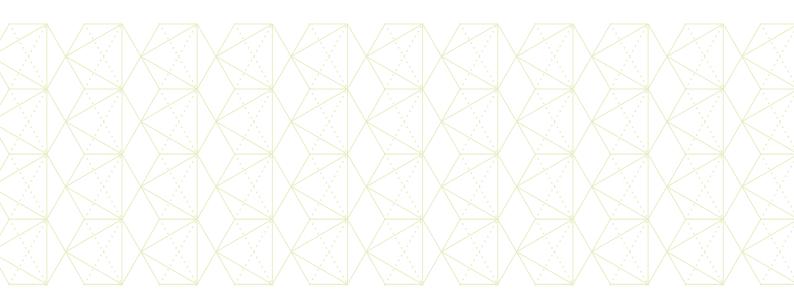




Australian College of Nursing

Achieving Quality Palliative Care for All: The Essential Role of Nurses

A WHITE PAPER BY ACN 2019







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EXECUTIVE SUMMARY

The diverse range of needs experienced by people affected by life-limiting illness means that health professionals working in a range of settings, from various disciplinary backgrounds, will have a role in the provision of care. Registered and Enrolled Nurses are the largest group of health care professionals who provide care to people with life-limiting conditions across all settings. These nurses have a unique and central role in the team as they respond to the range of physical, emotional, social and spiritual needs of people with a life-limiting illness and promote continuity of care across the care trajectory.

Given the demand for quality palliative care services in Australia is growing rapidly, urgent action is required to optimise the contribution of nurses in palliative care. This White Paper presents an overview of the context for contemporary palliative care service delivery, summarises evidence relating to the important role that nurses play in palliative care, and identifies urgent areas for action for governments and health system managers to ensure access to quality palliative care for all people with a life-limiting illness.

Specifically, the paper highlights the growing evidence base that demonstrates the multiple benefits of nurse-led models/interventions for patients, services and health systems. In particular, our systematic review identified evidence which demonstrated benefits where nurse-led models focused on promoting early palliative care intervention and on providing holistic, comprehensive care services. Key elements of these nurse-led models were symptom management, patient and carer education, goals of care discussions, and care coordination. Early intervention models positively impacted patient outcomes such as psychological function, health-related quality of life, and survival. Health service use outcomes, such as reduced hospital admissions were also positively impacted. The outcomes of nurse-led models positively impacted by comprehensive care delivery were patients end-of-life planning, emotional function/mood, satisfaction with their care, hospital admissions, and costs for hospital or community care settings. While this evidence highlighted many positive outcomes, a number of patient, health care, health care service/ organisation, or system/structural level challenges were identified which affected the optimal implementation of these models.

This paper highlights three urgent areas for action for governments and health system managers to ensure the delivery of quality palliative care for all Australians:

Action 1: provide funding models that address the needs of existing palliative care services and facilitates dedicated nursing positions across metropolitan and rural/regional settings. Funding models must provide for the development of education programs and professional development to enable the design, implementation and evaluation of evidence-based nurse-led models/interventions to ensure optimal outcomes for all Australians with life-limiting conditions.

Action 2: implement relevant policy, system and legislative reforms to remove structural barriers which limit scope of practice for nurses in palliative care, including the ability to refer to relevant services and prescribe appropriate treatments to ensure best outcomes.

Action 3: undertake a workforce planning activity to ensure sufficient numbers of nurses are available to meet growing demand for nursing services in palliative care.

INTRODUCTION

The Context of Palliative Care

There are around 160,000 deaths in Australia each year (Australian Institute of Health and Welfare [AIHW], 2018). It is estimated that around 70% of these deaths are due to expected causes (Palliative Care Australia [PCA], 2018a). The most common causes of death today are associated with a disease trajectory characterised by slow progression, and often accompanied by acute and unpredictable exacerbations of clinical problems (Phillips & Currow, 2010). The demand for palliative care, which is responsive to these complex needs, is likely to increase with an ageing population who live with a range of chronic conditions. For example, there has been 28.2% growth in palliative care hospitalisations in Australia during the five-year period between 2011-12 to 2015-16 (AIHW, 2018).

Palliative care needs are complex and span physical, emotional, social, and spiritual concerns. Research on the key concerns for people toward the end of life indicate that the most pressing needs relate to:

- · pain and symptom management
- · preparation for the end of life
- relationships between patients, family members and health care providers
- achieving a sense of completion (Steinhauser et al., 2000).

Such needs will vary by age, disease status, and social and cultural context.

Defining Palliative Care and End-of-Life Care

Various terms are used to refer to care provided for people with life-limiting conditions. For the purposes of this paper, we have adopted the PCA definitions of palliative care and end-of-life care, although we acknowledge the range of terminology used to refer to this important field of health care. That is:

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers is higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered. This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care. (PCA, 2018a)

Key Elements of Quality Palliative Care

Palliative care is provided by a variety of health professionals across multiple practice settings, including acute, community and residential care (PCA, 2018a) (See Figure 1).

Figure 1: Map of palliative care service settings (reproduced from PCA, 2018b)



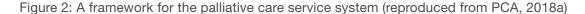
In Australia, there are several guiding documents, which inform contemporary understanding of the elements of quality palliative care.

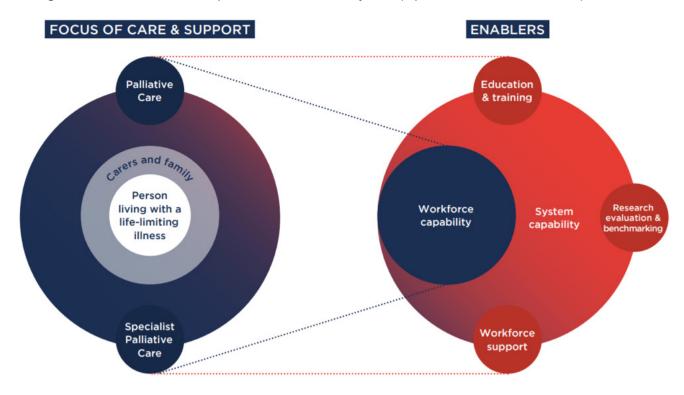
Palliative Care Australia National Standards and Service Development Guidelines

PCA identifies key principles of services for people with life-limiting conditions including:

- People, their families and carers should be at the centre of the service system.
- Families and carers often provide significant support for the person living with a life-limiting illness, especially during the time care is provided at home.
- The palliative care service system should provide care that extends beyond the person living with a life-limiting illness to their families and carers. This differs from many other types of health services where the person with an illness is the only recipient of care.
- People will have different needs for palliative care. Depending upon the complexity of a person's needs, palliative care can be provided by specialist palliative care services and/or by other health professionals with minimum core competencies in palliative care (PCA, 2018a; 2018b).

In their Service Development Guidelines (2018a), PCA identifies that people with life-limiting conditions will have different levels of health service need. They note that people with more complex needs should have access to specialist palliative care services comprising multidisciplinary teams with specialised skills, while recognising that people with less complex needs still require access to care from health professionals who have minimum core competencies in the provision of palliative care (See Figure 2).





An important feature of PCA's framework is that the service system must be underpinned by a robust workforce supported by a capability framework that identifies the continuum of palliative care that can be provided by a workforce with different levels of competencies. The framework also acknowledges the need for networking and regional planning between palliative care services and other health and aged care services. Nurses are the largest workforce in the multidisciplinary team, which provides palliative care across all settings.

Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care (ACSQHC, 2015) identifies 10 essential elements of quality end of life care in acute care settings. These include:

a. processes of care

- 1. patient-centred communication and shared decision-making
- 2. teamwork and coordination of care
- 3. components of care
- 4. use of triggers to recognise patients approaching the end of life
- 5. response to concerns

b. organisational prerequisites

- 6. leadership and governance
- 7. education and training
- 8. supervision and support for interdisciplinary team members
- 9. evaluation, audit and feedback
- 10. systems to support high-quality care.

Similar to PCA, the ACSQHC highlights the importance of a well-supported workforce in the provision of end-of-life care.

Aged Care Settings

In aged care settings, peak bodies identify that quality palliative care should include:

- · Consumers' physical and mental needs at end-of-life are assessed and recognised.
- Consumers, families and carers are involved in end-of-life planning and decision making.
- Consumers receive equitable and timely access to appropriate end-of-life care within aged care facilities.
- The end-of-life care needs of consumers with dementia or cognitive impairment are understood and met within residential aged care.
- End-of-life care is holistic, integrated and delivered by appropriately trained and skilled staff.
- Consumers, families and carers are treated with dignity and respect.
- Consumers have their spiritual, cultural and psychosocial needs respected and fulfilled.
- Families, carers, staff and residents are supported in bereavement (PCA, n.d.).

As in other settings, the importance of a nursing workforce with knowledge and skills in palliative care is fundamental to achieving expected standards in community and residential aged care settings.

Nurses as the Largest Component of the Palliative Care Workforce

Registered and Enrolled Nurses provide care to people with life-limiting conditions across all settings. Consistent with PCA's Needs Based Service Framework (2018a), while every person deserves quality palliative care according to need, not all people with life-limiting conditions will require access to specialist palliative care services. For example, there is a large nursing workforce providing palliative care on a day-to-day basis in contexts such as chronic disease management, aged care, or general medical care. These nurses are often not considered 'specialists' in palliative care, yet they provide essential nursing services and require appropriate knowledge, competence and skills to ensure they deliver key elements of quality palliative care. Other nurses practice in purpose-designed specialised palliative care units in hospitals or the community and require an advanced level of knowledge and skill. In 2016 there were 2,888 registered nurses in Australia identified in AIHW palliative care workforce data as being palliative care nurses, representing a ratio of 12.2 full-time palliative care nurses per 100,000 population (AIHW, 2018). These nurses provide both direct care and consultative services, with about one-quarter of palliative care nurses working mainly in community-based settings including with community palliative care services, in residential aged care, GP offices and Aboriginal Health Services. The remainder work across a range of hospital settings. These numbers do not reflect the substantial services provided by all nurses to people with life-limiting conditions across the whole health system.

Advanced Practice Nursing Models in Palliative Care

An ageing population and high burden of chronic disease have driven the need for service development and innovation in Australian health care (Swerissen, Duckett, & Wright, 2016). Advanced practice nursing models provide enormous potential to address the need for better value care within the health system in this context, especially for populations with complex and long-term care needs.

Advanced practice nursing has been defined as 'a level and type of clinical practice that involves cognitive and practical integration of knowledge and skills from the clinical, health systems, education and research domains of the discipline and positions the advanced practice nurse as a leader in nursing and health care' (Gardner et al, 2017). Advanced practice nursing is provided through many different models of care. For example, the integration of nurse-led models of care and nurse-led clinics is one such model that has been identified as a solution to meeting the accelerating health care needs of individuals and communities (Gardner, Duffield, Doubrovsky, & Adams, 2016) across acute and community care settings (Douglas, Schmalkuche, Nizette, Yates, & Bonner, 2018). Nurse-led models of care are defined as an approach to practice in which nurses have an allocated patient caseload for whom they have primary responsibility, with appropriate partnerships with other health professionals, where required to meet the person's health care needs (Douglas et al., 2018; Hatchett, 2008).

Nurses working within a nurse-led model of care undertake assessment, provide education, support, treatment and monitoring, initiate admission and discharge and referral to other health professionals (Hatchett, 2008). Nurse Practitioner led models also provide additional unique services, such as the ability to initiate diagnostic tests and prescribe medications. Nurse-led models are underpinned by high levels of autonomy and advanced decision-making (Douglas et al., 2018; Richardson & Cunliffe, 2003). Rather than acting as a substitute for single medical tasks, nurse-led models of care describe services underpinned by comprehensive and advanced practice nursing care (Corner, 2003). Such nurse-led models bridge traditional treatment silos in the provision of specialised and coordinated care, reshaping health services, improving the patient experience and addressing previous gaps in health care service delivery (Douglas et al., 2018). They are founded on specialist knowledge and the establishment of a therapeutic relationship (Harvey et al., 2018), lead to improved patient access to care (Bentley, Stirling, Robinson, & Minstrell, 2016; Randall, Crawford, Currie, River, & Betihavas, 2017), result in higher levels of patient satisfaction and positive outcomes for patient health (Randall et al., 2017) and are cost-effective (Bentley et al., 2016).

In the context of palliative care, advanced practice nursing models have been identified as offering an effective approach to care when providing evidence-based treatment, and enabling accessible and flexible service delivery (Harvey, Bennett, Burmeister, & Wyder, 2018). There is a growing body of evidence which supports the benefits of advanced practice nursing roles in palliative care (see later Section *The Impact of Nursing for People with Life-Limiting Conditions: What does the Evidence Say?*).

UNDERSTANDING THE CONTRIBUTION NURSES MAKE TO PALLIATIVE CARE

Key Domains of Nursing Practice

The diverse range of needs experienced by people affected by life-limiting illness means that health professionals working in a range of settings, from various disciplinary backgrounds, will have a role in the provision of care. In Australia, the Palliative Care Education and Training Collaborative developed a Palliative Care Workforce Development Framework to support inclusion of palliative care in educational programs designed to prepare the health workforce from entry to practice to advanced levels. Key principles inherent in the framework include:

- The health and support needs of people affected by a life-limiting illness are diverse and often change over time.
- Most health care providers will come into contact with people who are dying and therefore need to be prepared to provide appropriate care.
- Specialist palliative care services provide important services for people with more complex needs, but not all people approaching end of life require specialist palliative care.
- Appropriate, high quality end of life care can be delivered by health care providers in a range of care contexts.

The Framework goes on to define core capabilities for specialist and non-specialist health care providers across all professions in palliative care. These four core capabilities are identified as being integral for all health professionals to provide palliative care for persons with a life-limiting illness:

- effective communication in the context of an individual's responses to loss and grief, existential challenges, uncertainty and changing goals of care
- appreciation of and respect for the diverse human and clinical responses of each individual throughout their illness trajectory
- understanding of principles for assessment and management of clinical and supportive care needs
- the capacity for reflection and self-evaluation of one's professional and personal experiences and their cumulative impact on the self and others.

While palliative care is provided by a multidisciplinary team who should demonstrate the core capabilities listed above, the application of these capabilities vary according to scope and context of practice of the various professions. Nurses have a unique and central role in the team as they respond to the range of physical, emotional, social and spiritual needs of people with a life-limiting illness and promote continuity of care across the care trajectory. Australian researchers have identified specific competencies for specialist palliative care nurses (see Box 1) across five domains:

- therapeutic relationships
- complex supportive care
- collaborative practice
- leadership
- improving practice.

Competency Standard 1: sensitively establishes, maintains and adapts effective therapeutic partnerships with individuals with life-limiting illnesses, their caregivers and family according to individual needs, circumstances and preferences

Competency Standard 2: demonstrates respect for uniqueness and individual autonomy, when responding to the individual's experiences and responses to dying and bereavement

Competency Standard 3: negotiates mutually agreed goals of care within a therapeutic environment, and facilitates person-centred decision making to promote optimal outcomes for individuals with life-limiting disease, their caregivers and family

Competency Standard 4: recognises the effects of the intimate and intense nature of caring for individuals with a life-limiting disease, their caregivers and family has on the self and other members of the team, and responds effectively

Competency Standard 5: demonstrates advanced palliative care knowledge and skills in meeting the multiple, complex care needs of individuals with life-limiting illnesses, their caregivers and family, across the continuum of care including bereavement, and in the context of an interdisciplinary approach to care

Competency Standard 6: demonstrates advanced skills in collaborating with individuals, their caregivers and family, other nurses and members of the health care team to promote optimal palliative care outcomes

Competency Standard 7: builds the capacity of nurses, other health team members and the wider community to understand and respond to complex palliative care health and support needs for individuals, their caregivers, and family

Competency Standard 8: actively participates in professional activities that promote the continuing development of quality palliative care

Competency Standard 9: actively participates in policy and service development activities that contribute to the delivery of quality palliative care

Competency Standard 10: applies an advanced understanding of contemporary legal, ethical and professional standards relevant to the provision of quality palliative care services in the delivery and development of palliative care services

Competency Standard 11: creates and sustains processes, which support a positive culture of continuous critical inquiry in the provision of palliative care

Competency Standard 12: demonstrates an ongoing, high-level commitment to critical reflection and continuous professional development as a specialist palliative care nurse.

(Canning, Yates & Rosenberg, 2005)

These competencies are similar to those identified for palliative care nurses in other countries including Ireland (Ryan et al., 2014) and New Zealand (Palliative Care Nurses New Zealand, 2014). The competency documents highlight the unique contribution of nurses in addressing the complex needs of people requiring palliative care. Importantly, because people who are dying are present in nearly all areas of our health care system, the Australian Palliative Care Education and Training Collaborative's Whole of Workforce Framework is consistent with the Palliative Care Competence Framework from Ireland (Ryan et al., 2014) which describes different levels of competencies in end of life care for ALL nurses, whether they practice as a specialist or non-specialist setting.

THE IMPACT OF NURSING FOR PEOPLE WITH LIFE-LIMITING CONDITIONS: WHAT DOES THE EVIDENCE SAY?

Given the important role of nurses in palliative care, a systematic review of the literature was undertaken to examine the evidence base underpinning the value of nursing services for people with life-limiting conditions. In the context of caring for people requiring palliative care, the key questions underpinning the review were:

- 1. What types of nurse-led models/interventions are used?
- 2. What were the components of these nurse-led models/interventions?
- 3. What impact did these nurse-led models/interventions have?
- 4. Which nurse-led models/interventions and their components were most effective (i.e., contributed to improved outcomes)?

Of the 73 full-text articles assessed for inclusion in the review, 37 met inclusion criteria and described 38 nurse-led models of care/interventions. Studies were published from 2000 to 2018, most from 2011 onwards (28 of 37 studies, 76%). Included studies originated from North America, Europe, Africa, United Kingdom and Australia. Of the studies included in the review, 12 were randomised controlled trials (RCTs), 16 used quantitative designs, eight used mixed methods, and one was a qualitative study. Quantitative research included eight prospective, three cross-sectional, and five retrospective studies. Mixed methods studies used prospective (n = 7) and cross-sectional (n = 1) designs. The qualitative study was cross-sectional. The following sections summarise the key findings from the systematic review, with the full review to be published elsewhere. All studies were assessed for quality. Seven of the included studies were considered to be of high-quality. Despite the small number of studies, all studies were included irrespective of quality scores.

Key Features of Nurse-Led Models/Interventions

What type of nurse-led models/interventions were described in care for patients needing palliative care?

- 38 nurse-led models of care or interventions were described in 37 studies.
- Nurse-led models/interventions were predominantly provided by nurses working in advanced practice roles across hospital and community settings, for patients with chronic disease.
- Two main types of nurse-led models were described. These were differentiated based on the point in the care trajectory that the model or intervention was delivered to patients:
 - 1) early intervention; or
 - 2) across the trajectory of care (referred to as 'care delivery' models).

What were the components of nurse-led models/interventions in palliative care?

- All but two models included a symptom management component alone or in combination with components of care.
- Other commonly included components were patient and carer education, goals of care discussions, and care coordination.
- Approximately half of the models had a psychological support component.
- There was less focus on components that provide spiritual or existential support or bereavement services, although such services were generally acknowledged as important to holistic care.

Impact of Nurse-led Models/Interventions on Patient, Service and System Outcomes

What impact did these nurse-led models/interventions in palliative care have?

- 26 of the 38 models were associated with statistically significant benefits for patients, services
 or the health system. That is, in over half of the studies that measured outcomes, significant
 improvements were noted when symptom management, goals of care discussions, education
 and care coordination were included.
- Nurse-led models/interventions positively impacted patient's psychological wellbeing or emotional function and end-of-life planning, led to reduced hospital admissions (including ED and ICU admissions), and were associated with lower costs in some hospital and community settings.
- Early intervention models positively impacted patient outcomes such as psychological function, health-related quality of life, and survival. Health service use outcomes, such as reduced hospital admissions were also positively impacted.
- The outcomes positively impacted by care delivery nurse-led models were patients' end-of-life planning, emotional function/mood, or satisfaction with their care, hospital admissions, and costs for hospital or community care settings.
- There are few studies, and less consistent evidence from studies, evaluating the cost
 effectiveness of nurse-led models, although some limited evidence indicates that these models
 can achieve important changes within the health system that contribute to more effective service
 delivery.

Which nurse-led models/interventions in palliative care and their components were most effective (i.e., contributed to improved outcomes)?

- Almost all models used multiple components and it was not possible to determine the unique contribution or effectiveness of individual components on patient, health service use or economic outcomes.
- Symptom management, goals of care discussion, patient education, and care coordination
 appeared to be key components of models that positively impacted patient and health service
 use outcomes, regardless of when the model was delivered in the care trajectory.
- Early intervention models with these components (as well as psychological support) were
 associated with improved patient outcomes for people diagnosed with advanced cancer,
 although there is no evidence at this time about their effectiveness for other populations or in
 improving other outcomes.

BARRIERS TO OPTIMISING NURSING'S CONTRIBUTION IN PALLIATIVE CARE

10 studies reported barriers to the use of nurse-led models/interventions and 12 studies described lessons learned. Barriers were categorised in terms of patient, health care, health care service/ organisation, or system/structural level challenges. Lessons learned were similarly grouped.

Enablers and Barriers

Barriers to implementing nurse-led models/interventions and lessons learned

Factors	Barriers	Lessons learned (facilitators)
Patient	Acceptability Access	 Person-centred approach to care is preferred Regular and flexible appointments to facilitate access
Health care team	Acceptance by other team membersLeadershipPoor communication	 Improved and frequent communication Continuity of care Integrated/shared care models
Health care service/ organisational	Demand exceeds availabilityNurse competency	 Preliminary forecasting and scoping of existing services to better meet demand Highlight nurse's core strengths, provide skill development and administrative support
System/structures	 Funding models Integration and use of resources High case load Lack of program visibility and promotion 	Case management approach was key to success

THE WAY FORWARD

This paper has highlighted the unique and important role that nurses have in the care of people with life-limiting conditions. There is a growing evidence base that demonstrates the multiple benefits of nurse-led models/interventions for patients, services and health systems. Given the growing demand for quality palliative care services, urgent action is required to optimise the contribution of nurses in palliative care. This paper highlights three urgent areas for action for governments and health system managers to achieve this goal.

Action 1: Provide funding models that address the needs of existing palliative care services and facilitates dedicated nursing positions across metropolitan and rural/regional settings. Funding models must provide for the development of education programs and professional development to enable the design, implementation and evaluation of evidence-based nurse-led models/interventions to ensure optimal outcomes for all Australians with life-limiting conditions.

The Case to Support this Action: There is a sound evidence base demonstrating the positive impact of nurse-led models/interventions in palliative care in terms of improved symptom outcomes, psychological wellbeing, end-of-life care planning, and care coordination. The evidence indicates that such models/interventions could also achieve improved health system outcomes.

More specifically, the available evidence supports implementation of nurse-led models/interventions which:

- achieve early integration of palliative care for people with life-limiting conditions, as this enables a proactive approach to care planning, more effective goal setting, and improved care coordination; and
- provide a range of holistic care services throughout the care trajectory, including symptom
 management, goals of care discussions, education, psychological and spiritual support and
 care coordination, as such interventions result in improved quality of life for individuals and their
 carers.

These models should focus on meeting the standards of care published by Palliative Care Australia, and be developed using principles of co-design to ensure they address what matters most for patients and families.

The Productivity Commission Report on Reforms to Human Services (2017, p.2) identified the need for a stronger focus on users, better service planning and improved coordination across services and levels of government in the commissioning of palliative care. Moreover, the Commission argued that Governments should focus on the capabilities and attributes of service providers when designing service arrangements and selecting providers, not simply the form of an organisation (Productivity Commission, 2017, p.2). The Commission specifically mentioned the need to significantly expand community based palliative care services and to improve the standard of end of life care in residential aged care facilities. Nurse-led models/services provide great potential to achieve these goals and require appropriate resourcing within all sectors of the health care system. As one of the unique features of nurse-led models/interventions in palliative care is their ability to work with patients across settings of care and over time, actions are required to ensure funding models are in place to reflect the unique features of this cross-sector type of practice.

It was identified that nurse-led models/interventions require nurses who have advanced skills and knowledge in areas including, but not limited to, symptom management, psychological and spiritual support, advance care planning and care coordination. Resources are required to ensure education programs are provided to develop nurses' capabilities in palliative care at all levels, from entry to practice to advanced practice levels. For some, this includes the need to support Nurse Practitioner programs for palliative care nurses. This review has also identified the need to offer specific education programs to develop the business and management skills required for nurses to design, deliver and evaluate nurse-led services.

Support for ongoing professional development is also required to enable innovation and continuous improvement. Action is required to support the development of peer networks and communities of practice for nurses working in this important area of practice.

Action 2: Implement relevant policy, system and legislative reforms to remove structural barriers which limit scope of practice for nurses in palliative care, including the ability to refer to relevant services and prescribe appropriate treatments to ensure best outcomes

The Case to Support this Action: The available evidence has identified a range of barriers to effective implementation of nurse-led models/interventions in palliative care. It is essential to ensure that the nurse-led model are optimised as part of a multidisciplinary approach to care (Bookbinder et al., 2011; Izumi et al., 2018). Currently, barriers to optimising scope of practice exist in terms of:

- 1. The ability of nurses to engage with potential services users without the need for a physician referral (Bookbinder et al., 2011), and in terms of access to existing patient health records for the purposes of communication with other members of the patient's team (Izumi et al., 2018): health services need to ensure policies and communication systems exist that enable needs-based referral for nursing services and which facilitate communication across the care team.
- 2. Access to nurse-led services/interventions for all populations: the evidence presented in this review highlights the need to ensure available technologies are used to support nurse-led models/interventions in palliative care and ensure greater access to those in need. For service users, the option to choose between telephone and face-to-face consultations has been identified as essential, particularly when a person may not be well enough to travel (Schenker et al., 2015). Where face-to-face consultations are necessary or preferred, coordination with other care providers, such as specialist appointments should be prioritised to limit any extra burden to the individual in terms of travel time and costs (Long, Bekelman, & Make, 2014). Telephone assistance or advice provided by nurses outside of usual service hours is also essential and important to service users (Izumi et al., 2018; Johnston, Coole & Narayanasamy, 2016).
- 3. Legislative barriers which prevent nurses from being able to practice to the full scope: to achieve best outcomes for patients, actions are required to ensure restrictive Pharmaceutical Benefits Scheme and Medicare Schedule requirements are removed.

Action 3: Undertake a workforce planning activity to ensure sufficient numbers of nurses are available to meet growing demand for nursing services in palliative care.

The Case to Support this Action: This review has identified significant gaps in data to inform workforce planning in palliative care nursing at all levels, given the wide range of practice settings in which palliative care is provided and the rapid growth in the need for these services. Action is required to undertake dedicated workforce planning to ensure sufficient numbers of nurses with the appropriate level of skill are available to meet future demand. Urgent attention should be given to addressing gaps identified in this workforce planning. Inadequate planning to meet the growing demand for nursing services in palliative care will place extra burden on all areas of the health and aged care system and have significant impact on the quality of life for people with life-limiting conditions.

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"There are times in one's life when dignity and self determination in decision making is more prominent than other times. Those who are at the end of their life journey, surrounded by their loved ones, rely on the expertise, excellence and compassion of nurses to navigate through this emotional time. Just as nurses support patients and families, the Australian College of Nursing's End of Life Care Policy Chapter work supports the nursing profession to deliver their care with honour, acknowledgement and advocacy. For we are a profession driven by a deep desire to make a difference, knowing that the memories made at the end of one's life last a lifetime for the loved ones they leave behind."

ADJUNCT PROFESSOR KYLIE WARD FACN CEO, Australian College of Nursing



