



Generalist and Specialist Palliative Care

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Abstract

This chapter considers the development of generalist and specialist palliative care practice and the emerging understanding of respective

competences, roles, and responsibilities. Evidence relating to the effectiveness of partnership working and factors promoting (or hindering) collaboration are reviewed. Specialist and generalist palliative care practice are critically appraised through the lens of models of care. The question of whether research to date has adequately examined areas of commonality, separation, and overlap is posed, and the resultant implications for optimal palliative care practice are studied. An overview of research in the field of integrated care is provided, and it is suggested that consideration of integrated care frameworks offers opportunity

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for greater conceptual and methodological clarity in the design and implementation of palliative care interventions and models of care. Worldwide ranking systems of specialist and generalist palliative care are reviewed, and variability in developmental stage between countries is highlighted. The chapter concludes that research in palliative care practice arguable remains largely siloed, considering either generalist or specialist palliative care interventions separately and failing to move to a space where consideration of the “whole” might be more advantageous than considering the sum of the parts.

Keywords

Generalist · Specialist palliative care · Models of care · Integrated care · Outcomes

1 Introduction

The ancient Greeks recognized the need to consider the respective places of both healing and treatment in healthcare. “To cure sometimes, to relieve often, to comfort always” is a phrase attributed to Hippocrates, among others. It reminds us that there has always been a need to care for the seriously ill and dying in medicine. However, the importance of comfort care was increasingly marginalized from mainstream medicine until the mid-twentieth century and the work of Cicely Saunders. When Saunders founded St Christopher’s Hospice in South London in 1967, it quickly became a source of inspiration to others, and the palliative care movement spread globally. As the first “modern” hospice, it uniquely combined three key principles: education, research, and excellent clinical care that encompassed physical, psychosocial, and spiritual domains of need.

The role of specialist practitioners in the modern hospice movement was clear from the outset. Saunders explained the benefits of having skilled and experienced staff working in hospices, stating that “those working in them are specialists and from experience know how to deal with pain, fungating and eroding growths, mental distress,

fear and resentment” (Saunders 1958: 40). The importance of nonspecialists in providing palliative care was also clear; indeed, Saunders said that one of the main aims of work at St Christopher’s was that “... basic principles in teaching and research [should be] fed back into the health service” (Clark 2002). However, articulation of the exact role of nonspecialists and their relationship with specialists was more ambiguous. Ongoing definitional problems regarding palliative care contributed to lack of clarity over subsequent years.

As hospice and palliative care developed in the United Kingdom, interest in formally establishing it as a specialty grew. In 1987, palliative medicine became a sub-specialty of general medicine, initially on a 7-year “novitiate.” Once this was successfully concluded, the specialty was established (Doyle 2005). The journey to specialty status was not without its opponents, however. Many arguments focused on whether palliative medicine was really a specialist territory and not more properly the domain of the primary care physician or treating specialist and whether specialty status would lead to further over-medicalization and marginalization of dying (Doyle 1994). Nevertheless, by 2014, 18 - European countries had followed the UK’s lead in establishing certification programs in palliative medicine (Bolognesi et al. 2014). The growth of palliative medicine was not confined to Europe, for example, the Royal Australasian College of Physicians created a pathway for sub-specialty training in palliative medicine with the first trainees starting supervised training in 1991. In 2006, the American Board of Medical Specialties approved the creation of Hospice and Palliative Medicine as a sub-specialty of ten participating boards.

To date, certification programs remain heterogeneous in content and structure, however, and the most appropriate certification system, not only for palliative medicine specialists but also for other disciplines, has not yet been agreed.

To a certain degree, the historic arguments about the advantages and disadvantages of specialty palliative medicine have been addressed by the model proposed by Quill and Abernethy (2013) where contributions from both specialists and nonspecialists in palliative care are valued.

Quill and Abernethy argue that a care model is needed that distinguishes primary palliative care skills (skills that all clinicians should have) from specialist palliative care skills (skills for managing more complex and difficult cases) so that they can coexist and support each other. In this “coordinated palliative care model,” the primary care physician or treating specialist can manage many palliative care problems and initiates a specialist palliative care consultation for more complex or refractory problems. Patients may be returned to the sole care of the referring specialist or primary care physician once this is felt appropriate by all involved.

The authors argue that the advantages of this model offers are that it recognizes the important role of the primary (also known as “generalist” or “nonspecialist”) palliative care clinician, allows increased access to specialist palliative care for those who need it, reinforces existing relationships, increases satisfaction and enhances the skills of all clinicians in palliative care, and potentially contributes to cost control by reducing the number of specialists routinely co-managing cases. On their own, specialist palliative care clinicians will never be able to care for all patients with palliative care needs, and increasing demand is already outpacing capacity. The fragmentation of the healthcare system is well recognized, and the

addition of another layer of expert care, such as specialist palliative care, should only be considered when benefits outweigh disadvantages.

2 Defining Levels of Palliative Care Provision

The coordinated care model of Quill and Abernethy fits well with the thinking of the revised definition of palliative care published by the World Health Organization (WHO) in 2002 (Sepúlveda et al. 2002) and of the three-tier framework of the European Association for Palliative Care (EAPC) (Gamondi et al. 2013). The WHO description of palliative care as an “approach” to care and a core component of universal healthcare underscores the importance of weaving palliative care into the fabric of healthcare provision and making palliative care accessible to all that need it. The EAPC provides greater depth to the distinction between generalist and specialist practice by describing three recommended levels of education in palliative care for healthcare professionals (Table 1).

Internationally, several policy and strategy documents recognize the place of these levels of palliative care provision and core competencies; however, variation does exist. In some

Table 1 Agreed levels of education currently adopted by the EAPC to reflect the scope and focus of professionals involved in the delivery of palliative care

Palliative care approach
A way to integrate palliative care methods and procedures in settings not specialized in palliative care. Should be made available to general practitioners and staff in general hospitals, as well as to nursing services and nursing home staff. May be taught through undergraduate learning or through continuing professional development
General palliative care
Provided by primary care professionals and specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge. Should be made available to professionals who are involved more frequently in palliative care, such as oncologists or geriatric specialists, but do not provide palliative care as the main focus of their work. Depending on discipline, may be taught at an undergraduate or postgraduate level or through continuing professional development
Specialist palliative care
Provided in services whose main activity is the provision of palliative care. These services generally care for patients with complex and difficult needs and therefore require a higher level of education, staff, and other resources. Specialist palliative care is provided by specialized services for patients with complex problems not adequately covered by other treatment options. Usually taught at a postgraduate level and reinforced through continuing professional development

Reproduced from Gamondi et al. (2013)

documents, palliative care approach and general palliative care levels are collapsed into the one category of “generalist palliative care,” while other documents provide further subdivisions of three EAPC levels. Notably, these documents do not address the core competencies or training needed by informal carers and volunteers, despite the significant contribution they make toward supporting people with both generalist and specialist palliative care needs.

The different levels should not be regarded as descriptors that value the contributions of one group over another; in fact, the opposite is true. The value of recognizing different levels of palliative care provision is as follows. First, recognition of different levels of competence and service provision emphasizes that many palliative care needs can be met by generalists without the need for referral to specialist services. Second, it can inform the development of palliative care training programs for generalists and specialists. Third, distinctions based on healthcare professionals’ skills and training and patient complexity address ambiguity about the nature and scope of generalist and specialist palliative care and help clarify and value respective roles. Finally, defining levels of palliative care and their corresponding core activities facilitate measurement of the extent to which generalists and specialists are, respectively, addressing palliative care needs.

3 Respective Roles and Responsibilities of Generalist and Specialist Palliative Care Practitioners

As previously discussed, the coordinated care model proposed by Quill and Abernethy (2013) acknowledges the skills and expertise of both generalist and specialist practitioners. Indeed, the distinct advantages of supporting primary care providers to deliver palliative care were recently highlighted in a publication by the EAPC Taskforce in Primary Palliative Care (Murray et al. 2015). The Taskforce noted that primary care providers:

- Use their detailed knowledge of patients and families and strong relationships with them to reach all people with life-threatening illnesses and begin providing a palliative care approach immediately following diagnosis with a life-limiting illness.
- Address the various domains of palliative care needs including physical, social, psychological, and spiritual.
- Deliver care directly to patients in all relevant settings including home, clinics, and nursing or care homes.
- Support family caregivers and provide bereavement care.

The role of specialist palliative care providers then is to provide holistic care to patients and families with complex palliative care needs; support complex end-of-life decision-making; provide bereavement care; act as a resource for other healthcare professionals by providing education, training, and support; and demonstrate leadership in advancing the field of palliative care through research, practice, and policy development.

Rather than viewing the roles and responsibilities of generalist and specialist providers as discrete skill sets, some authors have suggested that palliative care input should be divided between generalists and specialists on a continuum (Ryan et al. 2014; Carroll and Quill 2015). “Core” competences are regarded as those attitudes, knowledge, and behaviors that are common to the care provided by all health and social care professionals. Discipline-specific competencies are described in ascending expertise of palliative care practice. There is broad agreement between bodies on what the core competences are that are common to all clinicians (Table 2).

Distinct groups of patients with varying levels of palliative care need may be identified as existing within the population of people with life-limiting or life-threatening conditions. A needs-based approach to palliative care provision advocates that services are provided based on need. For example, people who experience

Table 2 Core competences for generalist and specialist palliative care

European Association for Palliative Care—ten core competencies in palliative care (Gamondi et al. 2013)	National competence framework for palliative care, Health Service Executive, Ireland—six domains of competence (Ryan et al. 2014)
Apply the core constituents of palliative care in the setting where patients and families are based	Principles of palliative care Communication Optimizing comfort and quality of life
Enhance physical comfort throughout patients' disease trajectories	Care planning and collaborative practice Loss, grief, and bereavement
Meet patients' psychological needs	Professional and ethical practice in the context of palliative care
Meet patients' social needs	
Meet patients' spiritual needs	
Respond to the needs of family carers in relation to short-, medium- and long-term patient care goals	
Respond to the challenges of clinical and ethical decision-making in palliative care	
Practice comprehensive care coordination and interdisciplinary teamwork across all settings where palliative care is offered	
Develop interpersonal and communication skills appropriate to palliative care	
Practice self-awareness and undergo continuing professional development	

relatively uncomplicated (though potentially troubling) trajectories of illness should be cared for by generalist providers, while people who experience complex palliative care needs will require the input of a specialist palliative care team. Quality palliative care is best realized when strong networks exist between generalist and specialist providers and when clinicians work together to meet the needs of all people.

4

Factors Supporting Collaboration Between Generalist and Specialist Palliative Care Providers

Working in teams is an essential feature of palliative care delivery (Sepúlveda et al. 2002), and the need for partnership working and collaboration between generalist and specialist palliative care providers is at the center of international palliative care policy and guidelines. The emphasis on coordination within palliative care policy as a means for improving access and outcomes is supported by studies reporting the benefits of team working for both patients and healthcare professionals. A systematic review by Gardiner et al. (2012) found that for patients receiving palliative care, these benefits include increased likelihood of dying in most preferred location, improved symptom management, and greater opportunity for patient education. Generalists reported improved confidence in providing palliative care and increasingly positive attitudes toward specialist palliative care providers.

Given the critical role of effective collaboration in ensuring access to palliative care support for all patients living with a life-limiting illness, it is important to understand the factors that promote and sustain working relationships between generalists and specialists. Overall, studies examining the topic have drawn broadly similar conclusions about the factors influencing collaboration across all care settings. These center around three themes: characteristics and views of generalists, the nature of interpersonal and interprofessional relationships and communication, and organizational factors.

Factors related to generalist providers themselves influence the extent to which they engage in collaborative practice. Their preferences for collaboration with specialist palliative care are often shaped by their own perceptions about the necessity or value of team working. Limited knowledge about the nature or scope of palliative care may also serve as a barrier to collaboration. Similarly, professional judgments about

specialists' skill set also influence generalists' willingness to collaborate and the types of issues they seek input for. For instance, while generalists widely believe that specialist palliative care services provide a level of support that requires additional training and expertise, some have reported concerns that specialists have limited knowledge about disease-specific issues. Firm et al. (2016) report that these perceived gaps in proficiency directly impact on generalists' willingness to collaborate with specialists.

The nature of interpersonal and interprofessional relationships between generalists and specialists, and the quality of their communication, also influences partnership working. Good communication is central to collaboration but requires considerable time and effort, while working relationships are being established and often develop through personal interactions between generalists and specialists rather than any type of formal process or procedure (Gardiner et al. 2012). Studies have found that successful collaboration between generalists and specialist providers is often characterized as being built upon respect, trust, and expertise (Walshe et al. 2008; Firm et al. 2016). Specifically, generalists trust that specialist palliative care providers will respect the hierarchy of decision-making by continuing to consult with the referring team around the patient's care. This approach to communication and negotiation ensures that generalists and specialists are both acknowledging and supporting the expertise of the other and sharing decision-making responsibilities. Moreover, without this clear delineation in roles and responsibilities, the working partnership between generalist and specialist palliative care providers can break down (Brueckner et al. 2009).

Organizational factors also impact on collaboration. Often cited is generalists' need for efficiency and ease of access to specialist palliative care services in hospital or the community. Good partnership is fostered through specialist palliative care services being flexible, visible, and available to provide advice and support round-the-clock. With most patients accessing care across several settings, IT infrastructure is also crucial in

supporting efficient communication between healthcare professionals.

To date, the factors supporting collaboration tend to be ad hoc and driven by informal interactions rather than formal structures. There is also limited evidence about outcomes associated with or methods for evaluating various formal models of partnership working to guide practice and policy.

5 Specialist and Generalist Palliative Care Practice and Models of Care

A model of care broadly describes a framework that brings together regulatory, organizational, financial, and clinical aspects of service provision to outline best practice in patient care delivery. The concept is an important one because of the link between adoption of best practices (as described in a model of care) and improved patient outcomes. Viewing palliative care through the lens of a model of care demands that stakeholders consider how best health services can best utilize the skills of generalist and specialist palliative care professionals. It offers opportunity to critically appraise areas of commonality, separation, and overlap in generalist and specialist palliative care practice and to ensure that organization of practice is optimally configured to meet the needs of patients and their families.

In the traditional model of medical care, palliative care was only provided when curative or disease-modifying treatment was no longer felt to be appropriate. This is gradually being supplanted by an integrated model where palliative care, when needed, is provided at the same time as curative or life-prolonging treatments. To date, a range of different models of palliative care provision have been developed and implemented to meet the requirements of this paradigm shift. Many reviews have been published that have tried to identify the effectiveness and cost-effectiveness of these different models (Luckett et al. 2014; Kavalieratos et al. 2016; Brereton et al. 2017). The reviews acknowledge that palliative care

offers benefits to patients and their families but conclude that the evidence base for effectiveness of individual models of care remains limited by heterogeneity, methodological limitations, poor reporting, and a lack of consensus about outcome measures.

Much of the evidence that has been produced relates to models that predominantly focus on specialist rather than generalist palliative care provision. Moreover, within the models there has been relatively little explicit consideration of the interface between specialist and generalist palliative care and how that might optimally function. While this may in part be due to ambiguous terminology, methodological challenges, and poor reporting of components of the intervention, it contrasts with a growing focus in the general healthcare literature on the integration of primary and specialty care. Instead, research in palliative care arguably remains largely siloed, considering either generalist or specialist interventions separately and failing to move to a space where consideration of the “whole” might be more advantageous than considering the sum of the parts.

What has been learnt from the studies that have been conducted on models of palliative care? Kavalieratos et al. (2016) conducted a systematic review and meta-analysis of palliative care randomized clinical trials (RCTs). RCTs were included if the intervention comprised at least two of the eight possible domains of palliative care as defined by the National Consensus Project for Quality Palliative Care. Interestingly, interventions addressed a median of five (range two to seven) of eight palliative care components. The 43 randomized clinical trials included data on 12,731 patients (mean age, 67 years) and 2479 caregivers. In the meta-analysis, palliative care was associated with statistically and clinically significant improvements in patient QOL at the 1- to 3-month follow-up and symptom burden at the 1- to 3-month follow-up. Findings for caregiver outcomes were inconsistent. When analyses were limited to trials at low risk of bias ($n = 5$), the association between palliative care and QOL was attenuated but remained statistically significant, whereas the association with symptom

burden was not statistically significant. Evidence of associations with other outcomes was mixed.

Due to the diversity and lack of standardization of models studied, it is difficult to classify or group the interventions studied in these reviews. Models of specialist palliative care studied included services provided by unidisciplinary and multidisciplinary teams in hospital (inpatient and outpatient) and community settings. Models of generalist palliative care were similarly conducted across a range of settings, often focusing on communication, advance care planning, or improvements in needs assessment, psychosocial support, and symptom management. Notably, of the five RCTs focused on quality of life at 1- to 3-month follow-up that were judged by Kavalieratos et al. to be at low risk of bias, three comprised a specialist palliative care intervention (Bakitas et al. 2009; Temel et al. 2010; Zimmermann et al. 2014), one was generalist in nature (Rummans et al. 2006), and one comprised both specialist and generalist components (Higginson et al. 2014) (Table 3).

Luckett et al. (2014) adopted a different approach in their rapid review and aimed to identify the elements of effective palliative care models. They concluded that models of palliative care should integrate specialist expertise with primary and community care services and enable transitions across settings, including residential aged care. They considered the following elements to be essential to effective care: case management, shared care, specialist outreach services, managed clinical networks and/or health networks (clinical networks), integrated care, and the use of volunteers. Luckett also encountered the problems of heterogeneity of studies; methodological issues; problems mapping between evidence at the outcome levels of the patient, caregiver, provider, and service; and variable findings.

Indeed, the importance of the trials with negative or equivocal findings should not be overlooked in the search for understanding effective components of specialist and generalist practice. Negative studies highlight methodological issues that need to be addressed in future work and help us understand the “active ingredients” in palliative

Table 3 Generalist and specialist palliative care interventions

Bakitas et al. (2009)	A multicomponent, psychoeducational intervention (Project ENABLE [Educate, Nurture, Advise, Before Life Ends]) conducted by advanced practice nurses with palliative care specialty training consisting of 4-weekly educational sessions and monthly follow-up sessions until death or study completion versus usual care for patients with advanced cancer
Temel et al. (2010)	Early outpatient specialist palliative care for patients with advanced cancer
Zimmermann et al. (2014)	Early hospital, community, or outpatient specialist palliative care for patients with advanced cancer
Rummans et al. (2006)	Structured multidisciplinary intervention comprising eight 90-min sessions over 3 weeks for patients with advanced cancer scheduled to undergo radiotherapy
Higginson et al. (2014)	Short-term, single point of access breathlessness support service integrating specialist palliative care, respiratory medicine, physiotherapy, and occupational therapy

care interventions. For example, in their study of early specialist palliative care among advanced cancer patients, Groenvold et al. (2017) hypothesized that their negative result might be attributable to a failure to provide more specific guidance on the frequency and nature of the input of the specialist palliative care team, a relatively short intervention period, some degree of crossover, and contamination of control groups (as this was not a cluster RCT). Similarly, in Carson et al.'s (2016) RCT of the effect of palliative care-led meetings for families of patients with chronic critical illness, it has been hypothesized that the negative result was attributable to a highly structured study protocol that solely aimed to provide informational support with little regard to what makes this process meaningful to many patients, families, and clinicians: frequent and longitudinal follow-up, close involvement with the primary clinical team, and a focus on relief of physical and psychosocial distress (Malani and Widera 2016).

It is important to recognize that much of the research evidence on specialist and generalist

palliative care originates from high-income countries where more is spent on healthcare and research. Generalizability of findings to low- and middle-income countries cannot be assured, and there is a lack of research on models of generalist or specialist care set in these countries. Lowther et al. (2015) high-quality RCT that studied nurse-led palliative care for HIV-positive patients taking antiretroviral therapy in Kenya is a standout example of what can be achieved outside of high-income countries. It serves as an encouragement for further research to be undertaken to ensure that models of care are fit for each country's purpose.

6 Specialist and Generalist Practice and Integrated Care

"Integrated care" is a complex and still evolving concept. Integration (from the Latin integer, meaning whole, complete, entire) generally means combining parts so that they either work together or form a whole, although its definition in healthcare is somewhat more complex and multi-dimensional. The technical brief prepared for WHO's Department of Health System Governance and Service Delivery in 2008 (World Health Organization 2008) describes integration as "the organisation and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money." The purpose of integrated care is to reduce fragmentation of healthcare, duplication of health services, and missed opportunities for appropriate healthcare and instead improve the user experience and outcomes of care.

As previously discussed, the term "integrated palliative care" is commonly used to distinguish between the traditional dichotomous model of provision of palliative care at the end-of-life only and the model where palliative care is provided at the same time as curative or life-prolonging treatments. However, as the range of models of palliative care provision demonstrates, organizations have demonstrated considerable diversity in the structures and processes that they have used to achieve integration. While there is no single

agreed conceptual model for health systems integration, arguably efforts to integrate palliative care in the mainstream of health provision would benefit from a more considered application of organizational theory and management science. This would help policy makers, planners, managers, clinicians, and researchers study, promote, and implement integrated palliative care and consider the optimal place and relationship of generalist and specialist palliative care practice in achieving integration with the wider health system.

While a detailed review of integrated care is outside of the scope of this chapter, several key points about integration may be made. Fulop et al. (2005) describe five types of integration occurring within the system:

1. Organizational integration (where organizations are brought together through legal instruments or agreements such as mergers, collectives, or networks).
2. Functional integration (where back-office and support functions are integrated).
3. Service integration (where different clinical services are integrated at an organizational level such as through multidisciplinary teams).
4. Clinical (professional) integration (where care by professionals and providers to patients is integrated into a single coherent process within and between professionals and their organizations, such as the use of one care plan, shared clinical guidelines and protocols, devolved shared decision-making, etc.)

5. Normative integration (where an ethos of shared organizational and professional values enables trust and collaboration in delivering healthcare within and across organizations).

Levels and breadth of integration have also been described as important dimensions of integration in the literature. Authors variously describe three levels of integration as macro (regulation, policy, and strategic planning), meso (organizational and professional or physician), and micro levels (clinical) (Stevenson Rowan et al. 2007; Curry and Ham 2010). Breadth of integration is described as horizontal or vertical (Shortell et al. 1996). Horizontal integration refers to the combination of two organizations who are at the same level (e.g., two residential care units), whereas vertical integration refers to the combination of organizations who are at different levels (e.g., hospital, nursing home, and home care provider).

The general healthcare literature has used these frameworks of integrated care provision to explore real-life experiences of integration (Lasker and Committee on Medicine and Public Health 1997), categorize collaborations (Martin-Misener and Valaitis 2008) and outcomes (Ramsey et al. 2009), and identify and describe determinants of successful collaboration (Humphries and Curry 2011). For example, Powell Davies et al. (2008) reported on nine types of strategy used to coordinate care within primary healthcare and among primary healthcare, health services, and health-related services (Table 4). The

Table 4 Types of strategies used to coordinate care

Types of strategies used to coordinate care
<i>Patient and provider level</i>
1. Arrangements to improve communication between service providers e.g. case conferencing
2. Using systems to support care coordination e.g. patient held or shared records
3. Structured arrangements for coordinating service provision between providers e.g. joint consultations
4. Providing support for service providers e.g. training
5. Structuring the relationships between service providers and with patients e.g. case management
6. Providing support for patients e.g. education
<i>Organizational level</i>
7. Joint planning, funding, and/or management of a program or service
8. Formal agreements between organizations
<i>System level</i>
9. Changes to funding arrangements

Adapted from Powell Davies et al. (2008)

potential application of similar work in generalist and specialist palliative care is clear. Explicit consideration of integrated care frameworks offers opportunity for greater conceptual and methodological clarity in the design and implementation of palliative care interventions and models of care.

7 Ranking or Rating Systems for Palliative Care

Despite the difficulties inherent in describing and comparing models of specialist and generalist palliative care, several ranking systems have been devised for palliative care systems in Europe and across the world. The best known of these are the Global Atlas of Palliative Care Development at the End of Life (Lynch et al. 2013), the EAPC Taskforce on the Development of Palliative Care

in Europe (Martin-Moreno et al. 2008), and the Global Quality of Death Index (The Economist Intelligence Unit 2015). Global categorizations of palliative care development are correlated with the state of palliative care as a field of specialization in each system, although the relative weight given to specialist and generalist practice varies significantly between systems.

The Global Atlas uses a six-part typology to describe levels of hospice and palliative care development (Table 5). As can be seen from the descriptors, aspects of both generalist and specialist palliative care provision are considered in each typology.

The EAPC Taskforce describes the development of palliative care in the context of processes, structures, policies, and resources that support the delivery of palliative care. Data is gathered from multiple sources including

Table 5 Global atlas of palliative care typology (Lynch et al. 2013)

Group 1:
Countries with no known hospice-palliative care activity, i.e., best efforts have been unable to identify any palliative care activity in this group of countries
Group 2:
Countries with capacity-building activity, i.e., there is evidence of wide-ranging initiatives designed to create the organizational, workforce, and policy capacity for hospice-palliative care services to develop. Activities include attendance at, or organization of, key conferences, personnel undertaking external training in palliative care, lobbying of policy makers and health ministries, and an incipient service development, usually building on existing home care programs
Group 3 countries:
(3a) isolated palliative care provision, i.e., countries characterized by the development of palliative care activism that is patchy in scope and not well-supported, sourcing of funding that is often heavily donor-dependent, limited availability of morphine, and a small number of hospice-palliative care services that are often home-based in nature and limited in relation to the size of the population
(3b) generalized palliative care provision, i.e., countries characterized by the development of palliative care activism in a number of locations with the growth of local support in those areas, multiple sources of funding, the availability of morphine, a number of hospice-palliative care services from a community of providers that are independent of the healthcare system, and the provision of some training and education initiatives by the hospice organizations
Group 4 countries:
(4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision. This group of countries is characterized by the development of a critical mass of palliative care activism in a number of locations, a variety of palliative care providers and types of services, awareness of palliative care on the part of health professionals and local communities, the availability of morphine and some other strong pain-relieving drugs, limited impact of palliative care upon policy, the provision of a substantial number of training and education initiatives by a range of organizations, and existence of (or at least an interest in the concept of) a national palliative care association
(4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. This group of countries is characterized by the development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities, and society in general; unrestricted availability of morphine and most strong pain-relieving drugs; and substantial impact of palliative care upon policy, in particular upon public health

qualitative data by means of the Eurobarometer survey, quantitative data by means of the FACTS Questionnaire, bibliographic review, and interview of key informants. Both generalist and specialist palliative care data are collected, although it is arguable that the focus on specialist palliative care provision is greater than in other rating systems.

The Quality of Death Index is scored on 24 indicators in 4 categories, each with a separate weighting, as follows:

1. Basic end-of-life healthcare environment (20%)
2. Availability of end-of-life care (25%)
3. Cost of end-of-life care (15%)
4. Quality of end-of-life (40%)

Eleven of the Index's 24 indicators are based on quantitative data, such as life expectancy and healthcare spending as a percentage of GDP. Ten of the indicators are qualitative assessments of end-of-life care in individual countries, for example, "Public awareness of end-of-life care," which is assessed on a scale of 1–5 where 1 equates to "little or no awareness" and 5 to "high awareness." Three of the indicators describe whether something is or is not the case, for example, "Existence of a government-led national palliative care strategy," for which the available answers are Yes, No, and In Progress. Only one indicator (availability of hospices and palliative care services per million population aged 65 and over) refers specifically and solely to specialist palliative care.

Despite the different methodologies, the different systems show broad agreement, with the United Kingdom, Australia, New Zealand, and Ireland ranking highly. The rating systems should be used and interpreted with caution, however, as they are associated with both advantages and disadvantages. As should be clear from the preceding discussions on the evidence base for models of palliative care, the methodology underpinning the scoring systems is far from an exact science. Moreover, despite best efforts, data may be unreliable or unverifiable. While the systems provide some absolute measure of development as

well as change over time and can be used to advocate for development in specific countries, they can also prove to be demotivating for some countries where areas of achievement are not given adequate recognition or weighting.

8 Access to Generalist and Specialist Palliative Care

The way in which palliative care is delivered is determined by the nature of patients' and families' needs. The majority can have these addressed by generalists providing a palliative care approach, with referral for specialist input required only for more complex needs. As previously discussed, a growing body of evidence demonstrates that receiving palliative care support is associated with several positive benefits. Nevertheless, access to both generalist and specialist palliative care is less than optimal. Many who would benefit from a palliative care approach are never identified, and referrals to specialist palliative care services are often delayed or poorly managed. Access is also inequitable for those with non-malignant disease. Overall, current evidence suggests that only a minority of those who need specialist palliative care, approximately 14%, ever receives it (Connor and Bernedo 2014). Further to this, projected increases in the number of annual deaths and disease burden indicate that the need for palliative care will continue to grow.

Meeting this demand is a serious challenge for healthcare systems. However, returning to the coordinated palliative care model outlined by Quill and Abernethy, health systems need to ensure that they do not simply focus on ensuring access to specialist palliative care—rather they must also consider issues of access to generalist palliative care. To date, evaluations of access to palliative care have focused primarily on patients' utilization of specialist palliative services. However, if many patients can, and do, have their palliative care needs adequately addressed by generalists, it follows that using specialty as a proxy for measuring access to palliative care systematically underestimates how much palliative care people are receiving. Indeed, future research

activities should also seek to define what a palliative care approach is and develop methods for measuring and evaluating its delivery. Such exercises would allow for more informed discussion around how best to respond to the growing need for palliative care.

8.1 Timing the Introduction of Generalist and Specialist Palliative Care

Related to concerns about access to palliative care services is the issue of timing. Uncertainty about the nature or scope of palliative care can make it difficult for generalists to identify patients and families with multiple unmet needs who would benefit from a palliative care approach or specialist palliative care in a timely manner. This late identification is one of the main reasons people do not receive palliative care. Education and training has been cited as crucial for helping generalists develop the skills required to identify and address needs and the confidence to introduce a palliative care approach or seek specialist input, thus ensuring patients have timely access to the appropriate level of support.

It is worth noting that the literature on introducing palliative care tends to reflect concerns around appropriate timing of referral to specialist services. This development is understandable as referrals to specialist palliative care late in the disease trajectory are common and can have serious consequences for patients, families, and healthcare professionals including perceived poor coordination of care, unexpected death, and lower satisfaction with palliative care services (Gardiner et al. 2012). Hui et al. (2012) found the median interval between referral to specialist palliative care and death in patients with advanced cancer was 42 days. Delays can be significantly longer for patients with a nonmalignant disease, as demonstrated by Bakitas et al.'s (2013) chart review of access to specialist services among a cohort of patients with advanced heart failure which reported a median time between consultation and death of only 21 days. These delays in

referral to specialist services are often attributed to difficulties with prognostication and predicting disease trajectory, particularly for those with a diagnosis other than cancer.

Several tools have been developed to help generalists identify patients with palliative care needs. Some use prognostic estimates and clinical indicators to gauge when palliative care should be introduced. One example is the Gold Standards Framework Prognostic Indicator Guidance (GSF), a tool originally developed to improve quality of care for patients near the end-of-life. The GSF uses multidimensional criteria to assess need including the “surprise question” (*Would you be surprised if this person dies within the next 6–12 months?*), if they voice preference for comfort care only and clinical indicators relevant to the patient's diagnosis (Department of Health 2008). Alternatively, some tools, such as the Supportive and Palliative Care Indicators Tool (SPICT), focus on helping generalists identify patients who are *at risk* of deterioration or dying (Highet et al. 2014) for palliative care needs assessment and future care planning. The SPICT includes six general indicators suggesting increasing need or deteriorating health status and other indicators of advanced disease, depending on the patient's diagnosis. The SPICT also advises on assessment and review of current and future care needs, including considering referral to specialist palliative care. Like the GSF, the SPICT may be used in all adult patients with life-limiting conditions.

9 Conclusion

It is essential that policy makers, service providers, and service users all recognize that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist providers. Patients with life-limiting or life-threatening illness must be able to engage easily with the level of expertise most appropriate to their needs regardless of care setting or diagnosis. Quality service provision is best realized when generalist and specialists work together in an integrated and coordinated way to respond to, and

meet, those needs. However, worldwide, there is significant variation in the level of specialist and generalist palliative care service provision.

The success of generalist and specialist partnerships can be critically affected by lack of clarity and agreement regarding roles and responsibilities. Ideally, models of care should be developed that describe the optimal structures and processes of specialist and generalist practice so that patients and their families experience the best possible outcomes of care. To date, while palliative care has been shown to improve patient and family outcomes, research has largely focused on specific generalist or specialist interventions. As a result, the evidence base is not yet able to describe universal models of comprehensive, evidence-based palliative care that span services and settings. There are methodological and practical challenges to conducting clinical and cost-effectiveness work in palliative care, but these are not insurmountable and should not delay further study. Transferable learning from the fields of integrated care and implementation science may be of help in achieving the goal of designing whole system approaches to care and in ensuring that palliative care is an integral part of universal healthcare provision.

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