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Palliative Care and Research in Palliative Medicine: Ethical Response

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Abstract

Hospice and palliative care is well recognized as the ideal model of care for the terminally ill. As the number of terminal care patients has continued to increase in recent years, palliative care has been advocated as a moral responsibility of the health system. With advances in modern medicine, people are living longer, and the number of elderly persons is increasing. As a result, the ethical issues surrounding end of life care continue to gain importance in society. Research on issues at the end of life is rapidly growing, and its importance increases as our population ages. There is an urgent need to find better ways to improve pain and symptom management at the end of life, to help people die with dignity, and to comfort the bereaved. In the words of Hippocrates, 'The purpose of medicine is to do away with the sufferings of the sick, to lessen the violence of the disease and to refuse to treat those who are overmastered by their disease.'

Keywords: Palliative care, Medical ethics, palliative research

Introduction

Hospice and palliative care is well recognized as the ideal model of care for the terminally ill. As the number of terminal care patients has continued to increase in recent years, palliative care has been advocated as a moral responsibility of the health system.¹ However, ethical issues are frequently encountered during the provision of hospice and palliative care. The spirit of hospice has been routinized, institutionalized and medicalized as the result of overemphasis on techniques and efficiency, thus deviating from its original goal being holistic care and support for the terminally sick patients.² A broader investigation of the ethics of palliative care practice has not been given sufficient consideration in the growing accumulation of palliative care centers.

Institution-based palliative care was established in India in the 1980s.³ Prior to this movement, most individuals in terminal stages of illness were treated in homecare settings by family caregivers according to traditional spiritual, religious customs, and rituals.^{4,5} Lately, India's health managers, clinicians, and policy makers have been actively involved in setting bench marks for palliative care practices, creating innovative models of care, developing trainers and training programs, and providing evidence-based clinical guidelines for the care of the dying.³ These imperatives are necessary considering India's large population and the significant rise of late stage illnesses diagnoses (e.g. cancer) are presenting staggering demands on palliative care. Moreover, India's vast geographical area and multiplicity of religious affiliations compound the need for decentralized, more easily accessible, and culturally sensitive palliative care institutions. In addition to a growing demand for end of life care, India must also contend with limited health care resources, yielding the need to put forward creative and cost-effective supportive care modalities. The paucity of trained and experienced health care providers, such as oncologists, nurses, and other health care professionals, adds to the challenge of providing accessible end of life care to those in need.^{4,6}

Palliative care has undergone many changes since its humble beginning and continues to grow as a specialized field. As medical knowledge and technology increase, so do options for healthcare. When decisions arise concerning the treatment of dying patients,

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these options present complex ethical dilemmas. Many are faced with decisions about the best treatment to ease a patient's final suffering. Perhaps a decision will need to be made about terminating treatment altogether for a variety of reasons or to give complete treatment.⁷ These decisions—regarding their own care or the care of a dying loved one—confront people from all walks of life. With advances in modern medicine, people are living longer, and the number of elderly persons is increasing. As a result, the ethical issues surrounding end of life care continue to gain importance in society.⁸ we focus on ethical considerations of subjects that include the benefits and drawbacks of various types of modern treatment, or termination of treatment and options for preserving the individual autonomy of the patient.

Ethical principles in palliative care

Major ethical principles in palliative care includes^{9,10}:

1. **Autonomy:** It is ability of the person to choose and act for one's self free of controlling influences. The decision is coercion from physician, nurse, consultant, family members, coercion/pressure from religious group and dogmas. It is the ability to make decisions based upon personal values and pertinent information. Respect for autonomy requires honoring each person's values and viewpoints, listening to the other person as they share their values and choices and questions and to assure that they are capable of autonomous decisions.
2. **Beneficence:** It implies acting in the best interests of the patient. The best case scenario can be interacting with the patient in a way which maximizes the patient's values and their understanding of a good quality of life and the worst case scenario can be being paternalistic in the interactions with the patient without honoring their values.
3. **Nonmaleficence:** This implies do no harm, which means make no knowing act or decision, or lack of sharing information which will cause direct harm to the patient or for example not sharing treatment options which you disagree with, but which are beneficial.
Truth-telling: Truth – telling includes sharing all truly beneficial information which will assist the person in making a good decision.
Confidentiality: It is the duty to respect the privacy of shared information. It should not override when we need to enlist others to confront a patient who has made a decision which is inconsistent with prior decisions.
4. **Justice:** It is to consider individual decisions in context of the needs of the greater society, to understand all are integral part and an interrelated part of society. It is the knowledge that what I do, how I do things does have an influence beyond my own personal sphere.

Ethical Issues in Palliative Care

Telling the truth.

Truth telling is a concept that has received attention in the literature on palliative care and culture. Telling the truth is foundational to the process of informed consent. Without adequate information about risks and benefits, an individual cannot make a judgment about future care. Most western health care providers believe that information is good for

the patient. The dominant cultural assumption is that persons who are terminally ill not only need, but also want truthful disclosure and that they will benefit from this information. Health care practitioner's view that those who do not want to know about their condition are being in denial state. In Indian culture, however, disclosing the truth to a patient who is terminally ill is discouraged because of a fear that the patient will worry and be sad if his or her condition worsens. Family members will request that information be withheld from the patient to avoid harm, which is consistent with Confucian practice. Similarly, in the Muslim culture, using words such as death, dying, and cancer are viewed as taboo.

Place of care

Place of care and quality of final care are important components of terminal care for both the patient and the family. In Indian scenario patient may prefer the end place of care, their houses itself. Because of various reasons financial or therapeutic the family members may not be able to give optimal care in their houses.

Therapeutic strategy

With modern medical therapies life can often be significantly prolonged. Yet, sometimes in cases of severe illness and advanced disease a patient and his or her caregivers may be confronted with the question whether curative or life-sustaining treatment is still worthwhile. They may be of the opinion that the proposed treatment will not have the desired outcome or the side-effects of the treatment will outweigh the benefits. Patients and caregivers will have to decide whether they will initiate or withhold, continue or withdraw the treatment. Even if the caregivers want to administer the treatment, the patient may still refuse the therapy. There are three main types of treatment decisions regarding curative or life- sustaining treatment in advanced disease: (1) initiating or continuing a curative or life-sustaining treatment, (2) a non-treatment decision, and (3) refusal of treatment. Curative or life-sustaining treatments include all treatments through which the treating physician intends to cure or stabilize the illness, and/or prolong or sustain the patient's life. A non-treatment decision is a decision to withdraw or withhold a curative or life-sustaining treatment, because in the given situation this treatment may deem to be no longer meaningful or effective. In the case of refusal of treatment a curative or life-sustaining treatment is withdrawn or withheld because the patient refuses this treatment

Terminal sedation

Common law traditions connect ethical and legal arguments concerning diverse palliative sedation practices. Pain is being culturally reinvented: palliation is more than pain relief. On legal and clinical fronts pain is understood in terms of different kinds of rights and embodied claims to be "managed" as a "client service" in demand-based knowledge economies. Pain relief has emerged as different kinds of rights with guidelines that have developed for complex care.

Others

Ethical dilemmas also include regarding terminal hydration and nutrition of the patient. If the quality of life of the patient is not optimal dilemma arises between health care

professionals and family members regarding withdrawing the nutrition or continuing it. Another dilemma encountered is regarding blood transfusion. The palliative care center may not have the facilities for blood transfusion, even though it may be required for the patient. Relatives of the patient may not be willing to get the blood for transfusion from other health facilities.

Palliative Care Research Dilemmas and Barriers

Palliative care research confronts distinctive ethical dilemmas and barriers that extend far beyond those of standard research trials.¹¹ While many ethical issues are not unique to patients facing life's end, they are often magnified in this population and compound the potential ethical issues present in all clinical research trials. These include the vulnerability of the population from which study subjects are recruited, high rates of mental incapacity and emotional distress creating challenges to informed consent, addressing conflicts of interest within the dual roles of the clinician-researcher, the invasiveness and increased frequency of testing relative to standard clinical practice, and questions of scientific value that must balance the benefits and burdens of unproven interventions in a population in whom comfort may be a priority. Ethical concerns specific to palliative research include the difficulty in assessing the risks and benefits of research participation, randomization, especially if there is a "no treatment arm," and the unstable mental status of patients with difficulty assessing capacity. Methodological challenges include high rates of loss to follow-up due to physical and mental incapacity and death, the biases introduced by the need for surrogate respondents, and the difficulty of determining appropriate outcomes and methods for assessing those outcomes. Within palliative surgery and other invasive specialty areas, specific concerns include the risks of major morbidity and mortality these treatment approaches entail, patient loss of decision-making capacity and management of life-threatening emergencies in the peri procedure period, difficulty with equipoise¹² when faced with vastly different treatment options (surgical versus nonsurgical), and the "all-or-nothing" nature of surgery making irrelevant the idea that a patient should be free to withdraw from a study at any time. Despite the challenges alluded to above, the effectiveness of palliative interventions must nevertheless be assessed with the same rigor that is employed in assessing other medical interventions. As with all treatments of uncertain benefit, we must "overcome ethical objections to research and ingrained beliefs in established treatments¹³". While palliative surgery poses some unique dilemmas within the larger scope of palliative care research, even these barriers can usually be overcome with well-constructed studies carried out by thoughtful research teams.^{14,15} Indeed, the methodological difficulties in palliative care research are all surmountable through existing techniques and appropriately careful scientific design.¹⁶ Communication that these hurdles can be surmounted remains a barrier to the implementation in palliative care settings. In addition to the challenges described above, designing palliative care research with methodological precision must account for the diversity of ethnic, cultural, and religious backgrounds that patients bring with them into their experience of life-limiting illness. A patient's experience of illness is both

multidimensional—incorporating physical, emotional, social, and spiritual dimensions—and culture dependent, in that the experience is shaped in large part by the cultural milieu in which the patient resides. Researchers have identified deficiencies in the access of racial and ethnic minorities to palliative care services¹⁷, suggesting important opportunities for palliative care research to identify the unique perspectives and service needs of culturally diverse populations.

Opportunities

The dearth of high-quality clinical research in palliative care relative to other, non-palliative clinical conditions¹⁸ suggests a clear opportunity to advance the science, and improve the quality of care, for patients afflicted with end stage disease. At the same time, those interested in pursuing palliative care research could benefit from expert assistance in developing methods for the conduct of palliative care trials that will maximize the chance for trial results to be valid, safe, and ethical. Without such advancements in research methods, policies, and procedures, the field of palliative care risks a future where clinical practices are ill informed, where research may be sub-optimally conducted, and, ultimately, where patients will suffer less than optimal care. To ensure that these patients receive the best possible care, we must determine the optimal treatment regimens. As with all therapies, the gold standard continues to be the randomized prospective clinical trial. This goal has admirably been pursued with regard to cancer trials, which focus on cure; it is urgently needed in the palliative care of patients with advanced cancer and terminal disease.

Challenges

Research on issues at the end of life is rapidly growing, and its importance increases as our population ages. There is an urgent need to find better ways to improve pain and symptom management at the end of life, to help people die with dignity, and to comfort the bereaved. Although this research is important, it is not without ethical challenges. Therefore, efforts to improve the standard of palliative care through research and through quality improvement activities must be sensitive to ethical concerns. In summary, conference participants agreed that the ethical issues raised by palliative care research are, for the most part, not unique to this field. The principles of ethical research conduct that guide other forms of research can and should be applied to this field. For instance, the consent process should be careful and thoughtful, with adequate attention given both to an individual's decision making capacity and the voluntariness of his or her decision. Similarly, investigators should pay close attention to a study's design, to ensure that it offers an optimal balance of risks, burdens and potential benefits. Finally, as with any research, a study is only ethically sound if its risks are reasonable in proportion to its potential benefits, and the knowledge to be gained. Thus, palliative care researchers, like researchers in other fields, must demonstrate that their research questions are important, their methods are appropriate to produce valid results, and that their findings will be generalized.

Conclusion

According to legislation it is ethical to withdraw life-sustaining treatment from those unable to decide for

themselves, only when treatment can no longer achieve its intended clinical purpose and cannot provide any benefit. Such decisions should be made on the basis of what is right for that particular individual. The quality of life after treatment is a relevant consideration. Often we have no right answer to such dilemmas. The boundaries within which our decisions must lie should be learned. Knowledge of the relevant laws help, as having a framework for ethical decision-making. There is also a need to recognize cultural influences on decision-making. Finally, honesty to oneself is important; when all is said and done, we need to live with the consequences of our decisions. In the words of Hippocrates, 'The purpose of medicine is to do away with the sufferings of the sick, to lessen the violence of the disease and to refuse to treat those who are overmastered by their disease.'

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