Nursing and Palliative Care

33

Jane L. Phillips, Claudia Virdun, Priyanka Bhattarai, and Claire Fraser

Contents

1 **Introduction** 541
1.1 Key Constructs Underpinning Palliative Care Nursing 542
1.2 Policy and Practice 554
1.3 Conclusions 554

References 554

Abstract

Nursing is integral to meeting the growing demand for palliative care which is being driven by population aging and the increasing burden of chronic, noncommunicable disease. Palliative nursing and nursing in general share many of the same principles and practices. Both are committed to addressing the holistic domains of health (physical, psychological, emotional, cultural, social, practical, spiritual, and informational aspects of a person's health and well-being) (Fitch, Hosp Q 3(4):39–46, 1999). This chapter provides an overview of the role of nursing in the context of contemporary interdisciplinary specialist and primary palliative care, key constructs underpinning palliative nursing, the core competencies of specialist and primary palliative care nursing, and how these competencies can be applied to provide best evidence-based person-centered palliative care, regardless of the care setting.

J. L. Phillips (✉) · P. Bhattarai
Faculty of Health, Improving Palliative, Aged and Chronic Care Through Clinical Research and Translation, University of Technology Sydney, Ultimo, NSW, Australia

School of Nursing, University of Notre Dame Australia-Sydney, Darlinghurst, NSW, Australia
e-mail: jane.phillips@uts.edu.au

C. Virdun
Improving Palliative, Aged, and Chronic Care through Clinical Research and Translation (IMPACCT), Faculty of Health, University of Technology Sydney, Ultimo, NSW, Australia

C. Fraser
Faculty of Health, Improving Palliative, Aged and Chronic Care Through Clinical Research and Translation, University of Technology Sydney, Ultimo, NSW, Australia

1 Introduction

Nursing care is central to all hospice and/or palliative care ("palliative care") service delivery and is underpinned by the World Health Organization definition of palliative care (World Health Organization 2003). Having emerged from its informal religious roots, palliative nursing has evolved into a dynamic discipline that works with other interdisciplinary team members to improve care outcomes for people living with and dying from

R. D. MacLeod, L. Van den Block (eds.), *Textbook of Palliative Care*,
https://doi.org/10.1007/978-3-319-77740-5_43

progressive illness and their families. Palliative nursing, along with palliative care, has evolved rapidly since the late 1970s and has largely been driven by a social movement designed to improve the care of people dying from cancer (Phillips et al. 2015). Dame Cicely Saunders (1918–2005), a nurse, social worker, and physician, responded to this need and established St Christopher's Hospice in North London, where care was focused on the physical, psychological, and spiritual needs of dying patients (Pace and Lunsford 2011). This holistic care model was rapidly translated to other high income countries such as Canada and Australia, while the uptake of palliative care in the United States of America occurred much later, partially in response to the landmark "SUPPORT study" (Connors et al. 1995). This large randomized controlled trial conducted at five US teaching hospitals lent considerable support to the need to improve palliative care in the world's largest economy. The subsequent release of the Institute of Medicine's "Approaching death: improving care at the end-of-life" (Institute of Medicine 1997) strengthened this call to action. Emerging from these developments has been the establishment of specialist palliative care nursing and recognition of the increasing importance of primary palliative care (Box 1) (Quill and Abernethy 2013).

The purpose of this chapter is to provide an overview of the role of nursing in the context of contemporary interdisciplinary palliative care.

Box 1 Key Definitions

Nurses – Regulated health professionals who work across all care settings (acute care, aged care, primary care) and in doing so provide care for people with palliative care needs and their families. These nurses provide primary palliative care.

Palliative nurses – Nurses who work specifically in the care of people with palliative care needs and their families. These nurses might work in specialist inpatient services (e.g. hospices, palliative care units) or in a consultative role working alongside nursing and interdisciplinary colleagues. These nurses provide specialist palliative care.

Palliative care – The definition provided by the World Health Organization has been adopted for this chapter: http://www.who.int/cancer/palliative/definition/en/. This definition refers to people who are affected by a life-limiting illness and advocates for the nursing role (generalist and specialist) to enable those affected to live as well as possible with their complex healthcare needs managed as well as possible.

1.1 Key Constructs Underpinning Palliative Care Nursing

Palliative care demands a skilled interdisciplinary response, with nurses playing a central role. Several constructs underpin contemporary palliative care nursing practice, including domains of nursing practice, evidence-based practice, person-centered care, and a population-based approach to palliative care. Each is essential to providing best palliative care, at the right time, every time, as detailed below.

1.1.1 Evidence-Based Practice

The notion that health service evaluation must be guided by scientific evidence, not clinical impression, was first suggested in the 1970s (Rosenberg and Donald 1995). Since then, evidence-based healthcare has become a guiding force in clinical practice and gradually embedded across various disciplines, including nursing. Evidence-based nursing care extends beyond mere reliance on research evidence, with nurses required to concurrently assess the risks, benefits, costs, inconveniences, and patient preferences in relation to proposed care (Scott and McSherry 2009). In the palliative care setting, these considerations are even more crucial due to the complex interplay of a patient's

vulnerability, diagnosis, prognosis, goals of care (Owens 2009), and a rapidly evolving evidence base (Tieman et al. 2008).

In order to exercise astute clinical judgment, nurses need prerequisite capabilities to successfully integrate evidence with their clinical expertise and patient preference(s) (Scott and McSherry 2009). Despite having positive attitudes toward evidence-based practice (Mehrdad et al. 2012; Stokke et al. 2014), recent research suggests that many nurses minimally engage in providing evidence-based care (Stokke et al. 2014). Keeping abreast of new evidence is challenging (Phillips 2015), which has led to the development of various publicly available websites, including: CareSearch (www.caresearch.com.au); Cochrane Library; Joanna Briggs Institute; and eviQ, which all host specialized evidence-based resources relevant to palliative care.

Having located the evidence, the next challenge is to critically appraise this in a rigorous way. At a minimum, all nurses need to be able to evaluate a study's methodological strengths and weaknesses before carefully considering its results, relevance, and applicability to their own practice. Critical appraisal tools such as those electronically hosted in the Critical Appraisal Skills Program (CASP) and Joanna Briggs Institute website provide nurses with a framework to systematically analyze research evidence for their trustworthiness and relevance.

Notwithstanding, the step up from "best evidence" to "best practice" requires concerted system level efforts, and nurses have ample opportunities to integrate best evidence to practice in day-to-day decision-making and care delivery. As nurses continue to shape palliative care practice through their diverse roles, from providing bedside care in an institutional setting to working as advanced nurse practitioners, every nurse needs to consider how they can integrate and promote evidence-based care into all healthcare decisions.

1.1.2 Ethical Behavior and Consumer Rights

The responsibility of providing palliative nursing care to vulnerable patients is often associated with ethical challenges that need to be addressed judiciously. An understanding of beneficence, non-maleficence, autonomy, and justice (Webb 2005) helps nurses uphold high standards of ethical conduct while addressing the unique issues pertaining to a patient's end-of-life care needs. Some of the common ethical issues that nurses' encounter are determining competency to consent, advocacy, and withholding and/or withdrawing treatment. Determining a patient's competency to consent is critical to striking a balance between respecting their autonomy to making informed decisions and protecting them if they are unable to do so.

When a patient lacks the competence to make a decision about treatment, substitute decision makers must be sought. Nurses have a responsibility to ensure that competent patients are provided with relevant information to assist them in making informed choices about the goals of care, proposed treatments, and burdens and benefits of participating in clinical trials (Anyfantakis and Symvoulakis 2011). Vulnerable palliative patients may be easily persuaded to make choices that they would not normally make. In such situations, nurses have a responsibility to act as patients' advocates ensuring that the patient's voice is heard and their choices are respected (Webb 2005). As the discipline that spends the most time with patients, nurses are best placed to advocate for the patient's preference and goals of care, symptom management, and cultural and spiritual needs (Earp et al. 2008). Advocacy in palliative care is not limited to speaking up "on behalf" of the patient but also involves providing patients with the support and information they require to speak for themselves regardless of their level of dependency (Webb 2005). The strengths of the nurse-patient relationship provide nurses with unique access to the perspectives, preferences, wishes, and concerns of the patient living with and dying from progressive illness.

Nurses play a central role in ensuring that the patient's voice is heard, especially when decisions about forgoing and/or starting a medical treatment are made (Albers et al. 2014). Careful consideration of the benefits versus the burden of proposed treatment and its impact on the patient's quality of life ought to inform all decision-making processes.

While physicians are more often responsible for such decision-making, the involvement of nurses in this process is essential (Albers et al. 2014). It is also crucial for nurses to be able to differentiate between withholding and withdrawing treatment, and provision of effective symptom relief and euthanasia. While the former is carried out with an intent to minimize treatment burden and improve patient's quality of life, the latter is intended to end a patient's life (New South Wales Department of Health 2005). Nurses may receive requests from families asking for "something" to bring an end to the suffering of their loved ones in the last days of their life. Such requests demand the utmost care to identify why such a request is being made at this time and to determine alternative actions that could address the patient's and/or family's concerns (Caresearch 2017).

1.1.3 Person-Centered Care

Person-centered care is a fundamental component of effective palliative care and underscores the importance of interdisciplinary care for people living with and dying from progressive illness. There are many definitions of person-centered care; however, two are of specific relevance to palliative care nursing, namely: (1) dimensions of patient-centered care as articulated by the Picker Institute (Picker Institute Europe 2017) and (2) constructs articulated in a person-centered practice framework developed by McCormack and McCance (2017). The Picker Institute identified eight characteristics of care that are most important to patients and their families (Barry and Edgman-Levitan 2012) and has since detailed these as the principles of person-centered care, namely: (1) fast access to reliable healthcare advice; (2) effective treatment delivered by trusted professionals; (3) continuity of care and smooth transitions; (4) involvement of, and support for, family and carers; (5) clear, comprehensible information, and support for self-care; (6) involvement in decisions and respect for patient's preferences; (7) emotional support, empathy, and respect; and (8) attention to physical and environmental needs (Picker Institute Europe 2017). In the McCormack person-centered practice framework, four constructs are considered essential for the provision of person-centered nursing care: (1) prerequisites and/or nursing attributes; (2) care environment and/or context of care; (3) person-centered processes of care; and (4) person-centered outcomes (Fig. 1) (McCormack and McCance 2017).

Nurses are in a unique position to both lead and innovate in relation to provision of person-centered care especially as they are the only health professional available 24 hours a day in most care settings. This exposure to patients and families provides nurses with a unique opportunity to establish and develop therapeutic relationships that address the principles of person-centered care. Understanding how to achieve person-centered care is fundamentally important for all nurses but particularly for those providing palliative care given the complexity of patient and family needs. Indeed, a synthesis of a large body of research conducted over the past 25 years has identified the elements of care inpatients and their families considered to be most important at the end-of-life (Fig. 2) (Virdun et al. 2015, 2017). These areas of importance align with the principles and constructs of person-centered care. It is these elements of importance that ought to inform the provision of optimal person-centered palliative nursing.

1.1.4 A Population-Based Model of Palliative Nursing

The demand for palliative nursing continues to grow in response to changing epidemiology, population aging, the recognition of the value of early palliative care, and the need to extend timely palliative care to populations beyond cancer (Morrison et al. 2011; Temel et al. 2010). Meeting this increased demand will be challenging for specialist palliative care services, especially, if people with palliative care needs are to have access to a comprehensive and holistic service. There is now recognition of the importance of developing interdisciplinary population-based models that are designed to improve access to palliative care in accordance with need (Luckett et al. 2014).

A population-based approach to palliative care service planning focuses on strengthening the delivery of palliative care provided by the patient's usual care team ("primary palliative care") in the acute care, community, and aged care settings (Quill and Abernethy 2013).

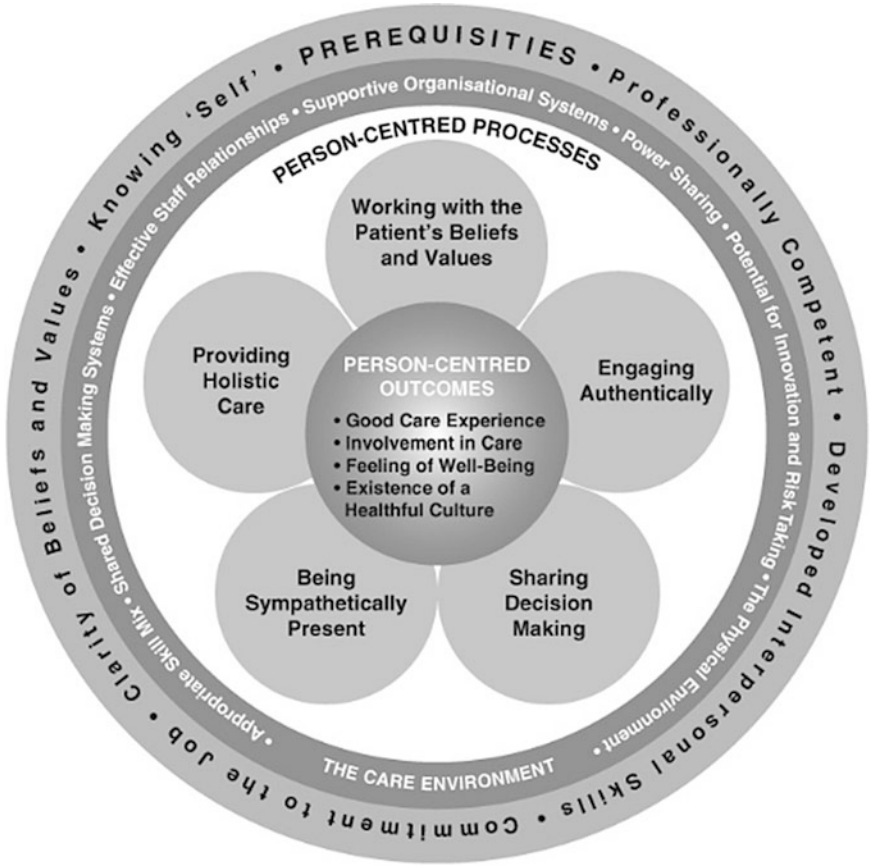

Fig. 1 The person-centered practice framework (McCormack and McCance 2017, p. 63) (Source: Permission obtained to use the figure)

Adopting a population-based approach helps to facilitate a responsive and inclusive method of addressing the particular geographical, social and cultural needs of people with a progressive illness (Palliative Care Competence Framework Steering Group 2014). It helps to ensure that palliative care is more accessible for Aboriginal-first nation peoples, socially disadvantaged people, people living with nonmalignant illness, and people living in rural and remote areas, all of whom often have more limited access to palliative care (Palliative Care Competence Framework Steering Group 2014). For example, a population-based model of care is key to improving the provision of palliative care to older people in nursing homes who have unmet palliative care needs. In this care setting, the primary palliative care ought to be provided by the older person's usual care team (care assistants, registered nurses, and general practitioner) and be augmented with specialist palliative care input and active patient and primary care engagement (Candy et al. 2011; Hall et al. 2011; Davies et al. 2011). Implementing this type of model would do much to address poor symptom control, unnecessary hospitalizations, suboptimal communication, inadequate advance care planning, and families who are dissatisfied with palliative care (Phillips et al. 2006).

Comprehensive interdisciplinary specialist palliative care services are central to operationalizing a population-based model of care. Providing direct care and/or consultative services in the tertiary, secondary and/or primary care settings, these specialist palliative care services (including specialist nurses) are ideally placed to provide local leadership, training, mentorship,

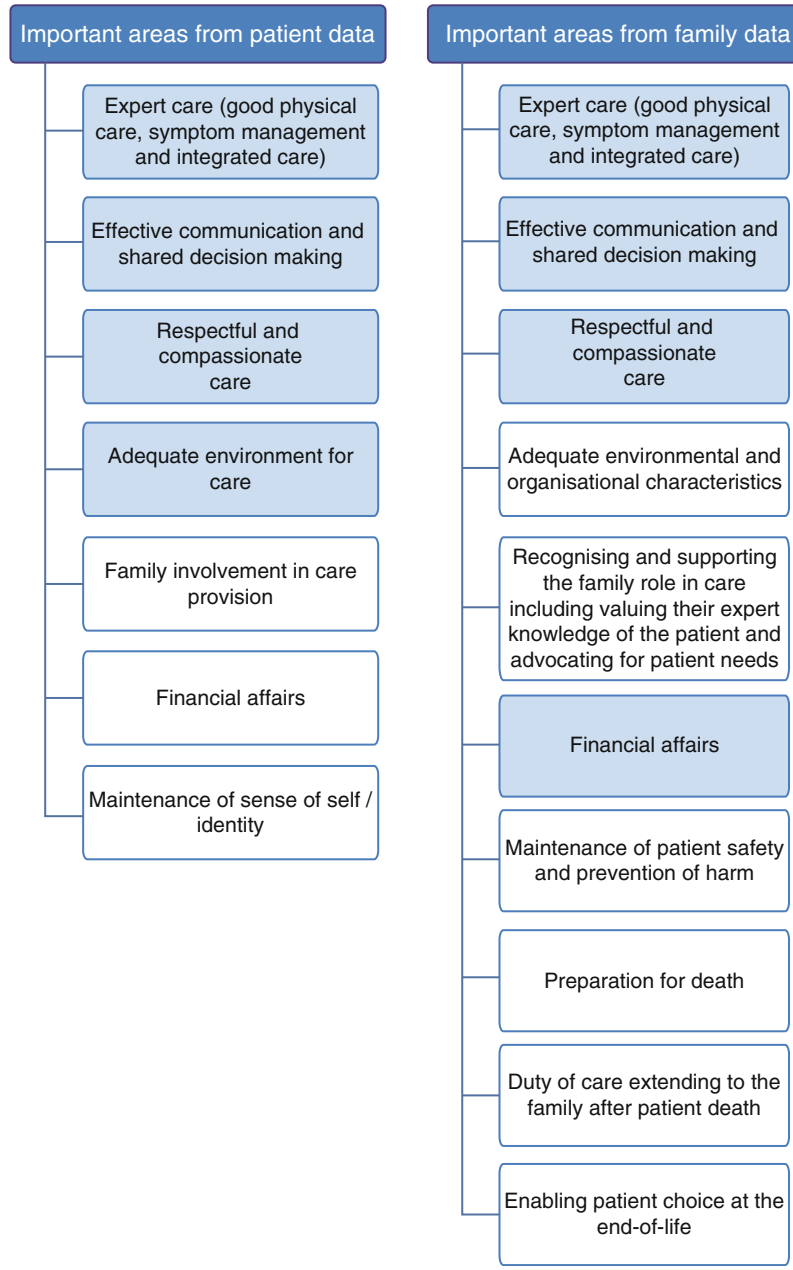

Fig. 2 Area of importance for optimal end-of-life care in hospitals: patient and family perspectives (Virdun et al. 2015)

and supervision to support the delivery of primary palliative care by other health professionals and to undertake research and/or quality initiatives (García-Pérez et al. 2009; Higginson and Evans 2010). Implementing a population-based approach requires that all nurses, regardless of specialty training, are able to provide primary palliative care to the patients and families they service. It also requires specialist palliative nurses to operate alongside nurses providing primary palliative care. Furthermore, a commitment to building collaborative care partnerships and the palliative care capabilities within the broader interdisciplinary care team is vital. By making better use of scarce resources, specialist palliative nursing is then reserved for patients and families with the most complex needs (Palliative Care Australia 2005).

1.1.5 Domains of Nursing Practice

Regardless of the care setting or population, all nurses are required to practice in accordance with the relevant legislation affecting nursing practice in healthcare. Nurses function within several key domains of practice, and while these may vary across countries and/or jurisdictions, they largely focus on (1) critical thinking and analysis; (2) engagement in therapeutic and professional relationships; (3) maintenance of the capability to practice; (4) comprehensive assessments; (5) development of a plan for nursing practice; (6) provision of safe, appropriate, and responsive quality nursing practice; and (7) evaluation of outcomes to inform nursing practice (Nursing and Midwifery Board of Australia 2016). In Australia, these standards are conceptualized as a matrix, with interrelated Standards 1–3 forming the y-axis, while Standards 4–7 describe the dimensions of practice and form the x-axis. Each standard has criteria that specify how that standard is demonstrated within the context of each registered nurse's practices (Nursing and Midwifery Board of Australia 2016).

Nurses are also required to operate within a professional and ethical nursing framework. Practicing within an evidence-based framework, participating in ongoing professional development, and systematically developing the capabilities of others are considered core competencies necessary for critical thinking and analysis. The provision of coordinated and effective care requires nurses to have the capabilities to conduct a comprehensive and systematic nursing assessment, plan care in consultation with other members of the interdisciplinary team and in accordance with patient preference, implement comprehensive safe and effective evidence-based nursing care, and evaluate the care. Establishing and/or maintaining therapeutic relationships as well as appropriately concluding them and collaborating with other members of the interdisciplinary team underpins all collaborative and therapeutic practices (Nursing and Midwifery Board of Australia 2016). The competency standards for registered nurses are the foundation upon which specialist competencies are built.

1.1.6 Palliative Care Competencies

Preparing the nursing workforce to operate within a population-based model requires consideration of the competencies required to fulfill the different levels of specialization and defined scope of practice. While there is considerable debate about the most appropriate definitions and methods of assessments, nursing competencies are generally considered to represent a dynamic combination of knowledge (basic or specialized), skills (assessment, communication, critical thinking, time management, customer services, technical skills, and teaching), and abilities (caring, character, and professional presentation) which contribute to understanding (Aranda and Yates 2009). In preparing the nursing workforce to provide palliative care, it is important to consider the competencies required for each of the four levels of nursing practice across the six domains of palliative care, namely: (1) principles of palliative care; (2) communication; (3) optimizing comfort and quality of life; (4) care planning and collaborative practice; (5) loss, grief, and bereavement; and (6) professional ethical practice in the context of palliative care (Palliative Care Competence Framework Steering Group 2014). The European Association for Palliative Care has identified the following ten core interdisciplinary palliative care competencies considered necessary for optimizing patient and family outcomes (European Association for Palliative Care 2013) (Box 2).

Box 2 Ten Core Interdisciplinary Palliative Care Competencies (European Association for Palliative Care 2013)

1. Apply the core constituents of palliative care in the setting where patients and families are based.
2. Enhance physical comfort throughout patient's disease trajectory.
3. Meet patient psychological needs.
4. Meet patient social needs.
5. Meet patient spiritual needs.
6. Respond to the needs of family carers in relationship to short, medium, and long-term patient care goals.

(*continued*)

Box 2 (continued)

7. Respond to the challenges of clinical and ethical decision-making in palliative care.
8. Practice comprehensive care coordination and interdisciplinary teamwork across all settings where palliative care is offered.
9. Develop interpersonal and communication skills appropriate to palliative care.
10. Practice self-awareness and undergo continuing professional development.

As the provision of high-quality palliative care is an essential responsibility of the whole healthcare system, many countries, jurisdictions, and/or professional bodies have developed palliative care competency frameworks (Palliative Care Competence Framework Steering Group 2014; Aranda and Yates 2009; Palliative Care Nurses New Zealand 2014). Competencies have been variously defined but generally refer to ". . .a cluster of related knowledge, skills and attitudes that affects a major part of one's role (a role or responsibility) that correlates with performance on the job, that can be measured against well–accepted standards, and that can be improved by training and development" (Parry 1996).

Recognition of the different levels of palliative care nursing specialization is central to developing a competency framework, with four different levels of palliative care nursing specialization evident across the healthcare system, including primary palliative care nurses ("all"), palliative care nurses' champions ("many"), specialist palliative care nurses ("some"), and palliative care advanced practice or nurse practitioners ("few") (Table 1) (Palliative Care Competence Framework Steering Group 2014; Aranda and Yates 2009; Palliative Care Nurses New Zealand 2014).

The palliative care nursing capabilities required for each of these four levels increases in intensity as the role becomes more focused on the specialty. At a minimum, all nurses require the capabilities to provide basic pain and symptom management, including managing anxiety and depression, and initiating conversations about prognosis, suffering, and goals of care and patient preferences, especially around resuscitation status (Quill and Abernethy 2013). Specialist palliative care nurses are required to have more advanced skills and the capabilities to manage refractory pain and other symptoms, including complex depression anxiety and existential distress; and assist with resolving goals of care, treatment, and/or family conflicts as they arise (Palliative Care Australia 2005). Palliative care nurse practitioners have a broader scope of practice and operate in accordance with the values, guidelines, and principles set out by their governing regulatory and professional bodies (Aranda and Yates 2009). All nurses will need to continue to learn throughout their professional life as new evidence emerges within this field.

As developing a sustainable nursing workforce capable of providing high-quality care requires a targeted response, several countries have established national professional development frameworks for cancer and/or palliative care nursing (Palliative Care Competence Framework Steering Group 2014; Aranda and Yates 2009; Palliative Care Nurses New Zealand 2014). Underpinned by a population-based approach, these professional development frameworks define nursing's contribution to palliative care and highlight the contribution all nurses make, irrespective of their role (Palliative Care Nurses New Zealand 2014). As previously described, four broad levels of palliative care nursing practice have been identified (Refer Table 1) to reflect the different levels of competencies required of nurses working in different contexts (Palliative Care Nurses New Zealand 2014). The level of palliative care competencies required at each of the four levels of practice reflects the number of palliative patients cared for by nurses and is best conceptualized as the "all, many, some, and few" competency framework as depicted in Fig. 3 (Aranda and Yates 2009; Palliative Care Nurses New Zealand 2014). Within each of the four levels, nurses will be functioning at differing levels of competencies from beginning through to advanced levels. This progression is reflected

Table 1 Levels of palliative care specialization (Palliative Care Competence Framework Steering Group 2014; Aranda and Yates 2009)

Level of specialization	Guiding principles
Level I – *ALL* Primary palliative nurses	Palliative care principles or a palliative approach needs to be practiced by all nurses working in the acute, community, or nursing home settings. Many people with progressive life-limiting illnesses will have their care needs met comprehensively by their usual healthcare team and not require referral to specialist palliative care units or personnel
Level II – *MANY* Palliative nurses champions	As an intermediate level, a proportion of individuals and families will benefit from the expertise of local palliative nursing champions who, though not engaged full time in palliative care, have undertaken additional palliative care training (i.e., graduate certificate and/or diploma levels) and/or intensive palliative care clinical internships and training. With this training and their networks, they are able to act as a palliative care resource within their organization. Many of these nurses will work in cancer, renal and/or respiratory care, intensive care, acute care, domiciliary care, and/or aged care
Level III – *SOME* Specialist palliative nurses	Specialist palliative nurses are focused entirely on the provision of palliative care. These nurses are involved in the care of patients and families with more complex and demanding palliative care needs. As a consequence these nurses require higher level palliative care training at the masters level in order to develop the competencies and specialist skills required for managing complex problems
Level IV - *FEW* Palliative care nurse practitioners/ advance practice nurses	Palliative care nurse practitioners or advanced practice nurses are able to work as independent nurses and in many countries have prescribing rights

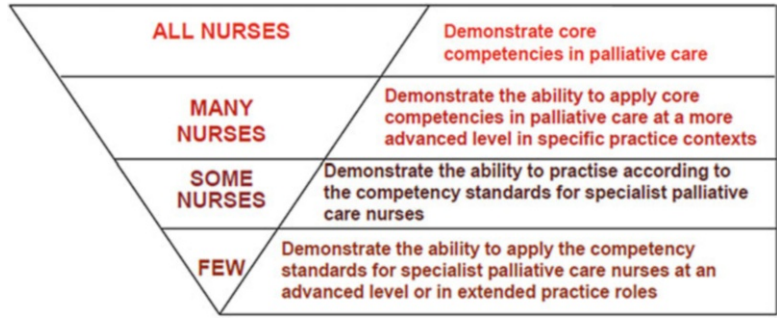

Fig. 3 A professional development model for palliative care nurses (Palliative Care Nurses New Zealand 2014, p. 6)

in their capacity to integrate theory, practice, and experience (Palliative Care Nurses New Zealand 2014). Increasing degrees of autonomy in judgment and interventions is evident as nurses become more specialized (Palliative Care Nurses New Zealand 2014).

1.1.7 Certification and Credentialing

In addition to the competency framework, some organizations have moved to introduce certification and/or credentialing processes. Certification is generally undertaken by professional bodies (i.e., Palliative Care Nurses Australia) on behalf of its members. Certification processes are designed to publicly acknowledge the achievements of nurses working in specialized areas against a predefined set of requirements (Aranda and Yates 2009). A major limitation of most certification processes is they lack the detail necessary to guide employers as to whether a particular nurse can function effectively in all areas of practice (Aranda and Yates 2009), whereas credentialing is a more comprehensive process that is normally undertaken by an employing organization. Credentialing clearly documents the scope of practice of a particular nurse in a specific practice setting and is often locally defined (Aranda and Yates 2009).

Table 2 Applying palliative care competencies to ensure the provision of person-centered palliative nursing (McCormack and McCance 2017)

Person-centered care (McCormack and McCance 2017)	Translation to palliative nursing	Opportunities for improvement/innovation
1. Prerequisites		
Professionally competent	Relevant registration requirements confirmed Implementation of palliative care nursing competencies for "all, many, some, and few" nurses Annual appraisal of competencies and identified areas for growth Ability to think critically, problem solve, predict outcomes, and use judgment and wisdom to devise optimal palliative care interventions and evaluation of care	Validation of competency frameworks for palliative nursing and competency indicators for each level of palliative care nursing Aligning nurses' continuing professional development (CPD) opportunities with their required competencies
Developed interpersonal skills	Interpersonal communication capabilities (managing workplace conflict, challenging conversations) clearly defined and measured in accordance with level of competencies Builds therapeutic relationship with patients and families Develops interpersonal and communication skills appropriate to palliative care	Partnering with universities and/or communication experts to build nurse's interpersonal skills Integrates communication into CPD opportunities Evaluates patient and family experience in relation to care received to drive improvement efforts
Commitment to the job	Rewards commitment with professional development and advancement opportunities Acts as a resource to others in the interdisciplinary team	Organizational efforts to value, develop, and reward excellence in care provision accessible to staff Evaluation and/or research of what fosters commitment to one's role to drive organizational strategies for staff development and retention
Clarity of beliefs and values	Shares a common philosophy of care Alignment of organization and individual beliefs and values Acts in accordance with national, international, legal frameworks and patient's wishes and values	Creates a values-driven workplace Development of and linkage to accessible CPD opportunities to provide information about legal frameworks with particular reference to advance care planning, directives, effective palliative care, and euthanasia to support staff understanding about the clear differences between palliative care and euthanasia
Knowing "self"	Engages with clinical supervision to support development of self-awareness and how this may impact on palliative care Practices self-awareness and undergoes CPD Implements self-care strategies to prevent burnout Recognizes early sign of burn out and seeks appropriate help	Builds the evidence on effective self-care and sustainability strategies for palliative care Identifies ways to strengthen resilience and prevent burnout Validates clinical supervision models to understand best practices Develops tools for nurses to use for self-care, based within emerging technologies Ensures integration of learning about strategies to prevent burnout and maintain health within undergraduate and postgraduate education
2. The care environment		
Appropriate skill mix	Provides the correct nursing and interdisciplinary skill mix requirements for optimal palliative care	Develops and tests innovative models of care Researches the unique contributions made by nursing within palliative care provision to enhance understanding of such roles in both

(*continued*)

Table 2 (continued)

Person-centered care (McCormack and McCance 2017)	Translation to palliative nursing	Opportunities for improvement/innovation
	Balanced skill mix to optimize patient outcomes	primary and specialist roles Identifies optimal skill mix models to drive policy support for best care across all settings (aged care, acute care, primary care). Such work could inform structural quality indicators for service commissioners to align with
Shared decision-making systems	Enables patients and families to participate, in accordance with their wishes, in consultations, case conferences, bedside handovers, articulation of goals and plans for care Supports patients and families to participate in daily planning sessions for their care to enable changes in priorities to be identified, over time Champion nurses' unique position to advocate for the patient and family voice in care planning and provision	Considers the role of emerging technologies to assist in shared decision-making Develops and tests new models that deliver integrated and coordinated care Evaluates patient and family experience in relation to shared decision-making
Effective staff relationships	Supports and fosters collaborative interdisciplinary relationships and effective communication Supports and mentors new graduates or staff new to a clinical area Palliative nurses actively support colleagues providing primary palliative care	Develops new models to promote interdisciplinary collaboration both within the specialist and primary palliative care teams Develops, utilizes, and evaluates explicit supports for new graduate staff and staff new to a clinical area which align with the constructs of a person-centered practice framework Evaluates current practice to identify areas for improvement
Supportive organizational systems	Creates an environment that actively implements the existing evidence and supports the delivery of best evidence-based nursing care Values and rewards the provision of excellent person-centered care at all times	Enables regular staff feedback in relation to supports provided and improvements required to allow optimal person-centered care Evident organizational support for identification and management of key areas for improvement Evident no blame culture – respect for staff reporting concern so as change can occur
Power sharing	Actively engage patients and families in organizational and patient level decision-making processes Understand and respect practice and disciplinary boundaries	Prioritizes consumer involvement (patients and their families) in organizational decision-making processes Considers use of technological feedback systems for staff to use in reviewing working relationships
Potential for innovation and risk-taking	Implements the existing palliative nursing evidence base Critically considers all aspects of care, questions appropriately, and fosters opportunities to develop new evidence Engages consumers in all change initiatives and/or new developments Displays agility in professional practice to	Builds the palliative nursing evidence base Develops and test new models of care and non-pharmacological strategies to improve care outcomes Seeks philanthropic funding to build palliative nursing research Specialist palliative care nurses to lead in the

(*continued*)

Table 2 (continued)

Person-centered care (McCormack and McCance 2017)	Translation to palliative nursing	Opportunities for improvement/innovation
	enable creative care options (based within the evidence) for people with complex care needs	adoption of new evidence for people with chronic and complex healthcare needs
The physical environment	Consider the needs of people living with and dying from progressive illness within each care environment Identify areas within each environment that can be improved and where possible, do so (e.g., visiting hours, supported parking fees, privacy for families) Work with each patient to understand their needs as these vary with each individual (e.g., single room, home setting, remote locations)	Self-assess a care environment to identify areas for improvement, some of which can be fixed much more easily than others Work with consumers to understand their areas of importance in relation to the care environment Consider partnerships with designers and architects to assist in altering clinical environments to enable best palliative care
3. Person-centered processes		
Providing holistic care	Provides optimal palliative care at all times, in accordance with patient wishes and preferences and best available evidence Applies the core constituents of palliative care in the setting where patients and families are based Enhances physical comfort throughout the patient's disease trajectory Meets patient psychological, social, and spiritual needs	Builds the evidence base to support palliative nursing interventions that, in conjunction with interdisciplinary care, drive optimal palliative care
Working with the patient's beliefs and values	Conscious and respectful of the patient's boundaries in terms of cultural taboos, values, and choices Ensuring the translation of unique patient's beliefs and values to the interdisciplinary team to inform care Provision of creative solutions where needed to enable person-centered care, irrespective of care environment (e.g., Enabling spiritual practices to occur; working to enable identified goals be achieved; considering opportunities to allow pets to visit)	Creates agile and adaptable organizational systems that accommodate the patient's beliefs and values Works closely with consumers to understand what aspects of care need improving in relation to care provision, organizational practices, or physical environment
Engaging authentically	Effectively engages patients and their families, clinicians providing primary palliative care, and other members of the interdisciplinary team	Creation of networked palliative care models Effective use of technology to optimize engagement Assessment of patient and family experience in relation to this aspect of care to drive improvement efforts
Shared decision-making	Optimizes patient and family engagement in decision-making Ensures patient and family information accurately translates into the care plan Understands when and how to refer for expert specialist advice	Researches patient and family requirements for shared decision-making in palliative care – What level of "shared" is of most support? Investigates the impacts of effective shared decision-making for families in relation to their bereavement needs Considers, designs, and evaluates educational needs for health professionals in relation to enabling effective shared decision-making
Being sympathetically present	Responds appropriately to the needs of patients and families and other members of the interdisciplinary palliative care team	Evaluates this aspect of care experience for patients and their families to highlight areas for improvement

(*continued*)

Table 2 (continued)

Person-centered care (McCormack and McCance 2017)	Translation to palliative nursing	Opportunities for improvement/innovation
	Recognizes the uniqueness and value of each patient and works to maximize their coping abilities Understands the meaning and impact of life-limiting illnesses on patients and their families Adheres to evidence-based guidelines for breaking bad news	Works with universities to create simulated opportunities for skill development for students at both undergraduate and postgraduate levels
4. Person-centered outcomes		
Good care experience	Utilizes patient reported outcome measures to drive practice assessment and change	Develops and tests novel approaches for understanding real-time patient and family experience Embeds real-time experience data into systems that drive opportunities for improvement and uture research
Involvement in care	Actively involves patients and their family in care planning and delivery Supports patients to receive palliative care in their setting of choice Enables patients to manage their personal affairs Actively promotes comprehensive care coordination	Develops mechanisms to regularly assess patient and family experience in relation to this aspect of care Considers novel technologies that enable real-time feedback for care teams in relation to patient and family experiences of care delivery
Feeling of well-being	Values the patient and works to provide a positive care experience Acknowledges patient's emotions and provides sensitive support Prevents suffering and unnecessary distress Promotes patients' and families' coping mechanisms Understands patients' and families' social context and how this may impact on their palliative care experiences Paces the provision of information according to patient preferences and cognitive capacity Identifies complex bereavement needs and refers accordingly Prioritizes work environments that are supportive and staff feel valued for their work and positive about their role	Develops and tests novel approaches for understanding patient and family experience in relation to this aspect of care Enhances the evidence base informing how to work and foster patients' and families' coping mechanisms Works with available evidence in relation to bereavement assessment and care to implement where possible and/or identify new research questions Considers unique population needs and allows consumers to drive service design in accordance with these
Existence of a healthful culture	Responds to the challenges of clinical and ethical decision-making Supports colleagues throughout emotionally challenging work Positively responds to opportunities for change and improvement Utilizes supportive and empowering leadership approaches based in mutual respect for colleagues and a willingness to continually work for excellence in care delivery	Considers novel technologies to support interdisciplinary staff feedback in relation to this aspect of organizational culture Clear management support for a positive organizational culture based in respect for staff and a shared vision for care delivery Development of CPD resources to shape understanding about leadership and change management

1.2 Policy and Practice

Operationalizing a population-based approach to palliative care requires consideration of the competencies required by all nurses working within the healthcare system and strategies to ensure the provision of best evidence-based person-centered care. Integrating the person-centered practice framework to palliative nursing in accordance with the EAPC's ten core palliative care competencies allows for the identification of systems, education, clinical service delivery, and research improvements and/or innovation opportunities to improve care outcomes for patients and their families with palliative care needs (Table 2). All such areas have implications for global palliative care nursing policy and practice.

1.3 Conclusions

Nurses globally are central to addressing the palliative care needs of people living with a progressive life-limiting illness and their families. In partnership with other members of the interdisciplinary team, nurses are responsive to palliative populations' needs within the context of the governing values, guidelines, and principles set out by the relevant regulatory and professional nursing bodies' and governments' priorities. The adoption of a population-based approach to planning offers opportunities to increase the access patients and families have to timely and best evidence-based palliative nursing care. Continuing to evolve and integrate new evidence into practice while building palliative care nurses' capabilities within their scope of practice will ensure that more patients have access to optimal palliative care. In order to improve outcomes for populations with palliative care needs, nurses need to develop new knowledge in partnership with their practice, education, and research colleagues.

References

Albers G, Francke AL, de Veer AJE, Bilsen J, Onwuteaka-Philipsen BD. Attitudes of nursing staff towards involvement in medical end-of-life decisions: a national survey study. Patient Educ Couns. 2014;94(1):4–9.

Anyfantakis D, Symvoulakis EK. Medical decision and patient's preference: 'much ethics' and more trust always needed. Int J Med Sci. 2011;8(4):351.

Aranda S, Yates P. A National Professional Development Framework for Cancer Nursing Canberra: Cancer Australia. 2009. 2nd:Available from: http://edcan.org.au/assets/edcan/files/docs/EdCanWeb_2nded.pdf.

Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. N Engl J Med. 2012;366(9):780–1.

Candy B, Holman A, Leurent B, Davis S, Jones L. Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: a systematic review of quantitative and qualitative evidence. Int J Nurs Stud. 2011;48(1):121–33.

Caresearch. Euthanasia 2017. 12 Apr 2017. Available from: https://www.caresearch.com.au/caresearch/tabid/1545/Default.aspx.

Connors AF, Dawson NV, Desbiens NA, Fulkerson WJ, Goldman L, Knaus WA, et al. A controlled trial to improve care for seriously III hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA. 1995;274(20):1591–8.

Davies SL, Goodman C, Bunn F, Victor C, Dickinson A, Iliffe S, et al. A systematic review of integrated working between care homes and health care services. BMC Health Serv Res. 2011;11(1):320.

Earp JAL, French EA, Gilkey MB. Patient advocacy for health care quality: strategies for achieving patient-centered care. Sudbury: Jones & Bartlett Learning; 2008.

European Association for Palliative Care. Core competencies in palliative care: an EAPC white paper on palliative care education – Part 1. Eur J Palliat Care. 2013;20(2):86–91.

Fitch M. Supportive care for cancer patients. Hosp Q. 1999;3(4):39–46.

García-Pérez L, Linertová R, Martin-Olivera R, Serrano-Aguilar P, Benítez-Rosario M. A systematic review of specialised palliative care for terminal patients: which model is better? Palliat Med. 2009;23(1):17–22.

Hall S, Kolliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. Cochrane Database Syst Rev. (Online). 2011;1–31.

Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J. 2010;16:423–35.

Institute of Medicine. Approaching Death: Improving Care at the End of Life. Washington, DC; 1997.

Luckett T, Phillips J, Agar M, Virdun C, Green A, Davidson P. Elements of effective palliative care models: a rapid review. BMC Health Serv Res. 2014;14(1):136.

McCormack B, McCance T. Person-Centred practice in nursing and health care–theory and practice. Oxford: Wiley Publishing; 2017.

Mehrdad N, Joolaee S, Joulaee A, Bahrani N. Nursing faculties' knowledge and attitude on evidence-based practice. Iran J Nurs Midwifery Res. 2012;17(7):506.

Morrison RS, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J, et al. Palliative care consultation teams

cut hospital costs for Medicaid beneficiaries. Health Aff. (Project Hope). 2011;30(3):454–63.
New South Wales Department of Health. Guidelines for end-of-life care and decision making. Sydney: NSW Health. 2005.
Nursing and Midwifery Board of Australia. Registered Nurses standards for practice Melbourne: Nursing and Midwifery Board of Australia; 2016.
Owens DA. A final thought on evidence-based practice. J. Hosp. Palliat. Nurs. 2009;11(6):313–4.
Pace JC, Lunsford B. The evolution of palliative care nursing education. J. Hosp. Palliat. Nurs. 2011;13(6):S8–19.
Palliative Care Australia. A guide to palliative care service development: A population based approach. Canberra: ACT; 2005.
Palliative Care Competence Framework Steering Group. Palliative care competence framework. Dublin: Health Service Executive; 2014.
Palliative Care Nurses New Zealand. National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand Wellington, New Zealand: Ministry of Health; 2014. Contract No: ISBN 978–0–478-42898-8.
Parry SB. The quest for competences: competency studies can help you make HR decision, but the results are only as good as the study. Training. 1996;33:48–56.
Phillips JL. Implementing evidence-based palliative care. Int J Palliat Nurs. 2015;21(2):55. London.
Phillips J, Davidson PM, Kristjanson LJ, Jackson D, Daly J. Residential aged care: the last frontier for palliative care. J Adv Nurs. 2006;55(4):416–24.
Phillips JL, Ingham J, McLeod R. In: Bruera EIH, editor. The development of palliative medicine in Australia and New Zealand. 2nd ed: Hodder Arnold; 2015.
Picker Institute Europe. Principles of patient centred care 2017. Available from: http://www.picker.org/about-us/principles-of-patient-centred-care/.
Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. N Engl J Med. 2013;368(13):1173–5.
Rosenberg W, Donald A. Evidence based medicine: an approach to clinical problem-solving. Br Med J. 1995;310(6987):1122.
Scott K, McSherry R. Evidence-based nursing: clarifying the concepts for nurses in practice. J Clin Nurs. 2009;18(8):1085–95.
Stokke K, Olsen NR, Espehaug B, Nortvedt MW. Evidence based practice beliefs and implementation among nurses: a cross-sectional study. BMC Nurs. 2014;13(1):8.
Temel JS, Greer JA, Muzikansky A, Gallagher ER, Jacobsen J, Pirl WF, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010;363(8):733–42.
Tieman J, Sladek R, Currow D. Changes in the quantity and level of evidence of palliative and hospice care literature: the last century. J Clin Oncol Off J Am Soc Clin Oncol. 2008;26(35):5679–83.
Virdun C, Luckett T, Davidson PM, Phillips J. Dying in the hospital setting: a systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. Palliat Med. 2015;29(9):774–96.
Virdun C, Luckett T, Lorenz K, Davidson PM, Phillips J. Dying in the hospital setting: a metasynthesis identifying the elements of end-of-life care that patients and their families describe as being important. Palliat Med. 2017;31(7):587–601.
Webb PA. Ethical issues in palliative care. Radcliffe: Abingdon; 2005.
World Health Organisation. WHO definition of palliative care 2003. Available from: http://www.who.int/cancer/palliative/definition/en/.