[5].

DIFFERENT MODELS[6]

- Hospices with both adult and children's programs e.g. South Coast Hospice in Kwazulu-Natal tend to focus on home-based care, including overseeing compliance with ART and Tuberculosis treatment, access to social grants, education and nutrition, using community caregivers supervised by professional nurses; and often include Memory Work
- The few children's hospices that have in-patient units e.g. Sunflower Children's Hospice in Bloemfontein admit children with HIV/ AIDS with complications to the unit but still provide most care in the home. The Sunflower Hospice works closely with the district hospital and Department

4. Connor S, Sisimayi C, MArston J et al. Assessment of Need for Palliative Care for Children in South Africa. International Journal of Palliative Nursing. 2014 vol.20 No3 Pg 130-134
5. S Connor; C Sisimayi et al. Assessing the Need for Palliative Care for Children. Three Country Report: South Africa, Kenya, Zimbabwe. 2014 UNICEF and ICPCN. www.icpcn.org
6. PatchSA Palliative Treatment of Children South Africa. www.patchsa.org Unpublished survey of programmes in South Africa

of Family Medicine to access professional, multidisciplinary resources, medicines and medicines.

- Umduduzi in Durban has a team of a doctors and social workers who see children in hospital or at home and advise the primary health care team. Umduduzi set up staff and fund play rooms in two government hospitals for long-term patients.
- PaedsPal in Cape Town employs a multi-disciplinary team led by paediatricians who provide a consultative service to Red Cross Children's Hospital and local hospitals, and gives some follow-up at home or work with other hospices to provide the ongoing care.
- Butterfly House, Drakenstein Palliative Hospice in Paarl provides palliative care as part of a variety of services to children and youth in their community in the Butterfly Centre.

LESSONS LEARNED IN SOUTH AFRICA

- Palliative care can be provided even when resources are limited.
- The vision of the founder and access to professional resources influences the development of the model.
- Education of health workers and the community is an essential part of each program.
- Access to play and developmental stimulation is an important element
- Close collaboration with the local health services is necessary for referrals and access to medicines, hospital beds and supportive services.
- Lack of sustainable funding threatens all programs.

CONCLUSION

Low-and middle-income countries, while lacking resources, have shown that effective palliative care can be provided for children. However, long-term sustainability is uncertain due to lack of ongoing financial support. Different models develop according to the vision of the founder, access to resources and the impact of disease. For palliative care to be available for all children, these models need to be thoroughly assessed for the reasons they are successful.

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