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RODERICK DUNCAN MACLEOD
LIEVE VAN DEN BLOCK
EDITORS

Textbook of Palliative Care

 Springer

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Roderick Duncan MacLeod
Lieve Van den Block
Editors

Textbook of Palliative Care

With 194 Figures and 184 Tables

 Springer

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Foreword by Luc Deliens

We recently commemorated the 100th birth anniversary of Cicely Saunders, born in 1918. She began her education by studying philosophy, politics, and economics at the University of Oxford and then qualified as a nurse during the Second World War in the Nightingale Home and Training School in London; as a medical social worker, again at Oxford; and then as a medical doctor in the 1950s at King's College London. Her multidisciplinary educational background, combined with her personal experience (she twice fell in love with dying patients, both Polish refugees) which included a period of what she called "pathological grieving" after a series of bereavements, will have had an impact on her thinking and the development of the concept of palliative care, but also on her activism and her decades-long campaign against the terminal neglect of those who are dying and the medicalization of death. She wrote her first medical paper on care for dying people in 1957, and by the summer of 1967, she had initiated palliative care as an interdisciplinary concept at St. Christopher's Hospice in London, in the establishment of which she was involved. She is now acknowledged worldwide as one of the founders of the palliative care and hospice movement. Ever since, the field of palliative care has grown rapidly across the world, and the scientific evidence for its effectiveness is steadily growing, as is the list of countries with a national palliative care policy. The number of scientific journals covering death, dying, supportive care, palliative care, and end-of-life care is also rapidly growing, and about 20 of these have an impact factor indexed by the Web of Science, with around 5 being classified in the upper quartile of their domain. Hence, this textbook is timely and one of the indicators that palliative care as a clinical as well as a scientific domain has come to full growth.

"Palliative care" can be understood in several ways. It can be understood as a clinical specialism for medical doctors, as it is now recognized by the Royal College of Physicians as a specialty within the UK; it can also be understood as a specialist palliative care service, e.g., an inpatient hospice or palliative care unit, in which a multidisciplinary team delivers the care of people with serious illnesses, or, as a concept of care, a holistic philosophy of care taking into account more than just medical problems such as the burden of physical symptoms. This is reflected in the holistic definition of palliative care by the World Health Organization in which (apart from the medical aspects), nursing, social, psychological, and existential aspects are covered, or ideally should be covered. The latter suggests that there is a difference between what palliative

care is in the real world and what it should be in the reality of our health-care systems; in most countries, the quality of palliative care in most care settings or contexts is suboptimal or can potentially be improved and further developed. This textbook can help clinicians, students, health-care providers, managers, researchers, and also policy-makers to improve their knowledge and skill in palliative care.

This textbook presents 101 chapters in 11 different parts: Palliative Care: Definitions, Development, Policies; Symptom Assessment and Management; Palliative Care Professionals and Provision; Organization of Palliative Care in Different Settings; Palliative Care in Specific Disease Groups; Palliative Care in Specific Populations; Palliative Care Emergencies; Ethics of Palliative Care and End-of-Life Decision-Making; Research in Palliative Care; Public Health Approach in Palliative and End-of-Life Care; and Financial Aspects and Cost-Effectiveness in Palliative Care. It offers a synthesis of the practice and knowledge base that has grown over the last 50 years. Since Cicely Saunders developed the concept of palliative care, focusing on preventing harm to people who are dying and promoting their quality of life, the field has evolved professionally and now covers a complex and wide range of aspects of care for all people with a serious illness, involving informal or family carers and volunteers as well as health-care professionals. Palliative care promotes life until death and should be understood as different from the narrow concept of terminal care. In order to challenge this narrow understanding, palliative care should also embrace the knowledge and skills of the disciplines of health promotion and public health, the latest developments of which are well covered in this textbook.

Cicely Saunders' multidisciplinary background is well reflected by the contents of the *Textbook of Palliative Care* and by its editors, a palliative care doctor, Professor Rod MacLeod from New Zealand, and a social scientist and clinical psychologist, Professor Lieve Van den Block from Belgium. The textbook, with over 100 chapters, covers the breadth of the domain, including clinical, health services, and public health-related aspects of palliative care. The editors should be congratulated on this impressive academic achievement and, more specifically because they have consulted a wide range of clinicians, far more social scientists, and public health experts than any other textbook on palliative care. I hope that this book, available online as well as in print, soon finds its way into the classrooms, universities, and vocational schools of all involved in the care of those who are dying or those with serious illness.

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Foreword by Sheila Payne

Palliative care has come of age. No longer can we claim, or make excuses, that palliative care is a young or novice discipline. This impressive *Textbook of Palliative Care* with over 100 chapters offers convincing evidence that palliative care is now a mature discipline. The textbook provides a comprehensive overview of numerous topics that form the core and substance of the discipline. The global reach of the chapter contributors and the distinguished section editors and the overall guidance from two remarkable editors have produced an outstanding testament to not only palliative care's place within medicine but also, importantly, within society.

However, let me caution you from any feelings of complacency and premature celebration. There are still many challenges ahead. We know from the work of the Lancet Commission on pain relief and palliative care that on a global scale, there remain very poor access to palliative care and woefully insufficient affordable and accessible pain relief (Knaul et al. 2017). According to the authors, in 20 health conditions where there were identifiable palliative care needs, 84% account for deaths in adults and 60% in children. Global projections indicate that between 40 and 80 million patients with advanced disease need access to palliative care, with 78–95% of them living in low- and middle-income countries (Knaul et al. 2017). Shockingly, infants and children have even less access to pain relief and palliative care than adults (Knaul et al. 2017).

One way forward is to ensure that the key principles of palliative care are taught as a fundamental part of all basic and post-basic health and social care education programmes. Let me draw a comparison here with the recognition of communication skills as a core element of all courses. When I trained as a nurse in the early 1970s in a well-respected London teaching hospital, my only communication skills education was the well-worn advice for nurses working in hospital wards, which was to *draw the curtains and reassure the patient*. Quite how I might provide that 'reassurance', when the poor patient was likely to be facing an uncomfortable, painful and/or embarrassing procedure, was never revealed. Fortunately, communication skills education is now a core topic in virtually all medical, nursing and other health professional programmes. In some countries, it is even mandatory. In my view, likewise, palliative care core competencies also need to be embedded in all health and social care programmes as essential aspects of professional education (Gamondi et al. 2013).

So what will be the future challenges facing palliative care? We need to be prepared to ‘give it away’ so that basic palliative care practices and knowledge move beyond the restricted domains of certain places such as specialist palliative care units, or disease groups such as those with cancer, or age groups, or professional disciplinary boundaries. I am not arguing that there is no future for specialist palliative care, as the people working in these settings, and with this expertise, are essential to drive the education of others; improve the quality of care, through research and reflective practice; and provide leadership. However, to ensure universal coverage and access to basic palliative care, more energy, resource and leadership need to be devoted to spreading the political and policy message that palliative care is not a luxury for the few but a fundamental human right.

Universal access to high-quality palliative care may not be quite within our grasp yet but should be a goal for everyone. Suffering, especially avoidable suffering, blights the lives of millions of people, creating a lasting impact on their families in terms of financial burden and emotional distress. Addressing the challenges of responding compassionately, while drawing on the best scientific evidence, to ameliorate suffering for those with complex, advanced and life-limiting conditions lies at the heart of palliative care. This textbook is a good example of this commitment to improve care for all in need.

This textbook is truly outstanding. I am not going to highlight specific chapters, as I am sure that all contributors will have fulfilled their brief under the guidance of the editorial team. It is a textbook to dip into, relishing the quality of the information contained in these pages. You, dear reader, will make your choices, but let me urge you to venture into new areas, perhaps reading those chapters that are outside your normal interest zone. Become a critical consumer of the material and resources presented in this textbook. How does it compare to your practice? What does it challenge you to think about in a new and different way? What do you agree with? This textbook, developed by an international team of experts, offers guidance on the development and establishment of all aspects of palliative care services, and it wonderfully captures the flourishing of a mature discipline.

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Preface

Nothing in life is to be feared, it is only to be understood.

Attributed to Marie Curie. *On ne doit rien craindre dans la vie—il suffit de comprendre* in Université Laval, Faculté de médecine, Société médicale des hôpitaux universitaires de Québec, Laval médical (1951), 16, 569

Palliative care has been identified as a discrete part of healthcare for over 50 years, and yet we still find ourselves having to explain the nature and practice of palliative care to many of our professional colleagues and to the public in general. Healthcare education and training has been slow to recognize the vital importance of ensuring that *all* practitioners have a good understanding of what is involved in the care of people with serious or advanced illnesses and their families. Because of this limited exposure, many laypeople and professionals still have understandable fear and anxiety about death and dying.

However, the science of palliative care is advancing, and our understanding of the evidence concerning many aspects of palliative care is developing rapidly. There are now excellent research teams and facilities around the world exploring different characteristics of this essential aspect of healthcare from a wide range of disciplines.

There have been many authoritative books on various facets of palliative care produced over the last years. In planning this *Textbook of Palliative Care*, we hoped to produce a comprehensive, clinically relevant, and state-of-the-art book, aimed at advancing palliative care, as a science, a clinical practice, and an art.

For this major reference work, we have been able to draw on our own collective experience and the goodwill of many fine people from around the world. We have endeavored to produce a *Textbook* that showcases the multi- and interdisciplinarity of palliative care and is unique in bringing together authors from all fields of palliative care – physical, psychological, social, and existential or spiritual. The majority of them are internationally recognized experts in their chosen discipline. We have been helped by dozens of authors and the committed section editors, who have given their time, expertise, and wisdom to ensure that this work can be disseminated around the globe to assist in the understanding of all aspects of illness and disease near the end of life as

well as death, dying, and into bereavement. Our authors have drawn not only on the evidence available but also on their own phronesis or practical wisdom. They have summarized and extended the state of the art in their field and challenge the reader with new insights, challenges, opportunities, and potential future evolutions. We are deeply indebted to all those who have been involved in the preparation, writing, and editing of this work. They all undertook their work with enthusiasm and commitment.

We expect this *textbook* will be of value to practitioners in all disciplines and professions where the care of people approaching death is important, specialists as well as nonspecialists, in any setting where people with serious advanced illnesses reside. It can also be an important resource for researchers, policy-makers, and decision-makers – national or regional – as well as for laypersons, patients, and/or families, seeking to learn more about palliative care. Neither the science nor the art of palliative care will stand still, so we hope to be able to keep this *textbook* updated as the authors find new evidence and approaches to care.

Our special appreciation goes to Vasowati Shome and Tina Shelton of Springer who have guided us expertly through the process of creating this reference work – we are deeply indebted to them.

March 2019

Roderick Duncan MacLeod
Lieve Van den Block

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About the Editors



Roderick Duncan MacLeod is a Palliative Medicine Specialist at Harbour Hospice in Auckland, New Zealand, and Consultant to HammondCare in Sydney where he is also Honorary Professor in the University of Sydney School of Medicine.

He gained his primary medical degrees from the University of Dundee in 1976 and went on to train for general practice. He was a Principal in general practice for almost 10 years before moving to the discipline of palliative care. He was first appointed as Medical Director of the Dorothy House Foundation in Bath, England, in 1989 after having completed a period of prolonged study leave exploring palliative care in the community. In 1994, he was appointed Medical Director and subsequently Director of Palliative Care at the Mary Potter Hospice in Wellington, New Zealand. He was made a Fellow of the Royal College of General Practitioners (UK) in 1999. He was a Foundation Fellow of the Royal Australasian College of Physicians, Australasian Chapter of Palliative Medicine, in 2000. He received his Ph.D. in 2001 from the University of Glamorgan (Prifysgol De Cymru) for his work and publications on “Changing the Way that Doctors Learn to Care for People Who Are Dying.”

In 2003, he was appointed to New Zealand’s first Chair in Palliative Care as the inaugural South Link Health Professor in Palliative Care at the University of Otago Dunedin School of Medicine and in 2013 was appointed Conjoint Professor in Palliative Care at the University of Sydney and worked clinically as Senior Staff Specialist in Palliative Care for HammondCare in Sydney. He has been a Member of the Australasian Chapter of Palliative Medicine

Education Committee, the NZ National Health Committee – Working Party on Care of People Who Are Dying, the NZ Palliative Care Expert Working Group, and the Council of the Asia Pacific Hospice Network. He was appointed to the Expert Advisory Group (Physician Education) and the Chapter of Palliative Medicine Committee of the Royal Australasian College of Physicians and the NZ Ministry of Health Palliative Care Advisory Group. He has also held a number of roles within Hospice NZ.

He has published over 130 peer-reviewed articles in the field of palliative care in national and international journals and has written over 20 chapters for palliative care texts. In addition, he has been on editorial boards of international peer-reviewed journals in the field of palliative care and has reviewed manuscripts for over 25 different academic journals. He has also published two anthologies of poetry, exploring what it might be like to approach death and experience bereavement and loss.

He is one of the authors of *The Palliative Care Handbook*, which has become a freely available standard text for healthcare professionals in New Zealand and parts of Australia.

He was appointed a Member of the New Zealand Order of Merit by Her Majesty Queen Elizabeth II in the Queen's birthday honors in 2015.



Lieve Van den Block is Professor of Ageing and Palliative Care at the Vrije Universiteit Brussel (VUB) and Chair of the Ageing and Palliative Care Research Programme at the End-of-Life Care Research Group of the VUB and Ghent University in Belgium. She holds a Ph.D. in Medical Social Sciences and a master's in Clinical Psychology. Professor Van den Block has been involved in palliative care research for over 15 years, focusing on national and international public health and interventional research aimed at monitoring and improving palliative and end-of-life care. She has received several scientific awards for her work, including the 2014 Early Researcher Award of the European Association for Palliative Care. She has published over 100 peer-reviewed articles on palliative care and is editor and author of several books and chapters. Her work has been supported by grants from the European Commission, national fundamental and applied research foundations, and leading medical and health charities.

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Part I

**Palliative Care: Definitions, Development,
Policies**



Approach and Nature of Palliative Care

1

Roderick D. MacLeod

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Abstract

Caring for people who are near the end of life has a relatively short timeframe as a specialist

health care activity. In this chapter, the history of palliative care is briefly outlined along with a description of who might provide such care. An introduction to aspects of learning in palliative care is followed by an emphasis on the importance of psychosocial-spiritual assessment and care; some of the universal needs of people who are dying is outlined. It is important to recognize the significance of understanding the social, emotional, psychological, cultural, sexual, and spiritual context of each

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clinical situation and to view these within our own and our institution's and perhaps our society's ethical framework. By doing so, we can begin to understand how best to understand the nature of palliative care and how best we might approach this most significant aspect of care in people's lives.

Caring for people who are dying is clearly not new but has been seen as a special form of care for centuries. In the first millennium, the Christian church was closely involved with this activity, and the original hospices were set up as resting places for travelers. Religious orders advanced the notion of care for people who were dying in the nineteenth century, and perhaps the first of its kind, St Joseph's Hospice, was founded in London in 1905. It was however as a response to the perceived inadequacies of medical care that what has become known as the modern hospice movement was born (Clark 2002). The pioneering work of hospices such as St Christopher's Hospice, which opened in Sydenham, London, in 1967, demonstrated that the principles of hospice care (good clinical practice, whatever the patient's illness, wherever the patient is under care, whatever his/her social status, creed, culture or education, <http://hospicecare.com/about-iahpc/publications/manuals-guidelines-books/getting-started/6-principles-of-palliative-care>) could be applied in a variety of settings.

Dame Cicely Saunders introduced the concept of whole person care in that institution and developed the model of "total pain" which highlighted not only the physical aspects of a person's pain but also psychological, social, and spiritual dimensions of their distress (Saunders and Sykes 1993). The term "palliative care" was coined in Canada in 1974 by Balfour Mount, a pioneering surgeon who had worked in London with Saunders and wanted to take the concept back to Canada where there could have been confusion among the French-speaking population about the term hospice. Using the term palliation to reflect the non-curative nature of care was not new – it had been used in the seventeenth century. This terminology was subsequently adopted in many countries, and a new medical specialty was proposed – that of

palliative medicine. The discipline received recognition by the Royal College of Physicians, London, in 1987 as a specialty within medicine in the United Kingdom (UK). Since that time other countries have adopted that approach, and palliative medicine and palliative care are practiced around the world in over 100 countries. A universally agreed definition of palliative care was disseminated by the World Health Organization (WHO) in 1986, followed by a revision in 1990. A revised and updated definition of palliative care was accepted by the WHO in 2002 (Sepúlveda et al. 2002).

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 or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the 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
- Will enhance quality of life and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Definitions are helpful in gaining consensus about the limits of a specialty, but what does it mean in practice? Generally speaking, people

with advancing disease need to be supported and cared for by clinicians with excellent skills.

1 Who Provides Palliative Care?

Palliative care is provided by two distinct categories of health and social care professionals:

- Generalist palliative care is provided by those working to provide day-to-day care to patients, families, and carers in their homes and in hospitals:
 - They should be able to assess the care needs of each patient and their families across the domains of physical, psychological, social, and spiritual needs.
 - Meet those needs within the limits of their knowledge, skills, and competence in palliative care, and know when to seek advice from or refer to specialist palliative care services.
- Specialist palliative care is provided by professionals with additional training in the discipline and who only work in palliative care (e.g., consultants in palliative medicine and clinical nurse specialists in palliative care).

2 Specialist Palliative Care Services

These services are provided by specialist interdisciplinary teams and include:

- Assessment, advice, and care for patients and families in any or all care settings, including hospitals and care homes, also known as palliative care consultation
- Specialist inpatient facilities (in hospices or hospitals) for patients and families who benefit from the continuous support and care of those specialist teams
- Intensive coordinated home support for patients with complex needs who wish to stay at home (this may involve the specialist palliative care service working with the patient's own doctor and community nurse to enable someone to stay in their own home).

- Many teams also now provide extended specialist palliative nursing, medical, social, and emotional support and care in the patient's home, often known as "hospice at home."
- Outpatient clinic appointments and day-care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological, and social interventions within a context of social interaction, support, and friendship. Many also offer creative and complementary therapies.
- Advice and support to all the people involved in a patient's care.
- Bereavement support services which provide support for the people involved in a patient's care before and following the patient's death.
- Education and training (and for many, research) in palliative care.

The specialist teams should include palliative medicine and palliative care nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, art and music therapists, dieticians, pharmacists, social workers, and those able to give spiritual and psychological support.

3 Who Should Receive Palliative Care?

Anyone with a life-limiting disease should be able to have access to palliative care services. Historically modern palliative care services were primarily involved with providing care for people with cancer and some neurological disorders such as motor neuron disease or other degenerative disorders of the nervous system.

The other major group of people who should receive palliative care are those with failure of one of the major organs of the body such as the lungs, heart, kidneys, liver, or brain. In these situations, people often have a prolonged period of time to adjust to the understanding that the body is failing. One problem though can be that medical science has become so adept at propping up failing bodies that the realization that death is approaching may not be so apparent. This can produce problems for families and carers as death approaches.

It has been suggested that the clinical course of people who do not die suddenly tends to follow one of three trajectories (Dy and Lynn 2007). The first is the maintenance of relatively good function until a predicted decline a few weeks or short months before death. The second is the course of chronic organ failure which shows a slow decline with exacerbations that may end in sudden death. The third trajectory is one where there is poor functional status over a long time with a slow but relentless decline; frail elderly people with many comorbidities fit into this group. It is important therefore that services are developed for people who are dying in any of these ways. There are a number of models available – for example, the Gold Standards Framework in the UK which incorporates resources and end-of-life tools into primary care, hoping to enable people to have real choice about where they wish to die (Thomas 2003; King et al. 2007).

Of course, the majority of people who are dying would prefer to do so at home being cared for by their primary healthcare professionals. Primary care shares common values with specialist palliative care – holistic, patient centered, and delivered in the context of their families – but too often it becomes difficult for a number of reasons for people to be cared for in their own homes (Murray et al. 2004). Developing primary palliative care is essential if people are to exercise their right to die in the bed of their choice.

Twenty years ago, David Field, an expert in the sociology of death and dying, identified two important differences between patients with cancer and those with nonmalignant conditions (Field 1998). Perhaps not much has changed over those 20 years? First, differences in disease progression mean there is a continuing benefit from curative/restorative interventions and treatments for the latter category. Second, there was greater uncertainty about the fact and likely time of death with non-cancer patients. Field identifies the latter as appearing to be the key obstruction to extending specialist palliative care services to non-cancer patients. This is because they will not be seen as suitable candidates for palliative care until they have been defined as terminally ill. One of the reasons that this may occur is because of the

difficulty many clinicians have in dealing with uncertainty in general. In medicine, and possibly in other disciplines as well, uncertainty stimulates and propels activity (Hall 2002) – doctors have a “propensity to resolve uncertainty and ambiguity by action rather than inaction” (Katz 1984). Increasing diagnostic uncertainty leads to a reluctance to withdraw from “active” interventions, leaving patients and families in a similar situation of ambiguity and doubt about the future (Christakis and Asch 1993). This relates to a tendency for the continuation of what might be deemed futile treatment in the face of relentlessly advancing disease. Taken out of context (i.e., without considering the person as a whole), almost any disease may be deemed “treatable” – such are the advances in medical science and technology. This confidence in the advancement of medical science is relayed not only to the medical and nursing professions but to the lay public as well, with a consequent sense of expectation that is unfortunately not wholly realized. This situation is compounded with the advancing age of people being treated. Many elderly patients have multiple clinical diagnoses involving multi-system pathology, and the diagnosis of dying is often made only by exclusion. Communication may be more difficult due to a combination of a higher incidence of confusion in elderly patients with nonmalignant disease than in younger people with cancer, and reduced social networks in the elderly may potentially lead to reduced care and support from family and friends. The incidence, duration, intensity, and type of symptoms follow a different pattern in cancer compared to other illnesses. People with nonmalignant disease also tend to be older. People aged 75 and over who do not die from cancer are more likely to have outlived their spouses, brothers and sisters, and even their children. They are predominantly women, and many live alone or in residential care and therefore present differing challenges for the provision of social support.

The scope of palliative care therefore extends beyond people with a diagnosis of cancer to include patients with other chronic life-threatening diseases.

Perhaps one of the greatest challenges for palliative care services is the provision of care for people with dementia – an area which until recently modern palliative care avoided (<https://www.nhpc.org/hospice-statistics-research-pressroom/facts-hospice-and-palliative-care>). The annual incidence of dementia in North Americans, for example, doubles nearly every 5 years from 7 in 1000 (65–69 years of age) to 118 in 1000 (86–89 years of age) (Hanrahan et al. 2001). The European Association for Palliative Care (EAPC) published a white paper which helpfully defines optimum palliative care for people with dementia and provides a set of 57 recommendations for practice, policy, and research (van der Steen et al. 2014). Further, the white paper provides a model of dementia progression and suggested prioritizing of care goals and a recommendation of further research into how to give shape to palliative care in dementia across dementia stages.

4 How Should Learning in Palliative Care Be Approached?

Clearly much of what is taught and what is learned is of a technical and knowledge-based nature. This is fundamental in any healthcare practice and particularly relevant in a specialty where so many patients have such a wide range of clinical problems. It would be seductive to imagine that the essence of palliative care lies within these technical and knowledge-based areas, but it is essential that those responsible for teaching and learning in this area maintain a focus on those aspects of the discipline that are less easily quantified and identified. In any domain of professional practice, it is important to identify the true nature of that practice. Professional practice involves not only professional content but also professional process, and it is in the untangling of these two elements that we can discern something of the difficulty facing those responsible for the training of palliative care clinicians for the future. Palliative care cannot be seen solely in terms of skills and knowledge – it must include those processes that can be identified as meta-cognitive and reflective as well (MacLeod 2000).

The care of seriously ill and dying people necessitates a philosophical and ethical basis. Palliative care must be based on a philosophy that acknowledges the inherent worth and dignity of each person. The ethic of care must include respect for autonomy, justice, non-maleficence, and beneficence. The context of death exerts a powerful influence over what is said, received, and interpreted, and professionals must relinquish control, share decision-making, and treat patients and families as partners.

Caring can be thought of in terms of behavior or as a motivation. As behavior, it is often thought to mean “looking after people and seeing to their needs.” As a motivation it can refer to being fond of someone, feeling sympathy or empathy for that person, being concerned for their well-being, or having a professional commitment to them. It could be argued that the best caring professionals show both of these aspects of care. If we care about anything or if we care for someone, it is because deep caring is part of the very nature of our being (van Hooft 1996).

Empathy is an essential component of the way that care is provided and can be an elusive concept in medicine. Empathy helps us to know who we are and what we feel. Empathy requires living and knowing – it requires the ability to put oneself imaginatively in the place of another. The aspect of empathy that is crucial for clinical practice is that of genuine attention to the individual’s concerns and the acceptance of those concerns. Empathy can be thought of as a mode of caring. Specifically, it involves caring for the fate of another human being – the concept of empathy is relevant to the care of people who are dying because more than anything they are people in need. Empathy is an understanding of how a disease or its treatment is likely to affect how patients actually live and hope to live their lives. It is an openness to, and respect for, the individuality of another human being.

Francis Peabody (1927) emphasized the importance of getting to know the patient as a major part of the art of medicine. By writing that the art of medicine and the science of medicine were not antagonistic but supplementary to one another, he was essentially saying that empathy is

a prerequisite for the effective care of any patient. It was perhaps particularly poignant that Peabody was terminally ill when he wrote the article.

Sir William Osler (1904) wrote “it is a safe rule. . . to have no teaching without a patient for text and the best teaching is taught by the patient himself.” This was written in 1904 in an attempt to encourage students to learn at the bedside rather than through books alone. This assertion encourages students to pay heed to the patients’ stories and the themes that flow from them. Empathic listening is a most powerful means of understanding a person and the things in their life that are of significance for them at that time. Until the start of the nineteenth century, the science of medicine was taught as an apprenticeship – not based on scientific principles but on clinical observation and narrative. Such stories were once the primary source of medical knowledge and the science of medicine developed through the collection of anecdotes. The case presentation is the narrative center of medicine as a discipline – the care of the patient begins with such a story, and the clinician translates those stories in a way that helps the patient understand their ill-health. Without the experience of such stories, the education of healthcare practitioners is incomplete. It is also possible though to encounter stories in other forms; literature, poetry, art, film, and music can all give indications of the human condition and can help us better understand the meaning of care.

Over the last 50 years, since the birth of the modern hospice movement, great progress has been made toward the alleviation of many symptoms that accompany the end of life – particularly in those who have malignant disease, so enabling the maintenance of the highest possible quality of life. Such progress has been made in clinical practice that in many minds the “mainstreaming” of palliative medicine into all healthcare is a given. Alongside this mainstreaming is a desire to see palliative care practiced with the same evidence-based approach that other specialties and subspecialties are adopting. This is clearly a laudable sentiment. However, there is a danger that in adopting such an approach much of what is unique about care at the end of life may be lost. If we are to focus on purely practicing from an

evidence base, we will surely lose aspects of the art of clinical care as we become more and more seduced by the science of what we have been led to believe is predominantly a scientific discipline. For example, the doctor’s role as technician, guided by standard empiricism, does not exclude their adopting other roles as a consoler, healer, or even friend. The evidence that is built from the “gold standard” double-blind, randomized, controlled clinical trial has been a powerful instrument in furthering medical knowledge, but it is often not enough in recommending a form of management or treatment for a particular individual. Medicine is an art that is especially concerned with human beings as individual and unique creations, but it provides us with a context that shows us that our bodies are fragile and that ultimately they will fail us. The good that medicine in particular and healthcare in general is purported to achieve is not just the maintenance of organic functioning. It is also to maintain a spiritual, emotional, and social well-being that enables each individual to function to some degree within the society in which we live. If we focus too strongly on the achievement of biomedical good, there is a danger that the shortcomings of modern healthcare will be exposed. Evidence-based practice and the strong beliefs of standard empiricism offer a structure for analyzing clinical decision-making but are not sufficient to describe the more tacit processes of expert clinical judgment. It is not possible to find or provide evidence for all aspects of clinical competence. There is a generally widely held belief that medicine has become so powerful that it enables us to overcome not only the bodily ills that we may all experience but also some of life’s other misfortunes, not only physical pain but human suffering as well. Part of the difficulty with developments in the academic aspects of medical and nursing sciences is that they tend to have a narrow focus on what constitutes knowledge (and therefore the “evidence base”). It is the application of the knowledge base that becomes problematic in health sciences. It is not sufficient to address only the technical approaches to disease management; there must also be a realistic context for social definition. Those who work with people at the end of life

soon realize that we often face the limits of medicine and the temporal and physical limits of being human. When we acknowledge that all our efforts are for the “good of the patient,” we also are confronted with the limits of our clinical expertise and face the reality that ultimately what we offer people is not our role as doctor or nurse but as human being. The challenge for clinicians is to identify not only the evidence base for the practice of palliative care but also the features of sound clinical judgment and the character of those clinicians who make those judgments. It is in this aspect that we must identify the role of wisdom in palliative care. Professional practices are refined by science and corrected by wisdom (Cogan 1953). Wisdom is a form of understanding that combines the practicalities of knowledge with a reflective approach to the utilization of that knowledge over time. There are certain aspects of wisdom that can be readily identified. Practical wisdom is that habit of mind that enables one to choose well, not only with respect to a particular domain of human action but in the whole of one’s life. It is the “intellectual virtue that orders human practice in order to attain truth for the sake of action as opposed to truth for its own sake” (Pellegrino and Thomasma 1993).

So, understanding the nature of care, the importance of empathy, and the utilization of wisdom are all essential in our approach to the care of people who are dying. There are some specific dimensions of care that we need to address, and these are identified below.

5 Psychosocial Care

Psychosocial care (a better term might be psychosociospiritual care) has been defined as that which is “concerned with the psychological and emotional well-being of the patient and their family/carers, including issues of self-esteem, insight into an adaptation to the illness and its consequences, communication, social functioning and relationships” (National Council for Hospice and Specialist Palliative Care Services 1997).

Psychosocial care addresses the psychological experiences of loss and facing death for the patient

and their impact on those close to them. It involves the spiritual beliefs, culture, and values of those concerned and the social factors, which influence the experience. Psychosocial care includes the practical aspects of care such as financial, housing, and aids to daily living and overlaps with spiritual care. Spiritual care is less easy to define and is often subjective, arbitrary, and personal. It is generally assumed to include an individual’s beliefs, values, sense of meaning and purpose, identity, and for some people religion. It may also encompass the emotional benefits of informal support from relatives, friends, religious groups, and more formal pastoral care. For many, existential questions about the human condition can be ignored during many phases of life but are brought into acuity at the end of life (Williams 2006).

Psychosocial care also includes the professional carers who are inevitably affected by their experiences and who thus require support.

Thus, psychosocial care encompasses psychological approaches, which are concerned with enabling patients and those close to them to express thoughts feelings and concerns relating to illness. It also incorporates interventions to improve the psychological and emotional well-being of the patient and their family/carers.

In the past there has been a greater emphasis on psychological needs than social needs – the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS 1997) have emphasized the importance of social care to patients:

The social fabric of their lives is central to how they make sense of their illness experiences, the meanings they draw upon to understand these and the range of resources they can call upon to help them manage them.

In practice, the social aspects of palliative care are often limited to a focus upon the patient’s family, ignoring community influences.

6 Psychosocial Assessment

Patients and families face a range of issues which are not only related to illness and approaching death. Healthcare professionals need to assess

individual strengths and coping styles, experience, and stress and attend to previous losses.

The initial assessment of a patient is carried out by a member of the specialist palliative care team and will include a detailed assessment of the patient's and family's/carers' needs. The time invested in this initial assessment is essential in creating a framework for the provision of future care, a partnership between patient and professionals. The initial assessment may indicate the need for more formal psychological, social, or spiritual assessment. This will for many include the need to maintain autonomy which includes respect for dignity and the opportunity to exercise choice.

In order to identify caregivers at risk of poor psychosocial functioning, self-reported anxiety and competence rating is suggested as an aid to care provision (Hudson et al. 2006). A small group of caregivers (35) was studied. Using a screening tool, these researchers identified the possibility of low-level psychosocial functioning as a potential determinant for family caregivers at risk of psychosocial distress.

There are however a multitude of assessment tools and techniques that will illuminate elements of psychosocial well-being and identify psychological and social needs of patients and caregivers.

The psychosocial aspects of care of the dying person whatever their diagnosis include the need for:

- Understanding – of symptoms and the nature of disease and of the process of dying
- Acceptance – regardless of mood, sociability, and appearance
- Self-esteem – involvement in decision-making
- Safety – a feeling of security
- Belonging – a wish to feel needed and not to feel a burden
- Love – expressions of affection and human contact (touch)
- Spirituality – an explanation of meaning and purpose, both religious and nonreligious
- Hope – for an improvement in any aspect of their life or of their living

In the provision of psychosocial care for people at the end of life, each of these needs must be identified and addressed.

7 Social Context

Social elements of care are often influenced by the disease that is ending a life. Dying from a non-malignant disease, in many ways, creates a different social structure or standing than dying from cancer. The language that we use is quite different – for example, people who die from cancer are often referred to as “brave” in their “battle” with cancer. They often talk of “beating” the disease or “fighting” it. Nonmalignant disease does not seem to have that same social cachet. Death from end-organ failure is often silent and slow – in many ways relentless in its nature. Without heroic medical interventions to replace organs or use artificial means to support ailing bodies, many of these people would die earlier and perhaps more suddenly. In identifying social or psychological care for these people, it is important to recognize this significant difference in perception of disease that is possible to have originated both from the individual and from society.

For many people with cancer, there are well-recognized social networks or programs that may provide both psychological and social support. Social supports for people with non-malignant diseases should emerge from people in similar situations, family, and friends and from the wider community. With the exception of some of the neuromuscular degenerative diseases, many of the current support systems for people with nonmalignant disease are focused on raising awareness and funding for curative interventions rather than supporting people in the last stages of their disease. The professions, while openly supporting cancer networks and programs, have been slower to acknowledge the need for similar systems for people with incurable nonmalignant disease.

8 Emotional Context

Some feelings and emotions are almost universally experienced near the end of life.

- Fear of being left alone or having to leave loved ones, of breaking down or losing control

- of the situation they are currently in, getting worse.
- A sense of helplessness in which physical and psychological crises show up human powerlessness. Alongside this is the knowledge of physical and emotional strength gradually deteriorating – loss of physical ability bringing with it attendant psychological and social helplessness.
 - Feelings of sadness for what is not to be and for the loss to come.
 - A sense of longing for all that has gone before and all that is not going to be, in the future.
 - Feelings of guilt for being better off than others or regret for things that have been done or not done.
 - A sense of shame for having been exposed as helpless, emotional, and of needing others or for not having reacted, as one would have wished.
 - Anger at what has happened, at whatever caused it or allowed it to happen, that the treatment hasn't worked, at the injustice and senselessness of it all and the shame and indignity and at the lack of proper understanding by others.

These feelings and emotions may also be influenced by memories of feelings or loss or of love for other people in their lives who have been injured or died, perhaps let down by doctors, by the system or society, or by the family.

9 Psychological Context

The fundamental clinical skill of medicine is acquiring the history of the illness from the patient, and providing the patient with the opportunity to identify their concerns is mandatory. Specific questions need to be asked to elucidate psychological distress; in particular, they should include questions concerning fatigue, hallucinations, and suicide risk (Macleod 2011).

Examples of psychological interventions include psychosocial support and psychotherapy, behavioral-cognitive therapies, and educational therapies.

Initially it is helpful to look for indicators of pathological levels of psychological disturbance such as clinical depression or other mood disturbance or personality disorder. These lend themselves well to specific psychological

interventions. Variables suggesting that the patient or family is at serious risk of psychological disorder or distress may be identified (e.g., social isolation or a history of psychiatric hospitalizations). All members of the healthcare team may observe and subjectively report distress that they feel is psychological in nature (fear or anger) or psychologically mediated (pain or breathlessness) but may not meet the criteria of a discrete psychological disorder. The team should also look for the potential for preventative interventions that may forestall, minimize, or bolster resources for predictable areas or times of vulnerability and hardship (similar patterns of ill-health, pre-bereavement work, or anniversary calls to the bereaved).

Specific psychoeducational interventions that may enhance coping skills, psychological insights, and quality of life should be employed, regardless of the presence or absence of clinical levels of psychological distress. (For an extensive review of psychiatric syndromes and interventions, see Macleod (2011).)

People with neuromuscular degenerative disorders such as motor neuron disease, multiple sclerosis, muscular dystrophies, and less frequently seen disorders like Creutzfeldt-Jakob disease may have particular psychological needs associated with their care. Such disorders bring with them potentially challenging communication issues. For example, some patients may not be able to communicate verbally but retain effective cognitive functioning. It is important to help families to differentiate between behavioral disturbances associated with cognitive impairment from other communication difficulties. Cognitive impairment, depressive symptoms, emotional incontinence, or lability all need expert assessment and careful explanation and management. All or any of these may significantly impact on coping ability, psychological adjustment, and communication both of the patient and family (Macleod 2001).

10 Cultural Context

In palliative care, the cornerstone of practice is the holistic approach to care that is exemplified by the management of “total” pain. As stated earlier, this

classically includes physical, psychological, social, and spiritual pain. Cultural pain or distress can be expressed through any of these dimensions. Often closely allied to culture is spiritual and religious beliefs that have a bearing on how people approach and understand their disease. In many societies people define themselves by their religious, cultural, or tribal grouping, even when their faith or immersion in religion or culture is limited. There are wide variations between people of differing faiths, ethnic backgrounds and national origins, and their approach to the end of life. Although documented evidence is sparse, there is anecdotal evidence to suggest that there is a difference in approach to dealing with malignant and non-malignant disease. In order to understand these differences, it is important to understand the culture from the perspective of the patient and family.

In caring from people of a different culture to our own, it is imperative that we understand the expectations of that culture in order that we act appropriately. For example, the notion of individual autonomy is essentially a western one – many peoples live together and make decisions together in extended families. Many people in China, Japan, and the Pacific Islands as well as many Māori in New Zealand, for example, consider the family as the fundamental unit of society and will expect the family to make medical decisions. Without the accurate and honest provision of information in the right form, at the right time, and in the right place, there can be little hope of an understanding being reached about the situation the patient and family is facing and the goals of care that are being formulated. Without asking, we cannot know what individuals need to make a difference to the end of their life. That asking must include an acknowledgment of difference – difference in culture, in religious beliefs, in understanding of the nature of disease, in expectations in a particular situation, and in perceptions for hope at the end of life.

11 Sexual Context

Sexuality is an element of being that is often easily sidelined or overlooked when caring for people at the end of life, particularly if those

people are elderly. It is too often assumed that because people approaching death are weak and tired that their sexual identity or needs are minimized, this fails to recognize the many ways in which human beings can express their sexuality. Staff often view people's sexual interests as "behavioral problems" rather than natural occurrences or expressions of needs for loving contact (Steinke 1997; McPherson et al. 2001). Many people approaching the end of life with a non-malignant disease have had a relentless decrease in their physical being for some time. Much of their time may have been spent in repeated hospital admissions and the physical isolation that encourages. Many treatments, as well as the diseases themselves, can affect sexual function, and of course sexual activity will most often not be at the forefront of people's minds as they approach death. Acknowledging that all people are sexual beings is a starting point in helping people address their sexual needs and wishes – it is in no way different to acknowledging that they are physical or emotional beings as well. This is one aspect of their functional health that can contribute to their sense of self-worth or self-esteem. Changes in physical appearance, size, skin color, and texture as well as increasing fatigue often decrease an individual's sense of self-worth or attractiveness. Identifying psychological elements of their functional health may help to reverse this decrease. Providing information and advice on ways of expressing sexuality other than through sexual intercourse may help to restore an individual's sense of worth in this aspect of themselves.

12 Spiritual Needs

Understanding spiritual needs is essential in the care of people who are dying as these needs are intertwined with an individual's meaning of life, hope, transcendence, and beliefs as they arise from social relationships. Near the end of life, for example, pain can present that defies the efforts of clinicians to manage it. Increasingly clinicians, researchers, and educators have acknowledged the importance of spirituality in the end of life. The

presence of spiritual pain, especially in people who are dying, can be recognized in terminal agitation or restlessness in the absence of other obvious factors. This can manifest as a pre-death event that indicates physical, psychological, and/or spiritual discomfort or distress.

A particularly helpful definition of spirituality that has been articulated by Puchalski et al. (2009) was arrived at by consensus in a conference of invited expert practitioners. This definition states: “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”

Meaning as related to life purpose is aptly described as “having a sense that one’s life has meaning, or involves the conviction that one is fulfilling a unique role and purpose in a life that is a gift” according to Frankl (cited in Chochinov and Cann 2005, pS107). Palliative care aims to recognize and facilitate resolution of spiritual, social, emotional, and physical issues to enable dying well. Clinicians need to be able help people to identify any sources of spiritual unrest and to contemplate their contextual meaning and importance so assisting in the alleviation of spiritual suffering at the end of life.

13 Ethical Context

In all of our care for people near the end of life, one of our goals is to help people to do what they want in the way that they want. In many ways that is what has become known as autonomy. People’s choices at the end of life are often different to those they may make earlier in their life. Patients’ authority to choose what interventions they have and even to refuse interventions is seen as one way of protecting dignity and autonomy. Being in charge is better than having control taken away (Carter et al. 2004). That idea of being in charge though will be different for people from different ethnic groups. Professional carers need to ensure that they understand the nature of communication and decision-making that is the norm for each

person and family they encounter. Assessment of family dynamics from a different culture may help ensure that their ethical constructs are not overridden.

The ethics of the provision of palliative care are really no different to those required for any form of healthcare; however, in providing care for the most vulnerable, there are particular issues to address. Palliative care must be based on a philosophy that acknowledges the inherent worth and dignity of each person and in order to understand that worth and dignity every facet of their being should be explored – not just the physical. This philosophy must be based on an ethical framework – this is most commonly represented by the “four principles” postulated by Tom Beauchamp and James Childress in their textbook *Principles of biomedical ethics* – autonomy, beneficence, non-maleficence, and justice (Gillon 1994). These principles encourage a sharing of decision-making between carer and cared for but also create the right environment for promoting patient well-being. In addition to this framework, virtue-based ethics may give some indicators for the way in which we could practice our professions. Virtues are often thought to be “old-fashioned,” but they are particularly relevant to end-of-life care.

Integrity and trust are perhaps the cornerstones of the caring relationship. Development of these can be gained by attending to the psychosocial and spiritual as well as the physical wants and needs of individuals and families. Trust is essential in any human relationship but in one where one party is so vulnerable then perhaps it is even more important. In all of our dealings with patients and their families, we must be truthful and honest. People who are dying have lost so many elements of their being that it is essential that they can maintain trust in their professional attendants.

Compassion, a further virtue required in all our dealings with patients and their families, could be described as suffering together *with* another or participation *in* suffering. Suffering is clearly not only related to the physical elements of our being, and in order to understand suffering in its broadest sense, we must address social, psychological, and spiritual elements as well.

Phronesis is a virtue rarely mentioned in modern practice, but it is essentially prudent. Nowadays this can be regarded as timidity, undue self-interest, or unwillingness to take risks, but it might also be considered to be discretion or common sense. In history, phronesis was thought to be practical wisdom – the link between the intellectual and moral life. Phronesis urges us to look for the right way of acting.

In modern healthcare practice, working from an effective evidence base, where randomized controlled trials are sought for as many interventions as possible to guide us, it is often forgotten that practical wisdom, phronesis, can guide us where there is no concrete evidence to do so.

The virtue of justice or fairness requires that people are not put down or labelled in any way. Such labels can determine how people are cared for in the future, and they may often have arisen from isolated encounters. So often, labels can imply intolerance – this in turn can lead to an expectation that there is a particular “right” way to live or a right way to die.

Integrity defines the nature of the individual, and it also integrates all the virtues.

A person with integrity is someone who can judge the relative importance in each situation of principles, rules, guidelines, and other virtues in reaching a decision. It implies honesty and righteousness. The integrity of a person is shown in the right ordering of the parts in relation to the whole, the balance, and the harmony between the various dimensions of human existence necessary for the healthy functioning of the whole organism (Pellegrino and Thomasma 1993). It is a balanced relationship between the physical, psychosocial, and intellectual elements of their lives. This could be a definition of what palliative care should be about.

The doctor/patient relationship relies on integrity and trust. Neither party must impose their values on the other. Overriding another person’s values is an assault on their humanity and their person.

Using these principles and virtues enables carers to address some of the challenging moral or ethical issues near the end of life. Aspects such as people asking for or insisting on futile treatments, balancing ordinary and extraordinary

treatment, the doctrine of double effect, and the relationship between killing and letting die have attracted much discussion and comment over the last four decades, and the debate has been considerably better informed by research, investigation, and dialogue between those in the palliative care community and their colleagues in the field of medical bioethics.

The developments in the provision and understanding of palliative care have enabled a more informed discussion of these topics, but resolution for many in our broader society is still a long way off. However, by attending to people as whole people within the context of their family whoever that may be, we stand a much better chance of meeting their needs – not just their physical needs but their psychological, their social, and their spiritual needs as well.

One aim of palliative care then is to care for people in a way that facilitates dying well. This notion is dependent on many variables that encompass the holistic dimensions of our existence. Dying well is likely to be different for everyone, and seeking a universal definition of what it means may be futile. Dying is, to a greater or lesser extent, a social event (Kellehear 2008), and denying the psychological, social, and spiritual aspects of the dying person leads to a less than optimal dying experience. Understanding the many dimensions of the approaches to and the nature of care then is a prerequisite to starting to get that way of caring right for each person and their family that we encounter as they approach the end of life.

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Abstract

Improving the quality of life is considered a central goal of palliative care, together with the

prevention and relief of suffering. However, there is no broadly accepted definition of palliative care. Quality of life may be defined as the gap between expectations, hopes, and ambitions and the present experiences (Calman gap). With progression of the underlying disease, and deterioration of physical and cognitive performance status, patients may still report good quality of life, if they reduce their expectations or shift the focus to other areas to find quality of life (response shift). However, patients experiencing rapid progression of severe illness may be overwhelmed with the

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next steps of deterioration, and may not be able to adapt their expectations quickly. Using quality of life measures as a primary outcome parameter for palliative care may be difficult, as there are so many things that affect it that have nothing to do with the provision of palliative care.

A large number of assessment instruments have been published for quality of life. The Short Form Survey of the Medical Outcome Study (SF-36) and its even shorter forms SF-12 and SF-8 are most prominent for health-related quality of life. The Functional Assessment of Chronic Illness Therapy (FACIT) and the European Organization for Research and Treatment of Cancer (EORTC) family of tools are used extensively for disease-related quality of life. The Schedule for the Evaluation of the Individual Quality of Life (SEIQoL) is a prominent example for the assessment of the individual quality of life.

However, many palliative care patients can only complete short and simple assessment instruments. The EQ-5D uses only six items, but also single-items have been tested.

A number of concepts overlap to some degree with quality of life, such as overall happiness, meaning in life, sense of coherence, or quality of dying and death. However, with all these concepts, some components of the quality of end-of-life care and the quality of dying may be difficult or even impossible to measure.

1 Quality of Life: A Central Goal of Palliative Care

Following the definition of palliative care of the World Health Organization from 2002, quality of life is central to the concept of palliative care: *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 (Sepulveda et al. 2002).

This has been confirmed in a discourse analysis of a broad range of English and German definitions of palliative care (Pastrana et al. 2008), which found a striking agreement that prevention and relief of suffering and improvement of quality of life are considered as central goals of palliative care.

As improvement or at least maintaining the best possible quality of life for patients and families is per definition the main goal of palliative care, this merits a close look at the concept, and more specifically, how to define quality of life and how to operationalize and assess it.

However, this may not be easy, as the lack of a satisfactory definition of quality of life has been highlighted by Randall and Downie in their critical review of the philosophy of palliative care, though they note that *judging by volume of literature on the topic, the search for one has not been abandoned* (Randell and Downie 2006).

The strong focus on quality of life is not unique for palliative care, as other areas of medicine, especially those that deal with chronic (incurable) disease such as Endocrinology, Genetics, or Neurology – share this goal (Strawson 2014).

Palliative care is not restricted to the terminal phase, and indeed early integration of palliative care in the disease trajectory of severely ill patients is an emerging focus. However, many patients are facing death, or at least the sudden impact of a short prognosis, and are grappling with a drastic reduction of the remaining lifespan. For these patients, the question arises whether they can experience any quality of life at all, or how there can be any improvement of quality of life when facing death.

However, clinical experience shows that palliative care patients are able to experience good quality of life. In some patients, quality of life is astonishingly high. Relief of suffering with adequate symptom control can increase quality of life, but also other factors may be essential to maintain or even increase quality of life in spite of the prognosis, e.g., a feeling of connectedness.

Even though patients would not often use the term quality of life, they have a clear understanding how to fill the concept for themselves.

2 Quality of Life Concepts

There is considerable agreement that quality of life is a multidimensional construct integrating a broad spectrum of indicators of personal well-being (Felce and Perry 1995). In general, quality of life will be influenced by the degree that the needs of the individual are met. These needs will vary widely depending on the setting.

In the resource pool setting, quality of life will depend largely on regular, if possible daily, access to clean water, food, shelter and heating, and if possible money. In richer settings, coverage of these basic needs is taken for granted, and quality of life will depend more on the pursuit of professional and personal ambitions.

Maslow has described this in the hierarchy of needs (Maslow 1943, 1954), which starts from the basic needs of living and ends with the need for personnel growth (Fig. 1). The first four levels are deficiency needs, which motivate people when they are unmet. These needs will become stronger when they are not met: the longer you lack access to water, the more thirsty will you become. When

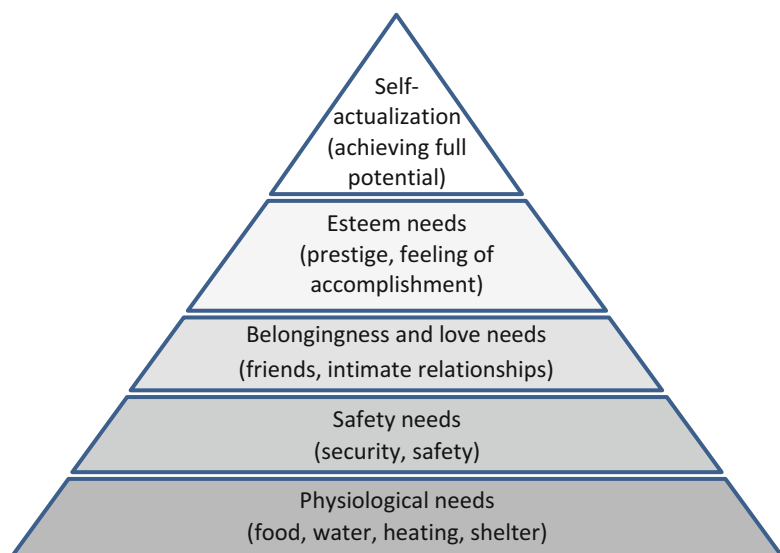
a needs deficit on one level has been satisfied, motivation will be directed toward the next level of needs.

In contrast to the first four levels of deficiency needs, the top level represents a growth or being need. Self-actualization includes realizing personal potential, self-fulfillment, seeking personal growth, and peak experiences. This is not a deficiency that can be fulfilled, and most often growth needs will even become stronger when they are being tackled by the individual, with higher goals for self-fulfillment and peak experiences.

The hierarchy of needs does not mean that higher levels of needs are correlated with higher quality of life. An increase in the standard of living, either by economic progress in general or by climbing up the social ladder for the individual, does not necessarily result in an increase in quality of life.

The General Social Survey (GSS) in the US is performed since 1972 (gss.norc.org). It does not ask about quality of life, but includes some questions about happiness. General happiness is assessed as: “Taken all together, how would you say things are these days, would you say that you are very happy, pretty happy, or not too happy?” Happiness has been promoted as a stand-alone indicator of well-being, as overall happiness was related to longer lives (Lawrence et al. 2015).

Fig. 1 Hierarchy of needs (Maslow 1943, 1954)



However, in spite of increased standards of living, due to technical advances and economic progress, the percentage of respondents rating themselves as very happy has remained roughly the same since 1972, with the 2014 level near the 1972–2014 average at 33% (Smith et al. 2015). Similar results have been reported for Great Britain (Blanchflower and Oswald 2004).

2.1 Health-Specific Quality of Life

For health care discussion, there is a high desire to assess and measure quality of life. For this purpose, the broad overall concept of quality of life had to be narrowed down to health-related quality of life. The World Health Organization has defined health not merely as the absence of disease, but rather as a state of complete physical, mental, and social well-being (World Health Organization 1948). In consequence, assessment instruments for health-related quality of life try to integrate these dimensions. The 36-item Short Form Health Survey (SF-36) developed in the Medical Outcomes Study is a prominent example of such an instrument (Ware and Sherbourne 1992).

2.2 Disease-Specific Quality of Life

With illnesses with a prolonged disease trajectory such as cancer, quality of life may be influenced by a number of disease- or treatment-related factors. Assessment of disease-specific quality of life, e.g., with the questionnaire of the European Organization for Research and Treatment of Cancer (EORTC) or the Functional Assessment of Chronic Illness Therapy (FACIT). Both instruments have a core questionnaire that assesses the main dimensions of quality of life, and a vast range of add-on modules for assessment of specific symptoms or common problems with specific diagnoses.

2.3 Individual Quality of Life

The standardized items of health- or disease-related quality of life questionnaires allow for

the calculation of total and subscale scores. However, with the selection of items, there is also an inherent bias, as the patient's quality of life will only be captured when it is defined by the items in the questionnaire. If the patient finds that activities or experiences outside of these items make up part of his quality of life, this will not be included in the assessment.

This produces a dilemma for assessment: either a validated and highly standardized questionnaire is used, with calculated scores that allow easy comparison, but does assess only that part of quality of life that is represented by the items in the questionnaire, or a broader assessment is used, with a higher chance to capture all factors that contribute to the patient's quality of life, but does not allow for easy calculation of scores. This is Heisenberg's principle of uncertainty as applied to palliative care. This principle has been described in particle physics. Heisenberg stated that it is impossible to measure the position and the velocity of a particle at the same time. Either the position is assessed, but this invariably will cause a change of velocity, or the velocity is determined, but then this would involve a change in position. Similarly, assessment of quality of life will either allow assessment of the nature of well-being or of the extent of quality of life, but not both at the same time.

However, an attempt to capture the individual quality of life has been made with the Schedule for the Evaluation of the Individual Quality of Life (SEIQoL) (O'Boyle et al. 1995). This instrument first asks the patient which are the favorite domains that contribute to his quality of life, then assesses the contribution and the degree of impairment in each of these domains. A sum score can be calculated from this information. As the disease progresses along its trajectory, some of the favorite domains may change, but the scores still can be calculated and compared with previous quality of life scores.

3 Quality of Life Assessment

A large number of assessment instruments have been published for quality of life. A systematic review on outcome assessment instruments in

palliative care identified 80 instruments for assessment of quality of life, the most frequent domain in outcome assessment (Stiel et al. 2012). QOL assessment can be used in a number of ways, e.g., for outcome measurement, for cost effectiveness calculations, and as accountability measurement. However, quality of life assessment as an accountability measure has some disadvantage, as quality of life is influenced by so many factors such as adaptation to illness and functional disability that have nothing to do with the provision of palliative care. Quality of life assessment can also be useful in clinical care and care planning.

3.1 SF-36

The SF-36 is the best-known example for the assessment of health-related quality of life. It includes items assessing health-related limitations in eight dimensions: physical functioning, social functioning, physical role, emotional role, emotional well-being, pain, energy/fatigue, and general health perceptions. Evaluation requires a complex algorithm, as the resulting scores are converted in standardized scores with a range of 0–100, where the general US population would reach mean scores of 50 with a standard deviation of 10. In addition to the subscores on eight dimensions, two main scores can be calculated for the physical and mental well-being. The SF-36 has been extensively investigated in a broad range of settings and languages (Gandek et al. 1998; Ware et al. 1998).

A shorter version has been developed with 12 items, which covers the same dimensions but results only in summary scores for physical and mental health (Ware et al. 1996). More recently, the SF-8 has been developed with eight single items assessing the same dimensions (Ware et al. 2001). Whereas the SF-12 is an excerpt of the SF-36, the SF-8 has similar, but not identical items compared to SF-36 and SF-12.

The SF-36 questionnaire may be too complicated for many patients with advanced disease requiring palliative care, and some questions may be deemed inappropriate by the patients. For example, in our own experience, the question “Compared to one year ago, how would your

rate your health in general now?” has been perceived as distressing by patients with advanced cancer and rapid deterioration in the last year.

3.2 FACIT

The Functional Assessment of Cancer Therapy (FACT-G) questionnaire aims at collecting data on the quality of life of cancer patients with 27 items in four domains: physical, social, emotional, and functional well-being. All items are rated on a 5-point Likert scale (0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, 4 = very much). All questions refer to the time frame of the last week. A general quality of life score is calculated as well as five subscores on physical, functional, social, sexual, and mental-emotional well-being (Cella et al. 1993). Higher scores represent lower QoL and higher impairment (“0 = best possible” to “108 = worst possible”).

The questionnaire has also been useful in other patient groups and has been renamed Functional Assessment of Chronic Illness Treatment (FACIT). The core questionnaire can be augmented with add-on modules for cancer- (or other diseases-) specific, treatment-specific or symptom-specific problems (e.g., for bone pain or fatigue). The FACIT website lists information on modules and language availability (www.facit.org).

An add-on module is available for palliative care (FACIT-PAL), which adds 19 items to the core questionnaire, resulting in a total of 46 items (Lien et al. 2011; Siegert et al. 2014). As this taxes the capacity of patients with advanced disease and cognitive and physical impairments, a shorter version with 14 items in total has been designed, the FACIT-PAL14. This short version provides a sum score, but no subscores (range 0–56, higher scores = better quality of life) (Zeng et al. 2013).

3.3 EORTC

The European Organization for Research and Treatment of Cancer has developed the core questionnaire for quality of life EORTC-QLQ-C30 (Aaronson et al. 1993). The questionnaire includes

30 items on the general condition of the last 7 days, except for the questions about the physical well-being which refers only to the current situation. Five subscales on the physical, role, cognitive, emotional, and social functioning are summarized with 2–5 items each. Nine additional symptom scores on fatigue, nausea and vomiting, pain, dyspnoea, insomnia, loss of appetite, obstipation, diarrhea, and financial problems are calculated from 1–3 items each. All items are rated on a 4-point Likert scale (1 = not at all, 2 = a little, 3 = quite a bit, 4 = very much). Additionally, a global health and QoL index is calculated from two items on a 7-point Likert scale reaching from 1 = very bad until 7 = excellent. For the five functional subscores and for the global health index, higher scores represent higher quality of life, whereas higher scores in the symptom scales indicate higher symptom intensity, resulting in lower quality of life.

An algorithm for the calculation of a summary score has been introduced only recently (Giesinger et al. 2016). The questionnaire has been used and validated in a range of settings and languages.

As with the FACIT, a large number of additional modules are available, mostly on different cancer entities, but also on other topics such as fatigue or information (<http://groups.eortc.be/qol/eortc-qlq-c30>).

A shorter version with 15 items has been developed as a core questionnaire for palliative care patients, the EORTC-QLQ-C15-PAL (Groenvold et al. 2005). This questionnaire includes the symptom scales for pain, dyspnea, insomnia, appetite loss, and constipation, as well as abbreviated subscales for physical and emotional functioning, nausea, vomiting, and fatigue, and one of the two questions on general health. The EORTC-QLQ-C15-PAL has been promoted as the new standard for quality of life assessment in advanced cancer (Groenvold et al. 2006) and has even been found useful as a prognostic indicator in patients with advanced cancer (Lee et al. 2014).

3.4 SEIQoL DW

SEIQoL: This tool assesses five domains of the patient's individual quality of life with a

structured interview (O'Boyle et al. 1992; Waldron et al. 1999). The patient is asked to name five domains of his life that he finds most important right now. He then is asked to rate his level of satisfaction with each of these domains, by drawing bars in a 100-mm box (0 = worst possible satisfaction and 100 = best possible satisfaction). In the original SEIQoL, the weight that each domain has for the patient's quality of life would be elicited in the interview. However, this process takes time, and most patients prefer a shorter assessment. The direct weighting version (SEIQoL-DW) uses a disk with five movable colored segments (O'Boyle et al. 1995; Hickey et al. 1996). The patient adjusts the segments according to the relevance (weight) he attributes to each domain. The cumulative products of level of satisfaction and weight represent the quality of life score, in a range between 0% and 100%, with higher scores representing higher QoL.

The most frequent domains named by patients with advanced cancer in the validation paper were family, health, social life, spiritual life, friendship/relationships, contentment/happiness, work, finances, marriage, mobility, and pain relief (Waldron et al. 1999). Other studies using the SEIQoL have confirmed the predominance of family and social relationships in other patient groups such as elderly patients or patients with amyotrophic lateral sclerosis or with congenital heart disease, with health issues only coming second (Neudert et al. 2004; Moons et al. 2005; Hall et al. 2011; Hamidou et al. 2017).

As the disease progresses, some domains that the patient has used for the SEIQoL rating may not be feasible or important for him anymore, e.g., work and career advancement may drop from the screen disease-related disability, or sport activities may become impossible because of physical impairment. However, other domains will then become more important. Allowing for changing domains in the quality of life assessment corresponds with the real life experience in palliative care, where patients sometimes explain that with progression of the disease lost abilities and chances are balanced by gaining a new focus on what they find really important in life.

However, completing the SEIQoL requires the ability to concentrate and the capacity for abstraction. It seems doubtful whether the majority of palliative patients are able to use this instrument as their physical and cognitive status and general condition often are rapidly declining. Use of the SEIQoL may be too time-intensive and not practicable in clinical palliative care routine.

3.5 Short Assessment Tools

Assessment tools that are well established in other settings often are not practicable in palliative care because of the limited physical, cognitive, or psychological status of patients. Assessment tools have to be short and simple to reduce the burden on the patient. Comprehensive questionnaires are feasible only for a minority of patients in the clinical setting of a palliative care unit (Stiel et al. 2011).

The EuroQoL consortium has produced a concise instrument, the EQ-5D. Five items cover one dimension each: mobility, self-care, usual activities, pain/discomfort, anxiety/depression. Two versions are available, one with three response options (no problems/some or moderate problems/extreme problems), the other with five options (no problems/slight problems/moderate problems/severe problems/extreme problems). In addition, a thermometer scale is used for rating overall health (0 = worst health that can be imagined, 100 = best health that can be imagined).

3.6 Specific Palliative Care QOL Instruments

A number of specific tools for quality of life assessment have been developed, including the McGill Quality of Life Index, the Missoula-VITAS Quality of Life Index (MVQOLI), the Needs at the End-of-life Screening Tool (NEST), and the Quality of Life at the End of Life (QUAL-E) (more information at <http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx>). However, these instruments have been used less frequently and are available in fewer languages other than English compared to the more general

quality-of-life questionnaires discussed above. The McGill index includes 20 items, the QUAL-E 26 items. The NEST questionnaire uses only 13 items, but with additional items, if the cut-off scores of any items are exceeded, so that the total length of the questionnaire can be extended up to 65 items. The MVQOLI uses three questions on five domains, one each on subjective assessment, function, and importance of the domain.

Patients at the end of life with reduced physical and cognitive function often need help for the completion of these questionnaires. Ideally for the palliative care setting, assessment of quality of life would be done with a single question. This approach has been recommended for specific areas in palliative care, e.g., depression (Chochinov et al. 1997) or fatigue (Radbruch et al. 2008). However, using the single item “How do you feel today?” we found only moderate correlations with the global scores of EORTC-QLQ-C30 and FACIT-G (Stiel et al. 2011). Highest correlations were found with physical and functional subscales of the comprehensive instruments. Most patients seem to understand the single item as a medical question addressing these physical-functional aspects in the clinical routine.

Ongoing research in our department has investigated two alternative single items. The single item “How would you rate your overall quality of life during the past few weeks?” was taken from the EORTC QLQ-C30 quality of life questionnaire, but correlations of other instruments with this single item were inadequate as well. However, the second single item “How satisfied are you currently with your physical and emotional well-being?” correlated well with the total score and with the physical, emotional and functional subscales and moderately with the social well-being subscale of the FACIT. This single item seems suitable as a short screening instrument for quality of life in palliative care.

4 Quality of Life as a Static or Dynamic Concept

Measuring health-related or disease-related quality of life with standardized instruments fosters the attitude that quality of life is a static construct,

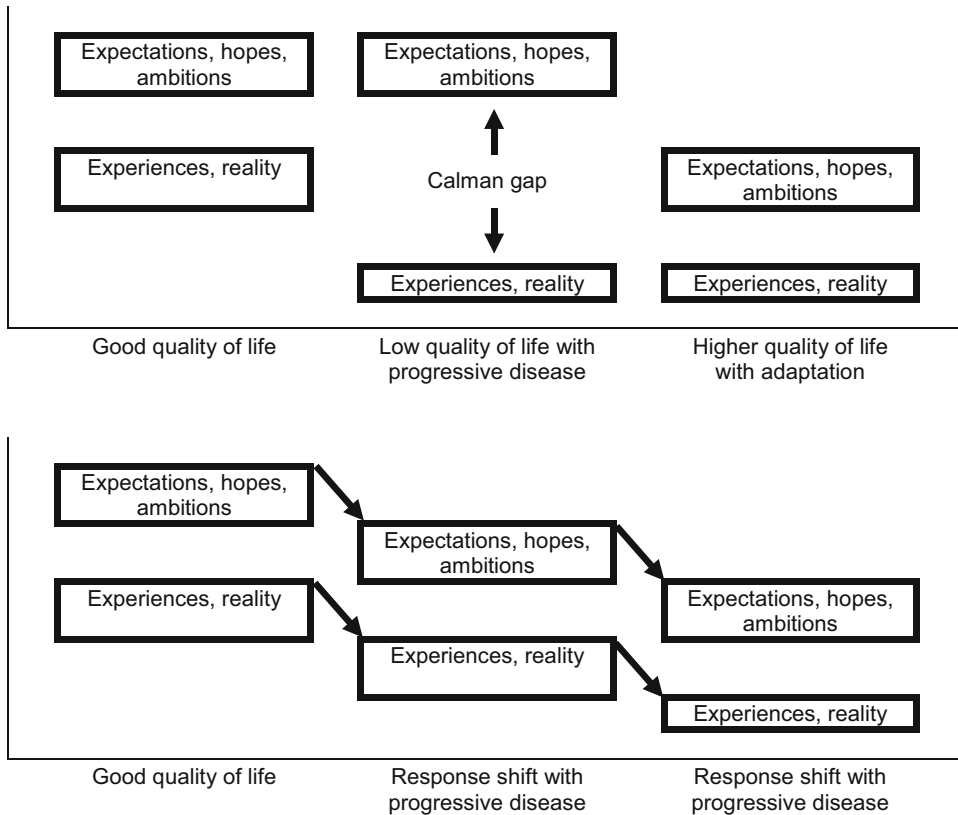


Fig. 2 Calman Gap and response shift

influenced predominantly by factors such as physical or cognitive performance status, physical symptoms, or social relationships. These contributing factors are to a large degree outside the influence of the patient. The patient’s quality of life remains unchanged, if there are no aggravating factors (e.g., disease progression) or alleviating factors (e.g., effective symptom control).

However, this is contrary to the experience in clinical practice that quality of life depends to a major degree on the patient’s needs, preferences, and expectations. In an influential approach, Calman proposed quality of life as the difference between the hopes and expectations of an individual and the individual’s present experiences (Calman 1984). This difference has also been described as the Calman gap, and support a dynamic construct of quality of life.

In consequence, patients with severe cognitive or physical impairments may report high quality

of life, if they have had time to adapt their hopes and expectations to the present situation (Fig. 2). This is similar to patients with chronic disabilities, who also quite often report normal or even high quality of life.

With progressive disease, patients often will reduce their hopes and expectations as they feel the deterioration. As the gap between experiences and expectations does not widen with the lower levels of expectations, patients will report no change in overall quality of life, even though their present experiences have become much worse. This is known as the response shift (Fig. 2).

However, adaptation takes time, and even experienced palliative care staff often underestimates the amount of time patients and caregivers need to adapt to a new situation. Patients experiencing rapid progression of severe illness may be overwhelmed with the next steps of deterioration, and may not be able to adapt their expectations quickly.

Defining quality of life as the difference between patient's expectations and present experience also means that quality of life can be improved in two ways, either by improving the experiences (e.g., with effective symptom control) or by lowering the expectations. This poses an inherent danger in palliative care, as lowering the expectations may be easier. Facilitating adequate adaptation of expectations to the deterioration with progressive disease may be perceived as very helpful by patients, but this should not be carried too far, as the patient and his caregivers also have a right to keep up their hopes and ambitions, even if they are clearly unrealistic in the face of the progressive disease.

Several studies have demonstrated the effect of response shift in patients with advanced cancer over time (Hagedoorn et al. 2002; Ahmed et al. 2004; Echteld et al. 2005) or compared to healthy controls (Stiefel et al. 2008; Fegg et al. 2010b). Response shift has also been discussed as a major confounder for the outcome evaluation in clinical trials (Ring et al. 2005; Verdam et al. 2015), and an expert panel recently recommended more research on response shift (Preston et al. 2013).

5 Concepts Related to Quality of Life

As there is no broad consensus on the definition of quality of life, it is not surprising that a number of concepts overlap to some degree with quality of life. Overall happiness (included in the General Social Survey) has already been discussed above.

Quality of life seems closely related to the search for meaning, as expressed in Viktor Frankl's famous quote "Those who have a 'why' to live, can bear with almost any 'how'" (Frankl 1962). A German workgroup has developed a Schedule for Meaning in Life Evaluation (SMiLE) that has been used in different palliative care settings (Fegg et al. 2008, 2010a). The evaluation uses a similar method as the SEIQoL, but patients are asked to name the major domains that contribute to the meaning they find in life. However, the domains that are selected by the patients closely overlap with those selected in the SEIQoL,

with a predominance of family and social relationships. This raises the question whether there is a meaningful separation between quality of life and meaning in life, or whether the two concepts are correlated so closely that only quality of life needs to be assessed.

Making meaning is also an integral part of the sense of coherence concept, together with understanding and being able to influence the environments or events happening. The Sense of Coherence Scale (SOC) includes 29 items or 13 items in a short version (Antonovsky 1993), but a number of other versions has been used as well (Eriksson and Lindstrom 2005). Subscales for the three dimensions manageability, comprehensibility, and meaningfulness have been calculated, though Antonovsky suggested to use only the total score of the instrument. A systematic review found a strong relationship between sense of coherence and quality of life: the stronger the sense of coherence, the better the quality of life (Eriksson and Lindstrom 2007). In addition, sense of coherence seemed to be a good predictor for good quality of life in longitudinal studies.

A quality of death index has been developed to describe the quality of life until the very end (Economist Intelligence Unit 2015). However, this is a macroeconomic indicator, compiling information on palliative care and healthcare environment, human resources, affordability of care, quality of care, and community engagement to compare the quality of palliative care available to adults in 80 countries. This does not provide information on individual patients.

On an individual level, the Quality of Dying and Death (QODD) questionnaire is used to interview family members after the death of the patient to evaluate the quality of care in the final stage of life (Curtis et al. 2002). The QODD includes 31 items assessing symptoms, patient preferences, and satisfaction with care. The total score ranges from 0 to 100 with higher scores indicating better quality of dying and death.

Other instruments have been developed for evaluation of the quality of dying, but a systematic review found only the QODD has been well validated and widely used (Hales et al. 2010). Shortcomings of the instrument have been critically

discussed, challenging that some components of the quality of end-of-life care and the quality of dying may be difficult or even impossible to measure (Curtis et al. 2013).

6 Conclusions and Summary

Quality of life assessment can be used in a number of ways, e.g., for outcome measurement, for cost effectiveness calculations, and as accountability measurement. Improving the quality of life is considered a central goal of palliative care, together with the prevention and relief of suffering. However, there is some variety in the definition and indeed the understanding of the concept of quality of life, and in consequence a range of assessment instruments have been developed.

The Short Form Survey of the Medical Outcome Study (SF-36) and its even shorter forms SF-12 and SF-8 are most prominent for health-related quality of life. The Functional Assessment of Chronic Illness Therapy (FACIT) and the European Organization for Research and Treatment of Cancer (EORTC) family of tools are used extensively for disease-related quality of life. The Schedule for the Evaluation of the Individual Quality of Life (SEIQoL) is a prominent example for the assessment of the individual quality of life.

However, many palliative care patients can only complete short and simple assessment instruments. With the limitations on assessment, the number of other factors influencing quality of life such as adaptation to illness and functional disability and the overlap of quality of life with other concepts such as meaning in life or sense of coherence some components of the quality of end-of-life care and the quality of dying may be elusive or even impossible to measure.

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Global Aspects of Palliative Care

3

Stephen R. Connor

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Abstract

In this chapter we will look at the growth of modern palliative care globally from its humble beginnings to finally becoming part of mainstream health care; major developments and milestones in global development, including involvement of the World Health Organization (WHO), the HIV/AIDS Pandemic, the

rise of non-communicable diseases, the millennium goals, and now the sustainable development goals; and the World Health Assembly resolution on palliative care. We will explore the current status of palliative care globally and look at future directions and challenges for palliative care to reach its goal of full access to those in need.

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1 Introduction

What was once a small movement confined to high-income countries is slowly becoming an essential part of any modern health-care system. Hospice palliative care is part of the solution to what ails the current health-care system. Consistently, palliative care leads to effective symptom control (Shu-Yu et al. 2016), improved quality of life (Temel et al. 2010), less unnecessary hospitalization (Morrison et al. 2008), realization of dignity (Chochinov et al. 2011), and reduced cost both for patients and families as well as providers (Smith et al. 2014).

Yet palliative care still remains on the fringes of mainstream health care and many myths persist resulting in too few patients able to access any care or are referred on the brink of death. Eighty percent of the need for palliative care is in low- and middle-income countries, while 80% of the current palliative care that is available is confined to only 20 high-income countries that have managed to achieve advanced levels of integration into mainstream health care.

Persisting myths include that hospice or palliative care is a building where you are sent to die, that patients are given morphine and no longer communicate or become addicts, that having hospice and palliative care will cause you to give up and die sooner, that palliative care is just for people with cancer, and that palliative care is just for old people. In the United States, the median length of service is less than 3 weeks. There are still many people that fear the idea of hospice or palliative care simply because of an association with dying.

2 History of Modern Palliative Care Development Globally

Modern hospice care began in 1967 with the opening of St. Christopher's Hospice outside London. Dame Cicely Saunders, founder of St. Christopher's, had a vision for a place where those facing the end of life could be cared for with the principles of pain and symptom control and whole-person compassionate care, using an

interdisciplinary team approach for both the ill person and their family. She pioneered the field of hospice care and became a beacon for all countries worldwide to learn this new approach to care. An education and training center was established at St. Christopher's where people from dozens of countries came to learn hospice care and then return to their home country to transplant this new approach to caring for the dying in their own setting and culture.

The term palliative care was introduced by Dr. Balfour Mount at the Royal Victoria Hospital in Montreal, Quebec, in 1974. The word *hospice* in French is understood to mean "home for the destitute" and was seen as an unacceptable term in Francophone Quebec. The word *palliate* originates from the Greek and translates as "to cloak," meaning that when we care for the dying, our interventions are meant to cloak or to prevent from seeing or experiencing pain or other suffering. Palliative care is the term generally used to refer to the practice of hospice and palliative care globally and encompasses hospice care. It also signifies the transfer of hospice principles into the wider health-care system including hospitals, long-term care facilities, clinics, primary care settings, and personal residences.

The hospice movement has grown slowly in the past 50 years but has mainly been confined to high-income countries.

3 Major Developments Globally

3.1 World Health Organization

Several significant developments have occurred in recent decades that have spurred the development of global palliative care. The World Health Organization (WHO) published the first monograph *Cancer Pain Relief* guidance on the assessment and treatment of cancer pain in 1986 that included a new WHO pain relief ladder. The ladder identified three simple steps for treating mild, moderate, and severe pain. This monograph was revised in 1996 with a guide to opioid availability. Also in 1990 WHO published the first definition of palliative care emphasizing symptom

management and pain control in a wider approach. This was followed in 2000 with the publication of an expanded definition of palliative care emphasizing treatment for all life-threatening illnesses from the time of diagnosis.

WHO's support for palliative care was crucial in its early development but was centered in the cancer department, giving the impression that palliative care was only for cancer though the WHO definition was much broader and referenced any life-threatening illness. There was also considerable attention to the palliative care needs of those with HIV/AIDS, especially before the advent of highly active anti-retroviral treatments. WHO has shifted its emphasis from communicable disease to the major cause of death being from non-communicable diseases.

3.2 Noncommunicable Diseases (NCDs)

WHO's realignment around noncommunicable diseases is an opportunity for palliative care to be vocal about the necessity of its inclusion in all aspects of policy, program development, and service delivery. Following criticism that WHO was too focused on HIV and TB treatment while 66% of all deaths from all causes were due to NCDs, WHO has shifted its focus to put a major emphasis on NCDs.

A global UN dialogue on NCDs has continued since 2012, informed by the Global Action Plan for the Prevention and Control of NCDs 2013–2020. A Global Coordination Mechanism on NCDs continues this dialogue, and a Global Monitoring Framework for NCDs has been developed. Palliative care advocates were successful in getting an indicator for palliative care at the country level that measures opioid consumption against total cancer deaths. This is one of 25 WHO-approved indicators that countries can use to measure progress.

NCDs kill 38 million people each year, almost three quarters in low- and middle-income countries. Sixteen million of these deaths are considered premature in those before the age of 70. There were 17.5 million cardiovascular deaths,

8.2 million cancer deaths, 4 million deaths from respiratory diseases, and 1.5 million from diabetes, these four accounting for 82% of all NCD deaths. All of these conditions are appropriate for palliative care.

3.3 Sustainable Development Goals and Universal Health Coverage (SDG/UHC)

The SDGs are a UN initiative officially known as “Transforming our world: the 2030 Agenda for Sustainable Development.” There are 17 aspirational goals with 169 targets. One of the goals (#3) is to “Ensure healthy lives and promote well-being for all at all ages.” One of the targets under SDG3 is to “Achieve universal health coverage, including financial risk protection, access to quality essential health care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.”

Palliative care advocates were able to include palliative care in the description of the continuum of services under UHC. The continuum is Promotion – Prevention – Treatment – Rehabilitation – Palliation. This was a major achievement and allows palliative care to claim its place in the SDGs. Without palliation, UHC cannot be achieved. Unfortunately, despite several attempts, palliative care advocates have not yet been able to get WHO approval for a palliative care indicator to hold countries to account for palliative care development.

3.4 World Health Assembly (WHA) Resolution on Palliative Care

Perhaps the greatest achievement for global palliative care to date is the unanimous passage of WHA resolution 69.17 (World Health Assembly 2014) “Strengthening of palliative care as a component of comprehensive care throughout the life course.” The WHA is the governing body of the WHO and is made up of all UN countries. It took 3 years of sustained advocacy to get this resolution on the WHA agenda. The WHO staff

then prepared a report to inform the resolution that used data from the WHPCA/WHO Global Atlas of Palliative Care at the End of Life (Connor and Sepulveda 2014). The Atlas describes the need for palliative care, the current status of palliative care delivery, the barriers to access, the limited resources devoted to palliative care, and recommendations for improving access to care.

The resolution calls for a series of actions by all countries and by the WHO itself to ensure that palliative care is part of every country's health-care system with an emphasis on community-based primary health care. Specifically, countries are called upon to:

- Develop and strengthen policies to integrate palliative care into health systems
- Ensure adequate domestic funding and human resources
- Support families, volunteers, and caregivers
- Integrate palliative care in health professional curricula at all levels
- Assess domestic palliative care needs including for essential medicines
- Review and revise drug control legislation and regulation and add palliative care medicines to national essential medicine lists
- Support partnerships between governments and civil society
- Integrate palliative care into plans for management and control of noncommunicable diseases

The resolution further calls on WHO to:

- Ensure palliative care is integrated into all health system plans
- Update or develop guidelines and tools on palliation in health system and across disease groups and levels of care, addressing ethical issues
- Support countries in reviewing and improving drug legislation and policy to ensure balance
- Explore ways to increase availability and accessibility of essential palliative care medicines
- Work with the International Narcotics Control Board and the UN Office on Drugs and Crime

to promote availability of controlled substances for pain and symptom management and support accurate estimates for opioids

- Collaborate with UNICEF to promote pediatric palliative care
- Monitor global situation of palliative care to evaluate progress
- Encourage countries to adequately fund PC programs and research on palliative care models in low- and middle-income countries
- Report back on implementation of resolution

4 Current Status of Global Palliative Care

To date progress on meeting all these recommendations from the WHA resolution is occurring slowly. Some technical assistance documents have been published, six countries have been identified to host official WHO demonstration projects, and work has begun on revision of the original WHO cancer pain guidelines. However, access to opioids is still overly restricted in 75% of the world; there is no measure of how many professional schools have added palliative care curricula or audit of policies that have been changed to include palliative care. Funding for palliative care implementation has if anything decreased. A new audit of levels of development in palliative care is planned for completion in 2018, and it is hoped that the 42% of countries lacking any palliative care last measured in 2011 will be decreased.

Findings from the most recent assessment of the state of palliative care globally can be found in the *Global Atlas of Palliative Care at the End of Life* (Connor & Sepulveda, 2014). The purpose of the Atlas was to paint a picture of palliative care globally by answering the following questions:

- What is palliative care?
- Why is palliative care a human rights issue?
- What are the main diseases requiring palliative care?
- What is the need for palliative care?
- What are the barriers to palliative care?
- Where is palliative care currently available?

- What are the models of palliative care worldwide?
- What resources are devoted to palliative care?
- What is the way forward?

The WHO's **2002 definition of palliative care** both for adults and children (World Health Organization 2017a) was used along with a definition of hospice. Some limitations in the definition are noted including lack of clarity on four points: first that palliative care is needed in chronic as well as life-threatening/limiting conditions, second that there should be no time or prognostic limit on the delivery of palliative care, third that palliative care is needed at all levels of care including primary and secondary as well as tertiary care, and fourth that palliative care is needed in all settings of care.

Palliative care has begun to be accepted as a **human right** in health care. There are a number of precedents for this belief including reference to the 1966 International Human Right to Health from the UN International Covenant of Economic, Social and Cultural Rights (Committee on Economic, Social and Cultural Rights (CESCR) General Comment 14 para.12), which calls for the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Further the UN Special Rapporteur on torture has said that denying access to pain relief can amount to inhumane and degrading treatment. It is governments that do not allow access to essential medicines such as opioids that are responsible, rather than clinicians. There are many other statements in support of this right.

In order to identify the main **diseases that require palliative care** and the number of these patients, the *Atlas* used WHO's most recent mortality data (2011). There were over 54.5 million deaths worldwide that year, most (66%) due to noncommunicable diseases. At minimum over 20 million of these were identified as needing palliative care. The primary diseases for adults included cardiovascular, cancer, pulmonary, HIV/AIDS, kidney, liver, dementias, multi-drug resistant TB, Parkinson's, rheumatoid arthritis, and multiple sclerosis. For children the major diseases included congenital anomalies, neonatal conditions,

protein energy malnutrition, meningitis, HIV/AIDS, cardiovascular, endocrine-blood-immune disorders, cancer, neurological conditions, and kidney and liver diseases.

This was the first time that WHO acknowledged that all these conditions required palliative care. Prior to this publication, WHO only provided guidance on palliative care for cancer and HIV. Further the *Atlas* looked at the distribution of need for palliative care and found that almost 80% of the need is in low- and middle-income countries. The majority of those needing palliative care are adults 60 years or older (69%) with 25% aged 15–59 and 6% being children from birth to 14 years. While the number of over 20 million refers to those at the end of life needing palliative care, we effectively doubled that number to 40 million to account for all those needing palliative care prior to the end of or last year of life. Add several family members to this need and you have well over 100 million people annually that need palliative care services.

When assessing the **barriers to palliative care development**, we use the WHO public health model. The model has four components: (1) policy, (2) education, (3) medication availability, and (4) implementation of services. For palliative care to develop in an individual country, it is often best to use a simultaneous bottom-up and top-down approach. A country champion is needed to advocate for palliative care within the country and to eventually develop a prototype palliative care delivery program. However, this is difficult to do if there is no recognition of palliative care in government policies and regulations. Therefore, the lack of government policies is often a barrier that must be overcome initially.

Conducting a national needs assessment can be a helpful starting point to educate officials as to the scope of the need for palliative care and to demonstrate the gap in lack of services. Examples of comprehensive national needs assessments and other key policy documents can be found at <http://www.thewhpc.org/resources/category/country-reports-and-needs-assessments>. Other key policy documents that should be developed include:

- National standards for program operation
- Clinical guidelines for palliative care provision

- Inclusion of palliative care in national policies on NCDs, HIV, TB, cancer, and health-care priority setting documents
- Legal recognition of palliative care in health-care law and regulation including licensing
- Recognition of palliative care as an area of health-care specialization
- Regulation of access to controlled substances
- National strategy for implementation of services

Controlled substances, especially opioids, are either unavailable or so tightly controlled in 75% of the world that they are not available for palliative care (International Narcotics Control Board 2015). It is essential that unnecessary and overly burdensome regulations are removed or modified so that they can be used for palliative care. The WHO has a model list of essential palliative care medicines (World Health Organization 2017b) that should be available in all countries. This is often a long and difficult process that involves multiple ministries to approve including ministry of health, drug control authorities, police and internal affairs, and ultimately the legislative and executive bodies in the country.

Gaining access to medicines, especially oral morphine, is critical to successful palliative care development and has to go hand in hand with provision of **education** for health professionals. The World Health Assembly resolution on palliative care (2017) calls on all governments to ensure that palliative care education is provided at all levels of health professional training including undergraduate, graduate, postgraduate, and specialization training. Practically this means that basic palliative care curricula should be included in medical and nursing schools, additional courses and practicums should be provided during residency and internships, continuing education should include palliative care, and a pathway for specialty or sub-specialty qualification should exist. Further, palliative care content should be included in social work, psychology, and chaplaincy education.

In addition to health professional education, it is equally important for the public to be informed and sensitized to the need and availability of palliative care. Most people, particularly in limited

resource settings, may assume that advance illnesses such as cancer inevitably result in unrelieved pain and suffering when we know that symptom relief and quality of life are possible and should be available to all citizens. Families faced with the need to care for seriously ill relatives also need practical hands-on training in caregiving to make it possible for loved ones to remain in the place they call home.

All of this should lead to the formation and growth of palliative care services **implemented** throughout a health-care system. While many initial hospice or palliative care programs begin as stand-alone programs effectively outside the mainstream health delivery system, the challenge to reach the majority of persons needing palliative care is to effectively integrate palliative care into all levels of health care including primary, intermediate, and tertiary levels in both the public and private health-care systems (Gomez-Batiste and Connor 2017).

5 Future Directions for Global Palliative Care

5.1 Low- and Middle-Income Countries (LMIC)

The future of palliative care depends on how successful we are in developing palliative care in limited resource settings. Since almost 80% of the need for palliative care is in LMICs, it is imperative that palliative care is successfully implemented there. There are a number of good models that have been described (Connor and Sepulveda 2014) that may be replicated, and there is a lot of work being done to develop, test, and implement models that are viable and sustainable in LMIC settings. Notably, WHO plans demonstration projects in six countries (Belarus, Jamaica, Oman, Malaysia, Thailand, and Zimbabwe) and the Worldwide Hospice Palliative Care Alliance another six (Bangladesh, Ethiopia, Jordan, Panama, Philippines, and Ukraine) that will hopefully develop and disseminate new models. The challenges are great, but it is critical that progress be made since less than 20% of current palliative care delivery is available in LMICs.

5.2 Community-Based Palliative Care

One of the critical factors in developing palliative care in limited resource settings is the degree to which palliative care is owned by the community. This is also critical in high-income settings but more so in LMICs. When resources are limited, there is a general tendency for people to take care of each other more readily and family connections are often closer. This is a strength, but so often without the support and training that palliative care provides, caregivers are left to helplessly witness unrelieved suffering. With modest investments in palliative care that support community care giving, community based palliative care can become mainly self-sufficient.

5.3 Medication and Education

In 75% of the current world, access to effective pain medication is so severely restricted (International Narcotics Control Board 2015) that it is essentially impossible to achieve pain relief and comfort for dying patients. This is the world's biggest drug problem. Notable efforts are beginning to change this severe imbalance, but a lot more work is needed to correct this situation. Fear of misuse of opioids has resulted in major interference in the practice of medicine throughout the world. Effective safeguards against misuse need to be in place, but the situation is so out of balance in most of the world that palliative care cannot be practiced effectively.

On top of this, education in palliative care and pain relief is still in its infancy worldwide. It is useless to train physicians and nurses in palliative care if essential palliative care medicines are unavailable. This includes not only opioids and other analgesics but other psychotropic medication including anti-anxiety and anti-depressant medication, anti-seizure, anti-emetic, and anti-psychotic medication. What is taught is forgotten in situations where relief of suffering is not possible. Most importantly bedside teaching, where real learning occurs, is not realistic if these medications are unavailable.

5.4 Funding

The ultimate test of whether palliative care is effectively implemented in a country is the willingness of governments to reallocate funding to palliative care, especially in non-hospital settings. In all countries most health-related funding flows to hospital care. What has been seen over and over is that hospice and palliative care reduce the need for unnecessary hospital care in favor of care in the community. The net result is usually a reduction in expense to the health-care system. The difficult part practically and politically is to shift funds now going to inpatient care to home care services. This requires evidence and political will. Corruption and self-interest often stand in the way, but this can and has been done in many countries.

6 Integration

Ultimately the future of palliative care is in its integration into the mainstream health-care system in every country. Palliative care will not succeed as a specialized form of care outside the mainstream of existing health-care delivery. Forty years ago many of us thought the need for hospice and palliative care would disappear in 20 years as we improved the care of dying patients. That has not occurred and the need for specialist palliative care is now well established worldwide. However, the majority of patients needing palliative care should be able to be effectively cared for by their primary health caregivers. This is where new development is occurring globally. Organizations like the International Primary Palliative Care Network and the European Association for Palliative Care's primary care task force have made great strides in promotion of palliative care as a core competency in family medicine, and oncology associations have called for early integration of palliative care in oncology practice. Still there are literally millions of health-care professionals that have never received training in palliative care and will need to do so.

7 Conclusion and Summary

The international hospice palliative care movement, now 50 years old, remains underdeveloped. Less than 10% of the global need for palliative care throughout the course of life-limiting illness is being met. The greatest need is in low- and middle-income countries where palliative care is available the least. Great strides have been made in identifying this need and getting the United Nations and international bodies to call for integration of palliative care throughout the life course. However, translating this progress to the ground is a long way off. It will require major improvements at the individual country level in setting policies that promote palliative care, education in palliative care for literally millions of health-care workers, removal of excessive restrictions on essential palliative care medicines, and resources and political will to implement both primary and specialized services. Further it will require major changes in the attitudes and beliefs of both the public and the health professions. Acceptance of palliative care at some level requires an acknowledgment that death and dying are essential parts of life and that care of those with life-limiting conditions and illnesses is an essential part of every health-care system. As the global population ages and confronts these realities, there is every hope that palliative care will grow and thrive in the future.

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Organization of Palliative Care in Different Parts of the World

4

Carlos Centeno and John Y. Rhee

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Abstract

Palliative care has developed rapidly and heterogeneously in the past decade around the globe. In this chapter, we present an overview of palliative care development in different regions of the world with a pair of case studies of models of palliative care delivery within each region. The textbook is divided into subsections based on the following regions: Europe, North America, Latin America, Africa, Asia-Pacific, and Middle East. Regions were decided based on existing palliative care networks, where available. Information regarding palliative care development in each region is organized based on the World Health Organization's Public Health Strategy for Palliative Care: (1) policies, (2) medicine availability, (3) education, and (4) implementation of services plus (5) vitality (professional activity). This chapter is intended for the reader to gain a high-level view of the state of palliative care development in regions of the world and the challenges and successes within each region. Two case models per region give the reader a quick view into the diversity of palliative care services offered in different regions of the world and give the reader insight into regional-specific delivery models.

1 Introduction

The aim of this chapter is to provide an overview of palliative care development globally with supplementary case studies to describe an array of existing models of palliative care delivery.

Outside of Europe, North America, and Australia, generally, access to quality palliative care services is rare (WHPCA and WHO 2014). However, palliative care has seen a remarkable growth in the past few years. In 2011, 58% of the world's countries had at least one palliative care service, a 9% increase since 2006, with the greatest gains in Africa (Lynch et al. 2013). Still, only 8.5% of countries have achieved advanced integration of palliative care into service provision (Lynch et al. 2013).

This chapter outlines the development of palliative care in different regions of the world, organized by the facets of the World Health Organization's Public Health Strategy for Palliative Care, which include (1) policies, (2) medicine availability, (3) education, and (4) implementation of services (Stjernsward et al. 2007). In addition, due to the fact that the growth in palliative care has often been due to advocates in various countries, we include information on a fifth category: vitality (Centeno et al. 2007, 2016; Woitha et al. 2016b). Each subsection is divided into different geographical regions: Europe,

North America, Latin America, Africa, Asia-Pacific, and Middle East. The regions were mostly based on existence of regional palliative care networks, which often provide much needed information on palliative care development in their respective regions. Each region also contains two case studies of two models of hospice and palliative care service delivery, recommended by experts, for the reader to gain a deeper insight into the different types of models available in palliative care delivery globally. The case studies, therefore, do not necessarily represent the most developed palliative care service in the region, but are available to show the richness in different types of palliative care service delivery throughout the world.

In this chapter, palliative care is defined as “care given to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer” (National Cancer Institute 2010). With its goal to “prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to the related psychological, social, and spiritual problems” (National Cancer Institute 2010). Hospice care has the same principles but palliative care is offered earlier in the disease process, and hospice care is a form of palliative care and is usually limited to a terminal diagnosis (usually defined as having a life expectancy of 6 months or less) (National Cancer Institute 2010).

It is important to note that, in different regions of the world, the concept of palliative care versus hospice care may manifest itself in different ways. In the United States, patients are enrolled in a hospice when a physician estimates a life expectancy of 6 months or less, whereas a hospice in Uganda may, in practice, be providing palliative care, not limiting its patient population to a particular life expectancy.

2 Europe

A total of 32 countries which are part of the European Association for Palliative Care were included in this section (Fig. 1). We thank Mr. Eduardo Garralda (University of Navarra) for reviewing and providing guidance on this section.

2.1 Implementation of Services

According to the European Atlas of Palliative Care, in 2013, the UK had 308 palliative care hospital support teams, 189 inpatient hospices, and 272 day hospice/day care centers (Centeno et al. 2013b). In addition, it leads pediatric palliative care services with 46 pediatric home palliative care support teams, 241 pediatric palliative care units in tertiary hospitals, 42 pediatric inpatient hospices, and 31 pediatric day care services (Centeno et al. 2013b). There is much greater variation in Central and Eastern Europe, where certain countries have no known palliative care capacity (such as Uzbekistan), while others have advanced integration of services (Poland) (Lynch et al. 2013).

Specialized palliative care services in Europe have increased greatly from 1,449 to 5,000 over a period from 2005 to 2012 (Centeno et al. 2016). However, most of the service growth has been in Western Europe, with minimal growth in Central and Eastern Europe (Centeno et al. 2016). In 2012, there were 2,063 home-care teams, 1,879 inpatient palliative care services, and 1,088 hospital support teams in Europe (Centeno et al. 2016) (Fig. 2). Generalist palliative care provision remains an issue and there is a lack of valid, feasible, and measurable indicators to compare generalist palliative care services in Europe (Centeno and Garralda 2016).

The UK has consistently been identified as among the highest performing countries in palliative care according to the Quality of Death Index (The Economist Intelligence Unit 2015), and Western European countries generally show a high level of service provision, with most of the countries falling under levels 4a/4b (preliminary/advanced integration of services) according to the world map (Lynch et al. 2013).

2.2 Policies

Since the development of Recommendation (2003) 24, a national palliative care policy framework, by the Council of Europe (2003), many European countries have adopted laws or frameworks on palliative care. A recent study showed



Fig. 1 Member countries of the European Association for Palliative Care

that out of the 46 countries that took part in the survey in 2013, 12 European Union (EU) and 6 non-EU countries had national palliative care plans (Woitha et al. 2016a). Sixty-three percentage of European countries had a national law where PC provisions were identified, and 52% had national documents with standards and/or norms regarding palliative care provision (Woitha et al. 2016a). Sixty-seven percentage of countries had specific responsibilities for palliative care delivery within the Ministries of Health; some countries delegate the responsibility to one person (e.g., Latvia, Bulgaria), while others have a national office supervising palliative care provision (e.g., Italy). Figure 3 outlines a map of national palliative care plans/strategies and laws by country in Europe.

With regard to the financial resources for palliative care provision, 32 countries (out of 45) provide palliative care free of charge, and

19 countries provide free medications (Woitha et al. 2016a). Full payment was only required in Bulgaria, whereas the majority of the countries had some type of subsidized system for consultation costs and medications (Woitha et al. 2016a). However, national palliative care leaders report that major barriers to palliative care development in Europe include lack of a national plan, lack of adequate regulatory frameworks, and insufficient funding. Particularly, lack of funding allocated specifically for palliative care was seen as the greatest issue in 19 countries (Centeno and Garralda 2016).

2.3 Education in Palliative Care

Twenty-eight European countries (65% of responding countries) have palliative medicine in the curriculum of at least one medical