

Models of Care in Palliative Medicine

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David C. Currow and Jane L. Phillips

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In resource-rich countries, chronic complex diseases have largely replaced acute causes of disability and death. There is now a need for every clinician to be able to take a *palliative approach*. This is defined as the ability to deal with key elements of clinical care for someone who has a progressive illness that is likely to lead to death and their caregivers. The key elements of a *palliative approach* are access; collaborative interdisciplinary team-based care; defining the goals of care; evaluating the “net effect” of any treatments or interventions addressing, where relevant, issues of withholding and withdrawing treatment; determining preferred place of care and, separately, the preferred place at the time of death; and managing care transitions.

For patients, there is evidence of improved symptom control, better met needs, better satisfaction with care and better quality of dying and improved comfort in the last 2 weeks of life. Having relinquished their roles, caregivers for people at the end of life who have used specialist palliative care services had better long-term survival and were better able to adjust to their changed circumstances. Specialist palliative care services are also associated with better met caregiver needs, improved satisfaction with care and less caregiver anxiety. For health systems, benefits include reduced inpatient stays, fewer presentations to the emergency department and reduced overall costs.

Patient-defined areas of importance include the ability to carry out one’s affairs as the end-of-life approaches, resolving relationship issues and being involved in decision-making. Specialist

D.C. Currow, MPH, BMed, FRACP (✉)
Discipline of Palliative and Supportive Services,
Repatriation General Hospital, Flinders University,
Health Sciences Bldg, Daws Road, Daw Park,
Adelaide 5041, SA, Australia
e-mail: david.currow@flinders.edu.au

J.L. Phillips, B.App.Sci(Nur), PhD
School of Nursing and Sacred Heart Health Service,
The University of Notre Dame Australia,
Cunningham Centre for Palliative Care, St Vincent’s
Health Network, Darlinghurst 2010, NSW, Australia
e-mail: jane.phillips@nd.edu.au,
jphillips@stvincents.com.au

supportive and palliative care has services which are charged with providing team-based clinical care to people with the most complex end-of-life care needs and their families, as well as and consultative support for colleagues providing care where the patient or family have less complex needs. Ensuring all people have access to best palliative care is dependent upon an on going commitment to ensuring that: there is adequate education at an undergraduate, postgraduate and post-registration level; and high-quality research that continues to refine the evidence base for clinical care that is offered; and health services are structured to optimally deliver these services.

2.1 Introduction

Palliative medicine grew out of a counterculture to perceptions in the 1950s and 1960s that the major causes of death and disability were all but addressed [1]. As such, death and dying were not areas that were receiving serious attention both academically and clinically. Palliative care was a reaction in many ways to the perception that death was a clinical “failure”. Although much of our health system spends time concerned that death may be a consequence of poor care or iatrogenic, the vast majority of deaths are, or should now be, expected in clinical care, since mortality patterns have changed rapidly in the last century.

In resource-rich countries, chronic complex diseases have largely replaced acute causes of disability and death. This has meant that life expectancy has increased but, at the same time, the causes of death have shifted from maternal and child health, trauma, infection and acute cardiovascular diseases to chronic, progressive illnesses such as cancer, organ failure and neurodegenerative diseases. For example, rarely are young healthy people dying of community-acquired pneumonia and the rates of death from acute myocardial infarction in the fifth and sixth decade continue to decline. Such changes in the causes of death and disability have required a significant paradigm shift in the clinical care of people across the community. There is now a need for every clinician to be able to take a *palliative*

approach. This is defined as the ability to deal with key elements of clinical care for someone who has a life-limiting illness as well as supporting their caregivers. A *palliative approach* is not limited by the physical setting in which care is delivered. Whether the person with the life-limiting illness is based at home, or in an institutional setting, quality palliative care can and should be delivered.

How does one define a patient where the intent should be palliative? Essentially, if a person has a progressive illness that is likely to lead to death, then a *palliative approach* should be taken. This in no way precludes the use of disease-modifying therapies. Indeed, a *palliative approach* should be taken in tandem with disease-modifying therapies, using both approaches to ensure that care is optimised for patients. Lynn et al. use the question “Would you be surprised to hear that this person had died in the next 12 months?” [2]. This question does not limit supportive and palliative care to the last 12 months of life, but does help to frame clinical thinking on the matter.

This chapter provides an overview of outcomes from quality research into the net effects of engaging palliative care, the palliative care needs of surgical patients and their caregivers, the models of care configured to address patients’ palliative care needs and the key elements that clinicians need to consider when providing a *palliative approach*.

2.2 What Differences Do Hospice/Palliative Care Services Make?

Evidence from good quality health services research has been evolving over the last 30 years. This has been complemented by increasingly sophisticated population-based studies that help to identify key associations between the uptake of specialist palliative care services and outcomes for patients, for their caregivers and for the health system in which they are treated. This creates two levels of evidence – rigorous randomised trials and other interventional studies from which causality can be derived – and observational studies

where only associations can be drawn. Data are available at patient, caregiver, service and health systems levels.

For patients, there is evidence of improved symptom control, better met needs, better satisfaction with care and better quality of dying and improved comfort in the last 2 weeks of life [3]. Both a randomised controlled trial (RCT) and a high-quality observational study have suggested that there may be survival benefit in late-stage disease with referral to palliative care [4, 5], although this may be that premature mortality was avoided in the hospice/palliative care group [6]. There appears to be benefit in better maintaining function in people with a multidisciplinary approach that includes specialists and primary clinical staff joining the patient and caregiver in at least one case conference [7]. Having controlled for major factors known to be associated with poor health in general, being a caregiver is a risk factor for poor health outcomes [8]. Having relinquished their roles, caregivers for people at the end of life who have used specialist palliative care services had better long-term survival and were better able to adjust to their changed circumstances [9, 10]. Specialist palliative care services are also associated with better met caregiver needs, improved satisfaction with care and less caregiver anxiety [3]. For health systems, benefits include reduced inpatient stays, fewer presentations to the emergency department and reduced overall costs [7, 11–13].

The World Health Organization has not only sought to define “palliative care” in ways that it has not done for other areas of clinical care but also set out the framework for service delivery [14]. The basic framework includes that:

- There should be early introduction of palliative care – that is, once there is recognition that this person’s life is likely to be shortened as a result of this illness.
- Palliative care can and often should be provided in parallel with disease-modifying therapies.
- This requires careful and repeated assessment of the patient and their caregivers throughout the course of the life-limiting illness.

2.3 Needs and Priorities of Patients and Families

Patient-defined areas of importance include the ability to carry out one’s affairs as the end-of-life approaches, resolving relationship issues and being involved in decision-making [15–17]. Without excellent physical symptom control, it is almost impossible to carry out these important end-of-life tasks [17]. Planning for one’s death includes being part of discussing what is important at that time, ensuring that legacy issues are actively addressed (How does one want to be remembered? Are there unfinished projects?) and ensuring that one’s wishes are known and are going to be respected while dying and once dead.

Being alert throughout the life-limiting illness is incredibly important to patients who are facing death. By contrast health professionals would often regard physical symptom control as more important than being cognitively intact [17]. Although a great deal of health policy is now advocating for home death, the place of care is actually far less important to patients if their family and friends are able to freely spend time with them and to support them. “Home death” as an outcome measure *per se* fails to reflect the complexities of care and the demands made of family and friends as they provide the bulk of that care.

2.4 Providing a Palliative Approach in the Surgical Setting

The speciality of supportive and palliative care has grown up charged with the responsibility of providing team-based clinical care to the people at the end of life with the most complex needs and their families and consultative support for colleagues providing care where the patient or family have less complex needs; ensuring that there is adequate education at an undergraduate, postgraduate and post-registration level; and ensuring that high-quality research is continuing to refine the evidence-base for clinical care that is offered and the way that health services are structured to deliver optimally these services.

In the developed world, the majority of deaths occur in acute care, and this trend is expected to increase in line with population ageing and changing patterns of caregiver availability. These secular trends in where care is provided, especially in the terminal phases of a life-limiting illness, vary widely from country to country depending on health and social system drivers. A small proportion of all acute care deaths will be managed by the patients' surgical team, with support from a specialist palliative care team, as required.

Despite the increase in the number of palliative care services within the acute care sector over the past two decades, in the USA these services are more likely to be based in larger hospitals, academic medical centres, not-for-profit hospitals and VA hospitals compared to other hospitals [18]. These consultative palliative care services are most frequently called upon to support the treating team with discussions about prognosis and goals of care, pursuing documentation of advance directives, discussion about foregoing specific treatments and/or diagnostic interventions, family and patient support, discharge planning and symptom management [19]. The input of hospital-based palliative care teams to patient's care has been shown to improve symptom control and quality of life, alleviate emotional burden and improve caregiver and patient satisfaction [3, 20, 21]. In the USA, palliative care provided to hospitalised patients with advanced disease has resulted in lower costs of care and less utilisation of intensive care compared to similar patients receiving usual care [22].

Following the high-profile randomised controlled trial (RCT) in the USA by Temel et al. [4] for people with advanced lung cancer where participants were randomised to either early referral to palliative care or to routine care, there is now increasing interest in encouraging earlier referral to specialist palliative care services [23], which is appropriate for people with more complex needs [24]. Simultaneously, the timely initiation of a *palliative approach* is appropriate for people whose care needs can be managed by their existing care team.

2.5 Key Elements of a Palliative Approach

The key elements of a *palliative approach* are access; collaborative interdisciplinary team-based care; defining the goals of care; evaluating the "net effect" of any treatments or interventions addressing, where relevant, issues of withholding and withdrawing treatment; determining preferred place of care and, separately, the preferred place at the time of death; and managing care transitions.

2.5.1 Access

Palliative care is not limited by diagnosis – people with cancer, AIDS, neurodegenerative diseases or end-stage organ failure are all going to benefit from a *palliative approach* and may require referral to specialist palliative care when the complexity of their needs exceeds the care offered by other disciplines including primary care or specialist surgery [25]. Likewise, palliative care is not limited by prognosis in the presence of a chronic, progressive life-limiting illness. The needs of patients and their caregivers should be the arbiter of the care that is offered in this setting. These needs include all of the domains that define each of us (physical, social, existential, sexual, emotional, financial and logistical). The aim of care is to optimise function and comfort in each of these domains having been adequately assessed, minimise dependence and determine each caregiver's willingness and ability to provide care and support. This approach enables the implementation of systematic care planning based upon a multifaceted assessment of the patients and their caregivers' support needs.

2.5.2 Collaborative Interdisciplinary Team-Based Care

Given the breadth of issues faced by people at the end of life, there is a need for true interdisciplinary care. Every team member brings

a combination of skills: those inherent in any fellow human, those of a health professional and those of the specific discipline in which the person has been trained. As noted, a number of skills need to be shared at the level of a health professional (a *palliative approach*) and those that are dealt with at specialist level (*specialist palliative care*). Configuring the interdisciplinary team to the patients' needs requires consideration.

A key clinician has to take responsibility for overseeing care and optimising its coordination. In many health systems this may be the general practitioner/family physician or the primary specialist charged with that care. Patients benefit from having the input of all of the disciplines that can add to the quality of their clinical care. Other specialist medical teams with skills related to the underlying life-limiting illness and any co-morbid conditions are crucial to optimise the care of anything that will predictably improve the control of the disease and to help in decisions about rationalising medications and contributing to discussions on the changing goals of care.

Nurses' proximity to patients and their caregivers enable them to identify people who would benefit from a *palliative approach* and to advocate for this approach to care. Nurse practitioners and nurse specialists have key roles including management of medications/medication compliance, overall evaluation of the patient in the setting of their caregivers and community more broadly and comprehensive evaluation of the health of the person. The expertise of a range of other specialist nurses is often required to manage surgical patient's complex wounds, continence and stomas.

In the light of widespread polypharmacy that increases as death approaches, the pharmacist's role is of critical importance [26]. Not only are medications for long-term co-morbidities continued, but medications for symptom control are added. This needs ongoing review and rationalisation with the emphasis on medications whose continuation will deliver a demonstrable benefit to the patient.

As people are living longer with non-communicable diseases, there is a need to optimise their level of physical functioning in a

setting where physical decline is an almost universal experience. Physical and occupational therapists are central to achieving this outcome [27]. Better maintaining function is a pivotal patient-centred goal of care.

The practical issues of facing death (ensuring that wills and powers of attorney are all in place, financial support) are also a central concern of many patients. Social workers have a key role in helping to ensure these issues are addressed. Counselling skills for patient and their families are another key part of the role.

For people who are exploring existential questions for the first time or in new ways, for people who may not have a faith community or where their faith community is not meeting his/her needs, contact with pastoral care can be helpful. These are often difficult issues and, at times, frightening conversations. Often people's world views and belief systems are challenged by news of their impending death.

Art therapists and music therapists can help in exploring ways of expressing difficult-to-articulate issues. By using a variety of media people may be able to create a legacy as an important part of their end-of-life work [28].

Oral historians help to capture particular aspects of life, some of which may not have been discussed or require a particular perspective. It is also a rich legacy that many people want to leave for their families.

2.5.3 Defining the Goals of Care

Above all, patients expect that clinicians are going to be honest in discussing issues about end-of-life care, are competent to raise these issues and will do so in a timely manner. This requires excellent communication skills by clinicians and a level of candour that balances hope (an incredibly plastic concept that sees people shift what they hope for, which at times may be for better moments as opposed to better days) and honesty. Above all else, patients will value honesty in this setting in a way that can optimise care and allow them the time to arrange their affairs as they would wish [15].

2.5.4 Evaluating the “Net Effect” of Treatment

A *palliative approach* requires integrating evidence-based palliative non-pharmacological and pharmacological interventions tailored to specific disease conditions and symptoms. However, interventions (whether they are pharmacological, surgical or psychological) need to be evaluated for their “net effect”. This means that both the benefits and the burdens of any interventions need to be carefully, prospectively evaluated. Anything less than this is likely to limit the ability of clinicians to provide quality care predictably and limit the ability to tailor interventions to individuals who are most likely to benefit from them.

There should be a focus on optimising the management of the life-limiting illness. Again, this needs to be in the context of the net clinical effect (benefit and burdens). Treating with low odds of benefit and high risk of toxicity is unlikely to be of net benefit for most patients late in the course of most life-limiting illnesses. Interventions need to predictably improve this person’s well-being in order to be justified.

While in developed countries approximately one in three people referred to palliative care services are under the age of 65, many people referred to palliative care are elderly, which means that an increasing number of co-morbid illnesses will be encountered and also have to be managed actively. In this setting, the goals of care in treating the co-morbid illness need to be clear. For example, many patients are continued on anti-hypertensive medications long after they have lost weight, have become normotensive and indeed may now have iatrogenic postural hypotension. In managing type II diabetes with increasing cachexia, weight loss and anorexia, an early decision needs to be made in order to avoid fatal or life-threatening hypoglycaemia. It is crucial that we better understand the role of other long-term interventions such as the use of “statins”. If the number needed to treat (NNT) requires hundreds of people to be treated for several years in order to avoid one particular event, continuing those medications late into the course

of a life-limiting illness is probably going to be counterproductive more often than not. The balance between benefit and an increasing likelihood of toxicity as frailty becomes prominent needs to be considered carefully.

2.5.5 Addressing Issues of Withholding and Withdrawing Treatment

The clinical decisions surrounding withdrawing and withholding treatment towards the end of life are particularly challenging when many of the life-sustaining interventions, such as renal dialysis and implantable defibrillators, are initiated earlier in the person’s illness with the goal of managing symptoms and prolonging life [29]. If the reality of needing to withdraw treatment at some stage has not previously been discussed with the patient and his/her family, then these conversations take on a new urgency and often become more challenging as the patient’s condition deteriorates and these interventions become progressively more burdensome. Clarifying and renegotiating the goals of care with the patient and family is crucial as it allows them to plan accordingly, limits their exposure to unnecessary and potentially distressing care [30] and ensures that the interdisciplinary team is clear on the intent(s) of treatment. Reviewing and clarifying the goals of care with the patient and their caregivers is something that clinicians should actively initiate. In the future, with technological and pharmaceutical advances, it is likely that health professionals will be faced with these clinical dilemmas on a more frequent basis.

2.5.6 Determining Preferred Place of Care and Place of Death

There is an often expressed view that people with life-limiting illnesses would most like to be cared for at home. Certainly in surveys of well members of the community, there is a preference that home is where people would like to be if they have a life-limiting illness. However, this

should not be translated into a policy that home is where care must be, especially in the terminal phases (last hours or days of life) of a life-limiting illness. Indeed, many people would actively choose an inpatient setting as the place they would like to die even if they had expressed a wish that the majority of their care were to be provided in the community setting. People's preferences for where care should be may also change over time [31].

Central to this is the need to have an able and willing caregiver [32]. It seems that clinicians assume that a person will happily take on the caregiving role, and rarely do we ask if they are willing or able to do so. Yet, the strongest predictor of care at home and subsequent death at home is the presence of a caregiver who is prepared to take on the role. If there are disagreements between the person dying and the caregiver, it is ultimately the caregiver who makes the greatest impact on where care will be. Recent data suggest that having taken on a caregiver role, there are an identifiable group of people who would not take on such a role again [33].

2.5.7 Managing Care Transitions

A rapid change in the palliative patient's clinical status and or caregiver circumstances often necessitates transitions between hospitals, sub-acute and post-acute nursing facilities, the patient's home, primary and specialty care offices and long-term care facilities. A rapid change may also include, at times, an improvement in their condition where people may wish to make the most of "windows of opportunity" to return home from an inpatient unit while they still can. Coordination and continuity of care between different locations or levels of care within the same location are a priority for palliative patients and their families. Patients and caregivers may lack knowledge of what services are available and how to access them [34]. Navigating the transition from inpatient to community-based care requires intensive effort and coordination to put management plans and caregiver support in place. Current information about the patient's

goals, preferences and clinical status along with a comprehensive plan of care needs to accompany the transfer of the patient across care settings. Specifically planning for patient's and caregivers' responses to clinical scenarios that may occur for this patient is a key role for health professionals when caring for someone in the community. For example, if systemic sepsis from a urinary tract infection has precipitated two admissions to hospital in the last 7 weeks, then contingency planning for the next episode is crucial.

2.6 Minimal Palliative Care Competencies Required by All Health Professionals

In a recent Australian process, a survey sought views from specialist palliative care providers, generalists and educators nationally [35]. There was widespread agreement that there were four competencies required by all clinical staff in order to be able to provide a *palliative approach*. These include:

- Basic principles of palliative care including understanding disease trajectories (with and without disease-modifying treatment) and the net effects (burdens and benefits) of any clinical intervention
- Good communication skills
- Excellent assessment skills not limited to physical well-being, but also to the social, emotional and existential problems that people frequently face in these circumstances
- Optimising the comfort and function of the person and their caregivers in each of the domains outlined in the third competency

2.7 Summary

The heterogeneity of the palliative care population requires collaboration across care teams, with a focus on a *palliative approach* for the majority of people and referral to specialist palliative care services for a smaller number of people based on needs rather than diagnosis nor

prognosis. Such a system-based approach delivers benefits to patients, their caregivers and the health system in which care is delivered. Existing evidence reinforces the importance of shared communication, skill enhancement and clarifying goals of care through advanced care planning.

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