International Journal for Multidisciplinary Research (IJFMR)
E-ISSN: 2582-2160 ● Website: www.ijfmr.com ● Email: editor@ijfmr.com

Role of Nurses in Palliative and End-Of-Life Care

Ms. Unnati Chisla[1], Ms. Riya Patel[2]

[1]2nd Year M.Sc. Nursing, P P Savani School of Nursing, PPSU, Gujarat, India
[2]Nursing Tutor, P P Savani School of Nursing, PPSU, Gujarat, India

Abstract
Palliative care aims to alleviate patients' physical, psychological, and spiritual symptoms while also providing complete assessment and treatment to patients and their families. More forceful palliation of a patient's symptoms may be necessary when death draws near. The family of the dying patient should receive more support as the comfort measures do. Palliative care largely addresses grieving and family assistance Following the patients death.

Keywords: End of life, palliative care, symptom management.

1. Introduction

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-Cantered treatment given to an individual or family who has an advanced, actively progressing illness for whom there is little to no chance of recovery and who is anticipated to pass away; the main objective is to maximize the individual's 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 recognized 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 recognized as imminently dying, death and extends to bereavement care. (PCA, 2018a)

SCOPE OF PALLIATIVE CARE

The scope of palliative care encompasses a wide range of services and interventions aimed at improving the quality of life for patients facing serious illnesses. Here's a detailed description of the scope of palliative care:

1. **Holistic Care:** Palliative care addresses the holistic needs of patients, focusing not only on physical symptoms but also on psychological, social, and spiritual aspects. This comprehensive approach ensures that patients receive care that considers their entire well-being.
2. **Symptom Management:** One of the primary objectives of palliative care is to effectively manage symptoms associated with serious illnesses. This includes pain, nausea, fatigue, shortness of breath,

constipation, and other distressing symptoms. Palliative care specialists employ various pharmacological and non-pharmacological interventions tailored to each patient's needs.

3. **Communication and Shared Decision-Making:** Palliative care emphasizes open and honest communication between healthcare providers, patients, and their families. This facilitates shared decision-making regarding treatment options, goals of care, and end-of-life preferences. It helps ensure that patients' values and wishes are respected throughout their healthcare journey.
4. **Psychosocial Support:** Palliative care addresses the emotional and psychological impact of serious illness on patients and their families. It provides counselling, emotional support, and interventions to help patients cope with anxiety, depression, grief, and existential distress. Social workers and psychologists play a crucial role in assessing and supporting these needs.
5. **Spiritual Care:** Recognizing the importance of spirituality in healthcare, palliative care includes spiritual support tailored to patients' beliefs and practices. Chaplains or spiritual counsellors offer guidance, comfort, and religious rituals as requested by patients and families.
6. **Caregiver Support:** Palliative care extends support to family caregivers who play a critical role in the care of patients. This includes education, training, respite care, and emotional support to help caregivers cope with the demands of caregiving and maintain their own well-being.
7. **Advance Care Planning:** Palliative care encourages advance care planning discussions to help patients articulate their preferences for future medical care. This includes decisions about life-sustaining treatments, resuscitation, and preferences for end-of-life care. Advance directives and durable power of attorney for healthcare are often discussed and documented during these conversations.
8. **Continuity of Care:** Palliative care promotes continuity of care across different settings, including hospitals, outpatient clinics, skilled nursing facilities, and home care. This ensures seamless transitions and consistent management of symptoms and supportive care regardless of where the patient receives treatment.
9. **Bereavement Support:** After the death of a patient, palliative care extends support to bereaved family members. This includes counselling, support groups, and resources to help loved one’s cope with grief and adjust to life after loss.
10. **Interdisciplinary Approach:** Palliative care is delivered by an interdisciplinary team of healthcare professionals, including physicians, nurses, social workers, psychologists, chaplains, pharmacists, and others. This team-based approach ensures that all aspects of patient care are addressed comprehensively and collaboratively.
11. **Education and Research:** Palliative care contributes to education and research in healthcare by advancing knowledge and understanding of symptom management, patient preferences, quality of life outcomes, and healthcare delivery models. Research in palliative care informs evidence-based practices and improves the quality of care provided to patients.

BENEFITS OF PALLIATIVE CARE

- **Symptom Management:** Effective control of pain and other distressing symptoms.
- **Emotional Support:** Addressing anxiety, depression, and existential distress.
- **Family Support:** Providing guidance and support to family caregivers.
- **Quality of Life:** Enhancing overall well-being and quality of life.
- **Communication:** Facilitating effective communication between patients, families, and healthcare providers.

CARE OF SETTINGS

Palliative care is versatile in its delivery, spanning multiple care settings to accommodate the diverse needs and preferences of patients facing serious illnesses. Here's a description of the different care settings where palliative care can be provided:

1. **Hospitals:** Hospitals are common settings for palliative care, particularly for patients with complex medical needs requiring intensive management of symptoms. Palliative care teams in hospitals collaborate closely with other medical specialists to ensure comprehensive and coordinated care. This setting is suitable for patients requiring acute symptom control, advanced care planning, and support during hospital stays.
2. **Outpatient Clinics:** Palliative care outpatient clinics offer services to patients who do not require hospitalization but still need specialized care and symptom management. These clinics provide a more relaxed environment for consultations, ongoing assessment of symptoms, medication adjustments, counselling, and support for patients and their families. Outpatient palliative care allows for continuity of care while patients continue to live at home.
3. **Skilled Nursing Facilities (SNFs) and Long-Term Care Facilities:** SNFs and long-term care facilities provide palliative care to residents who are chronically ill or nearing the end of life. These settings offer 24-hour nursing care and support services, making them suitable for patients who require ongoing symptom management, assistance with activities of daily living, and psychosocial support. Palliative care teams collaborate with facility staff to ensure comprehensive care tailored to individual needs.
4. **Home Care:** Home-based palliative care allows patients to receive care in the comfort of their own homes, surrounded by familiar surroundings and loved ones. This setting is ideal for patients who prefer to remain at home and have adequate support from family caregivers or home healthcare providers. Home-based palliative care includes visits from a multidisciplinary team who provide medical management, symptom control, emotional support, caregiver education, and assistance with advance care planning.
5. **Hospice Care:** Hospice care is a specialized form of palliative care provided to patients who are terminally ill and no longer seeking curative treatments. It focuses on enhancing quality of life and providing comfort in the final stages of illness. Hospice care can be provided in various settings including hospice facilities, nursing homes, hospitals, and at home. It includes comprehensive support for patients and families, bereavement services, and assistance with end-of-life care decisions.

Factors Influencing Care Setting: The choice of palliative care setting depends on several factors including the patient's medical condition, symptom severity, personal preferences, caregiver availability, and access to healthcare services. The interdisciplinary palliative care team collaborates with patients, families, and referring healthcare providers to determine the most appropriate setting that aligns with the patient's goals of care and ensures optimal support throughout the illness trajectory.

ETHICAL CONSIDERATIONS

- Palliative care respects the principles of autonomy, beneficence, non-maleficence, and justice. It promotes dignity, respect, and compassionate care for patients and families facing difficult decisions.

CHALLENGES IN PALLIATIVE CARE

- **Access:** Disparities in access to palliative care services, especially in rural or underserved areas.

- **Awareness:** Limited awareness among patients, families, and healthcare providers about the benefits of palliative care.
- **Integration:** Challenges in integrating palliative care into standard medical practice and across different healthcare settings.

CRUCIAL COMPONENTS OF HIGH-QUALITY HOSPICE CARE

Numerous health professionals work in acute, community, and residential care settings when providing palliative care (PCA, 2018a) (See Figure 1).

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

MODEL OF CARE

The conventional medical treatment paradigm has become binary, with doctors first offering aggressive or curative care and then starting comfort care only after all other options have been exhausted. Palliative medicine does not only provide comfort care or end-of-life care; it also sets goals to alleviate suffering in all phases of disease (Figure 2).

Models of healthcare delivery. (Reproduced with permission from the National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 2008.

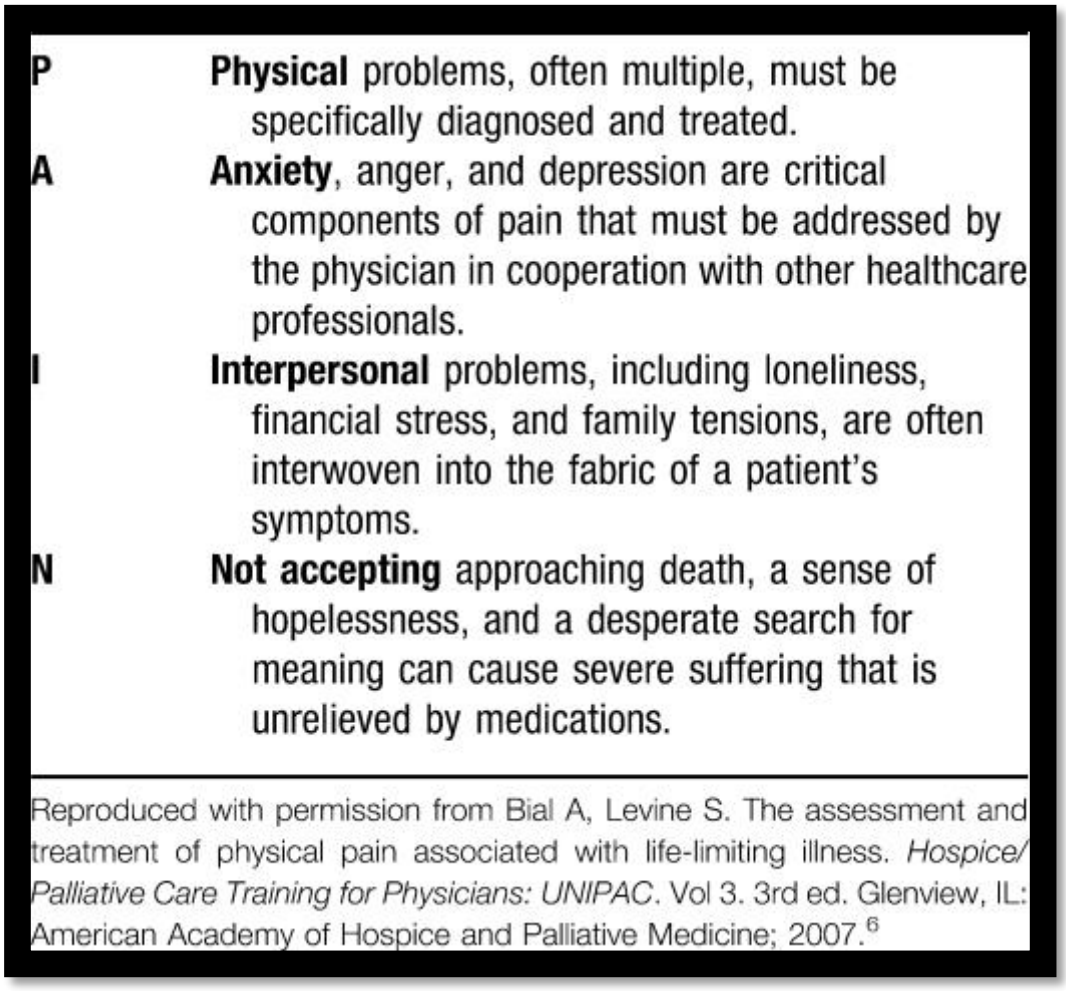
Sometimes, the phrases hospice care and palliative care are used interchangeably. When a patient's life expectancy is six months or less and curative or life-prolonging therapy is no longer necessary, hospice

care, according to the National Quality Forum, is a system of care delivery that offers palliative care and medication. Consequently, it's critical to understand that while palliative care is provided by hospice, hospice is not the same as palliative care. The hospice service delivery system does not offer every therapeutic palliative care modality that is available.

THE CONCEPT OF TOTAL PAIN

One of the main objectives of medical care is to lessen suffering. Providers must first identify pain and suffering, though, before they can cure it. Saunders originally discussed the idea of total pain and how different types of pain and suffering interact with one another. The patient's overall pain is the culmination of their bodily, psychological, social, and spiritual suffering. The evaluation and diagnosis of pain and suffering depend heavily on this idea. Advanced Practice Nursing Models in Palliative Care.

Four Components of Total Pain



Especially near the end of life, treating a patient's entire pain is essential since there is a correlation between psychological discomfort, a lack of social support, and physical suffering. If not all aspects of overall pain are treated, optimal pain alleviation will not be achievable. To effectively treat suffering associated with the many categories of total pain, clinicians should make use of additional multidisciplinary team members, such as social workers and chaplains.

As their lives are coming to an end, patients may have severe symptoms such as psychological, spiritual, and bodily pain. Palliative medicine aims to prevent and manage these symptoms while maximizing quality of life during the dying process. Achieving self-control, avoiding the prolongation of the dying process, finding purpose in life, finding adequate pain and symptom management, and relieving the care burden on family and loved ones while completing and strengthening those relationships are all important factors for patients who are seriously ill. The load of symptoms rises as death draws nearer, yet the patient's and their family's ability to handle mental and physical strain declines. Right now, the emphasis should shift away from restorative care and towards primary palliative care approaches. The triggers for the shift to palliative care include the following four symptoms.

PHYSICAL PAIN

Towards the end of life, pain is one of the most common symptoms. In addition to exacerbating other symptoms, unrelieved pain can cause patients and their family serious grief. Pain treatment at the end of life must therefore be appropriately addressed. The mistaken belief that opioids cause respiratory depression and speed up death is a major obstacle to the widespread use of opioid analgesics in the treatment of moderate to severe pain in patients with terminal illness, despite the fact that this is the standard of care. Yet when opioids are administered at the right dosages, these side effects are rare. Gaining proficiency in pain management is essential for clinicians who treat patients who are terminally sick or chronically unwell.

DYSPNEA

The subjective feeling of being out of breath, or dyspnea, is a common and upsetting symptom, especially in terminal patients. Opioids and benzodiazepines are the most often recommended drugs for managing dyspnea. If scheduled or as-needed doses are insufficient, a doctor may employ continuous infusions as death draws near to control symptoms and alleviate pain. The physician should continuously evaluate the patient and make changes to manage symptoms.

RESTLESSNESS

At the end of life, carers need to be aware of the telltale signs and symptoms of restlessness linked to delirium (Table 2).Thirteen Among the medications used in hospitals, anticholinergics, sedative-hypnotics (such as benzodiazepines), and opioids are the most often recognized causes of delirium. A person experiencing delirium or restlessness towards the end of their life may experience physical, mental, or spiritual agony as well as anxiety, agitation, and cognitive impairment. Usually, a strong tranquillizer like haloperidol is needed to treat terminal delirium.

The constellation of end-of-life restlessness symptoms may include the following:

- Skin mottling and cool extremities
- Mouth breathing with hyperextended neck
- Respiratory pattern changes such as Cheyne-Stokes
- Calling out for dead family members or friends
- Talking about packing bags, taking a trip, going for a car ride (any reference to preparing for a trip)
- Periods of deepening somnolence

Reproduced with permission from Policzer JS, Sobel J. Management of selected nonpain symptoms of life-limiting illness. *Hospice/Palliative Care Training for Physicians: UNIPAC*. Vol 4. 3rd ed. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2007.[13]

DEATH RATTLE

As responsiveness decreases toward the end of life, it becomes increasingly difficult for patients to control oropharyngeal secretions. The death rattle of the actively dying is the sound of air movement across pooled secretions. Although not a cause of suffering for the dying, the death rattle can be disturbing for loved ones to hear. Repositioning the patient's head and using anticholinergics such as atropine or scopolamine are the mainstays of treatment.

PSYCHOSOCIAL, SPIRITUAL, AND BEREAVEMENT SUPPORT

Once the physical adverse symptoms and distress have been successfully addressed, it is important to broaden the integrated response of the interdisciplinary treatment team to address the psychosocial and spiritual issues that are an inherent part of the dying process. A comprehensive psychosocial and spiritual assessment allows the team to lay a foundation for healthy patient and family adjustment, coping, and support. Skilled expert therapeutic communication through facilitated discussions is beneficial to maintaining and enhancing relationships, finding meaning in the dying process, and achieving a sense of control while confronting and preparing for death.

Psychosocial and Spiritual Assessment of the Patient with a Life-Threatening Illness: Sample Screening Questions

Psychosocial Assessment Domain	Screening Questions
Meaning of illness	*"How have you made sense of why this is happening to you?"* *"What do you think is ahead?"*
Coping style	*"How have you coped with hard times in the past? What have been the major challenges you have confronted in your life?"*
Social support network	*"Who are the important people in your life now? On whom do you depend and in whom do you confide about your illness?"* *"How are the important people in your life coping with your illness?"*
Stressors	*"What are the biggest stressors you are dealing with now?"* *"Do you have concerns about pain or other kinds of physical suffering? About your and your family's emotional coping?"*
Spiritual resources	*"What role does faith or spirituality play in your life? What role has it taken in facing difficult times in the past? Now?"*
Psychiatric vulnerabilities	*"Have you experienced periods of significant depression, anxiety, drug or alcohol abuse, or other difficulties in coping?"* *"What kinds of treatment have you had and which have you found helpful?"*
Economic circumstances	*"How much of a concern are financial issues for you?"*
Patient-physician relationship	*"How do you want me, as your physician, to help you in this situation? How can we best work together?"*

Reproduced with permission from Block SD. *JAMA*. 2001 Jun 13;285(22):2898-2905.[16]

In order to provide compassionate palliative care, professionals in this sector must be prepared to investigate concerns of integrity preservation that will promote the development of transcendence and dignity. In order to maximize this communication and gauge the patient's and carers' readiness to participate, thoughtful, open-ended questions are essential. In order to improve the patient's calm and psychological spiritual comfort, healthcare professionals such as doctors, psychologists, nurses, social workers, and chaplains can integrate and negotiate the interpersonal interaction skills and intimacy needed.

Useful Questions for Clinicians

A. Mobilizing a patient's coping strengths and inner resources

- *"What will help you feel that you have lived up to your own ideals in the way you've dealt with your illness/your death?"*
- *"What could you do that would help you feel that this has been a meaningful time for you and the people you care about?"*
- *"How do you want to be remembered by the people you care about?"*
- *"What are some of the ways you have found yourself growing or changing, or hoped that you could grow or change in this last phase of your life?"*
- *"What are some of the moments when you've felt most discouraged and downhearted as you've faced your illness?"*
- *"What are the biggest barriers you find to feeling secure and in reasonable control as you go through this experience with your illness?"*
- *"What are the resources and strengths within you that can help you cope?"*

B. Eliciting a patient's goals for healing and strengthening relationships

- *"Are there important relationships in your life, including relationships from the past, that need healing or strengthening?"*
- *"Are there relationships in which you feel something important has been left unsaid?"*
- *"Do the important people in your life know what they mean to you?"*
- *"Are there stories, values, or ideas that you want to transmit to people as part of your legacy?"*
- *"Are there ways that you can help your family now to prepare for and deal with your death?"*
- *"How might you be able to continue to be a presence in the lives of people you love after you are gone?"*
- *"How would you like to say goodbye to the people who have been important to you?"*

Reproduced with permission from Block SD. *JAMA*. 2001 Jun 13;285(22):2898-2905.[16]

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 categorized in terms of patient, health care, health care service/ organization, 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-centered approach to care is preferred • Regular and flexible appointments to facilitate access
Health care team	• Acceptance by other team members • Leadership • Poor communication	• Improved and frequent communication • Continuity of care • Integrated/shared care models
Health care service/ organizational	• Demand exceeds availability • Nurse competency	• Preliminary forecasting and scoping of existing services to better meet demand • Highlight nurse's core strengths, provide skill development and administrative support
	• Funding models	

System/structures	• Integration and use of resources • High case load • Lack of program visibility and promotion	• Case management approach was key to success

NURSING ROLE FOR PALLATIVE CARE AND END OF LIFE CARE

1. Patient-Cantered Care

- **Assessment and Planning:** Explain how nurses assess the physical, emotional, spiritual, and social needs of patients in palliative care.
- **Care Plan Development:** Discuss the process of developing individualized care plans that prioritize patient comfort, dignity, and quality of life.
- **Case Management:** Illustrate examples of how nurses coordinate care across different settings to ensure continuity and comprehensive support.

2. Pain and Symptom Management

- **Assessment of Symptoms:** Detail the methods nurses use to assess and prioritize symptoms such as pain, dyspnea, and nausea.
- **Interventions and Therapies:** Describe the range of pharmacological and non-pharmacological interventions nurses employ to manage symptoms effectively.
- **Collaboration with Multidisciplinary Teams:** Explain how nurses collaborate with physicians and other healthcare providers to optimize symptom control and improve patient comfort.

3. Communication and Advocacy

- **Patient-Family Communication:** Discuss the importance of clear and compassionate communication in discussing prognosis, treatment options, and end-of-life preferences with patients and their families.
- **Advocacy for Patient Preferences:** Provide examples of how nurses advocate for patient autonomy and ensure that their preferences and wishes are respected throughout their care journey.
- **Ethical Considerations:** Address ethical dilemmas that nurses may encounter in advocating for patient rights and preferences in palliative and end-of-life care settings.

4. Emotional and Spiritual Support

- **Psychosocial Assessment:** Explain how nurses conduct psychosocial assessments to identify emotional needs and provide appropriate support.
- **Spiritual Care:** Discuss the role of nurses in addressing patients' spiritual beliefs and practices, and facilitating access to spiritual care resources.
- **Support for Families:** Describe strategies nurses use to support families and caregivers, including grief counselling, emotional support, and practical guidance.

5. Coordination of Care and End-of-Life Planning

- **Transitional Care:** Outline how nurses coordinate care transitions between different healthcare settings, such as hospitals, hospices, and home care.
- **Advance Care Planning:** Detail the process of advance care planning, including discussions about advance directives, goals of care, and preferences for end-of-life interventions.
- **Documentation and Evaluation:** Discuss the importance of thorough documentation and ongoing evaluation of care plans to ensure they align with patients' evolving needs and wishes.

Summarize the pivotal role of nurses in providing holistic, compassionate, and patient-centered care in palliative and end-of-life settings. Highlight the significance of their contributions to enhancing quality of life, promoting comfort, and supporting patients and families during challenging times.

Conclusion

palliative care and end-of-life care play crucial roles in supporting patients and their families during challenging times. By focusing on enhancing quality of life, managing symptoms effectively, and addressing the holistic needs of patients, these specialized approaches provide comfort and dignity throughout the course of serious illness. They promote open communication, empower patients to make informed decisions about their care, and offer valuable emotional and spiritual support. Ultimately, palliative care and end-of-life care affirm the importance of compassionate and comprehensive healthcare that respects the individual's journey and values, ensuring that every patient's final chapter is filled with comfort, respect, and meaningful support.

REFERENCE

1. Australian Commission on Safety and Quality in Health Care, 2015, National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care, Retrieved from Sydney.
2. Australian Institute of Health and Welfare, 2018, Palliative care services in Australia. Canberra,
3. ACT: AIHW Retrieved from https://www.aihw.gov.au/reports/palliative-care-services/ palliative-care-services-in-Australia/contents/summary
4. Bentley, M, Stirling, C, Robinson, A & Minstrel, M, 2016, 'The nurse practitioner–client therapeutic encounter: an integrative review of interaction in aged and primary care settings', Journal of Advanced Nursing, 72(9), pp. 1991-2002, doi:doi:10.1111/jan.12929
5. Bookbinder, M, Gleichen, M, McHugh, M, Higgins, P, Budi's, J, Solomon, N, Homel, P, Cassin, C, & Portnoy, RK, 2011, 'Nurse practitioner-based models of specialist palliative care at home:
6. Sustainability and evaluation of feasibility', Journal of Pain and Symptom Management, 41(1), pp. 25-34, doi:10.1016/j.jpainsymman.2010.04.011
7. Canning, D, Yates, & Rosenberg, J, 2005, Competency Standards for Specialist Palliative Care Nursing Practice, Retrieved from Brisbane, QLD: https://www.pcna.org.au/PCNA/media/docs/ competystds_1.pdf
8. Corner, J, 2003, 'The role of nurse-led care in cancer management', The Lancet Oncology, 4(10), pp. 631-636.
9. Douglas, C, Schmalkuche, D., Nizette, D, Yates, P & Bonner, A, 2018, 'Nurse-led services in Queensland: A scoping study', Collegian, 25(4), 363-370, doi:10.1016/j.colegn.2017.10.011
10. Gardner, G, Duffield, C, Doubrovsky, A & Adams, M, 2016, 'Identifying advanced practice: A national survey of a nursing workforce', International journal of nursing studies, 55, pp. 60-70, Doi: HTTPs://doi.org/10.1016/j.ijnurstu.2015.12.001
11. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA. 1995 Nov 22-29;274(20):1591–1598. Erratum in: JAMA. 1996 Apr 24;275(16):1232. [PubMed] [Google Scholar]

12. National Consensus Project for Quality Palliative Care. 2008. Clinical Practice Guidelines for Quality Palliative Care. http://www.nationalconsensusproject.org. Accessed September 21, 2011. [Google Scholar]
13. Meir DE, Bishop TF. Palliative care: benefits, services, and models of care. In: UpToDate, Basow DS, editors. Waltham, MA: UpToDate; 2011. [Google Scholar]
14. National Quality Forum. A National Framework and Preferred Practices for Palliative and Hospice Care Quality. Washington, DC: National Quality Forum; 2006. http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=22041. Accessed September 19, 2011. [Google Scholar]
15. Cassell EJ. Diagnosing suffering: a perspective. Ann Intern Med. 1999 Oct 5;131(7):531–534. [PubMed] [Google Scholar]