



Quality of palliative care: A Literature Review

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Abstract

This brief article on pre-conference CME topic ‘How to plan Research in Palliative Care’ is aimed to provide an overview of the background, concept, domains, present research activities and the future prospect for research opportunities. Advances in Palliative Care are made with a focus to address the quality of medical practice and ‘quality of death’, in those patients who have advanced stage diseases where cure may or may not be possible. The issues which can improve the palliative care delivery and the areas where evidence of practice is still weak can be identified by forming network and collaborative groups for the application of study and research methods in India.

Keywords: Palliative care, Research, theory, India

INTRODUCTION

While dying is a normal part of life, death is often treated as an illness. As a consequence, many people die in hospitals, alone and in pain.¹ Palliative care focuses primarily on anticipating, preventing, diagnosing, and treating symptoms experienced by patients with a serious or life-threatening illness and helping patients and their families make medically important decisions. The ultimate goal of palliative care is to improve quality of life for both the patient and the family, regardless of diagnosis. Although palliative care, unlike hospice care, does not depend on

prognosis, as the end of life approaches, the role of palliative care intensifies and focuses on aggressive symptom management and psychosocial support.

Objective: The aims of the current study are to assess the prevalence of cancer-related fatigue, to examine the difference in cancer-related fatigue severity in relation to patients' characteristics (age, gender, type of cancer, and palliative performance status), and to explore the correlation between cancer-related fatigue and pain, dyspnea, insomnia, and depression among palliative care patients.

Use of the Concept:

The terms for the concept were identified in and out of the nursing literature to explore other uses of concept language. Palliative is identified as relieving care without curing or an individual who relieves an uncomfortable condition.²⁰ The word hospice has origins in Latin that means "guests" or "hosts," and its current use is as a care model or a location for care. Taber's Cyclopedic Medical Dictionary defined it slightly differently than other sources; here, it was described as a program derived from palliative and supportive services, interdisciplinary in nature, that focused on the "physical, spiritual, social, and economic needs" of terminally ill patients and their caregivers.

The Role Of Ethics And Palliative Care

In a health care system where "medical futility" lacks clear definition and consistency in legal support for providers, how can the large number of caregivers experiencing professional burnout and moral distress be appropriately addressed.

In many of these challenging cases, ethics and palliative care teams come together to provide the staff working with patients day in and day out with a new care perspective. The nature of bioethics is to approach individual patient cases by looking not just at what can be done, but rather what should be done. Ethics consultants are often brought on board in cases where there is moral dilemma or conflicting values about patient autonomy, surrogate decision making, goals of care, and transitions to EOL care. Palliative care teams may be called upon for similar reasons, and their presence is growing rapidly as health care professionals and patients are benefiting from the added layer of physical, spiritual, and psychosocial support provided at various points along the disease trajectory. Palliative care specialists can provide guidance with difficult and complex treatment choices as well as help patients and families navigate the health care system. The services have been known to work synergistically with each other to alleviate patient and family conflicts with care teams and conflicts between teams and also to provide support for staff working in an environment prone to ethical dilemmas and moral distress.

Principle Theory;

The principles of autonomy, beneficence, nonmaleficence, and justice as emphasized in the Belmont Report are the basis of most bioethical deliberations used by clinicians in the West and will be reviewed in most detail. Aspects of the previously discussed general theories are imbedded within it.

Autonomy;

The principle of autonomy is based on respect for the individual and can be recognized as influenced by Kantian ethics.³⁻⁵ It proscribes that persons with decision-making capacity should be allowed to make health care decisions for themselves. Patients with capacity may appoint another person to make decisions for them. This is an autonomous decision on their part. Consent cannot express autonomy unless it is informed and without undue influence. Informed consent is a process in which patients with decision-making capacity are provided information about a treatment or procedure that they may choose to undergo or not to undergo. Patients need to have adequate information to be able to weigh the possible risks, benefits, and consequences of deciding to accept or forgo a treatment, intervention, or procedure. Both the disclosure of information and the active participation of the individual are important to this process.

Beneficence;

The principle of beneficence refers to doing good—providing care that enhances the patient’s well-being and reduces risk of harm. The Belmont Principles also address research subjects. Research that can present risks of harm to the subject can still be performed within the principles if the subject has given informed consent. The health care team works together to minimize patient risks and optimize patient benefit. This involves advocating for the patient and family and making sure that their voice is heard.

Nonmaleficence;

This is reflected in the Hippocratic oath: “I will use treatment to help the sick according to my ability and judgment but I will never use it to injure or wrong them.” Offering nonbeneficial or futile treatment would be an example. This principle asserts a duty to avoid harm and reduce the risk of harm. It requires weighing relative risks and benefits of any action or inaction to the patient in front of you. Some treatments may cause a degree of harm, but the benefit to the patient outweighs the harm. For example, chemotherapy may be recommended to reduce tumor size or pain but may cause adverse effects such as nausea and vomiting.

Justice:

This principle refers to providing care that is equitable and fair to all and includes the fair distribution of scarce resources. The availability of palliative care and hospice care is a good example. All patients should have access to palliative care and hospice care services, interventions, and support; and care provided should be based on patient need regardless of socioeconomic state or social status.

Conclusion

The role of palliative care at the end of life is to relieve the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms patients experience. As death approaches, the symptom burden of a patient may worsen and require more aggressive palliation. As comfort measures intensify, so does the support provided to a dying patient's family. Once death has occurred, the role of palliative care focuses primarily on the support of the patient's family and bereavement.

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