



Original Research Article

Ethical Dilemmas in Care of Patients Admitted to a Palliative Care Unit in South India: A Qualitative Study

Catherin Nisha¹, Johnson Avita Rose²

¹Post Graduate Student, ²Assistant Professor,
Department of Community Health, St. John's Medical College, Bangalore, Karnataka, India.

Corresponding Author: Catherin Nisha

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ABSTRACT

Introduction: Hospice and palliative care is well recognized as the ideal model of care for the terminally ill. However, ethical issues are frequently encountered during the provision of palliative care. Data on ethical dilemmas faced by health care providers in palliative care settings in developing countries is scarce.

Objectives: To identify ethical dilemmas in the care of patients admitted in a palliative care unit in South India and factors related to these ethical dilemmas.

Methods: Qualitative data was collected by in-depth interviews of all the nurses involved in the care of terminally ill patients in a palliative care unit in rural Kerala from November 2013 to July 2014. The data was interpreted, coded and grouped into key domains before analysis.

Results: A total of seven in-depth interviews were conducted, which revealed a number of ethical dilemmas and challenges that the nurses encountered while providing palliative care. It was noted that patients' preferences and decisions were influenced by family members. Dilemmas were not faced while taking decisions regarding hydration and nutrition. There were ethical dilemmas with regards to the place of care, alternative treatment and therapeutic strategy.

Conclusion: This study identified ethical dilemmas with regards to place of care, alternative treatment and therapeutic strategy. Ethical issues in palliative care settings need to be addressed, with a possible role of institutional ethics committees to help in decision-making. Training in ethics for health professionals would assist in solving the ethical dilemmas in palliative care.

Key Words: palliative care; ethical dilemmas; hospice; qualitative study

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 of any country. ^[1] However, ethical issues are frequently encountered by

health care providers in hospice and palliative care. The spirit of hospice has been routinized, institutionalized and medicalized 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 has not been given sufficient importance in the growing accumulation of palliative care

centers. The most frequently encountered ethical dilemmas are truth-telling, hesitancy to use morphine for fear of causing respiratory failure, issues related to parenteral nutrition, difficulty in meeting the needs of delirious patients, place of care and decisions based on financial considerations. [3]

As medical knowledge and technology increase, so do options for healthcare. When decisions arise regarding the care and treatment of dying patients, these medical options present complex ethical dilemmas among health care providers. Many are faced with decisions about the appropriate treatment to ease patient's final suffering. Perhaps decision may need to be made about terminating treatment altogether for a variety of reasons or to give complete treatment. [4] This study presents significant ethical issues related to palliative care, including death and dying. With advances in modern medicine, people are living longer and the number of elderly persons is increasing. As a result, the ethical issues of end of life care continue to gain importance in the society. [5] This study offers a broad introduction to a number of ethical dilemmas faced by health care providers in care for the patients which affect treatment and care practices. Both basic and comprehensive, this overview provides a starting place for those wishing to explore the complex subject of the most frequently encountered ethical dilemmas in a palliative care unit, exploring factors related to it and helps in formulating guidelines for ethical practice of palliative care.

METHODOLOGY

A qualitative study model was utilized to lay the framework of the study. It was conducted at a palliative care unit run by missionaries in Cochin, South India during the period of November 2013 to July 2014 after obtaining clearance from

Institutional Ethics Committee, St. John's Medical College, Bangalore, Karnataka, India. Data was collected by in-depth interviews of all the nurses involved in the care of terminally ill patients in the palliative care unit after obtaining written informed consent. An interview guide was developed and pilot tested to explore participant perceptions.

In-depth interviews were conducted with seven nurses, at which we reached the saturation point of our data. The interviews were conducted by the first author, who was not involved in the clinical care of the study participants. All interviews were conducted in a quiet room at the study site ensuring privacy and audio recorded with the participants consent. Each interview took an average time of 20 minutes per person and was conducted in the local language i.e. Malayalam. The domains of enquiry (Table 1) consisted of open ended questions and were broadly divided into questions that included telling the patient the truth, place of care, therapeutic strategy, use of medication and others. Probes were used to clarify and obtain better understanding of the respondent's views.

Table 1: Domains of enquiry

Ethical dilemmas faced during decision making
1)Telling the truth
2)Decision regarding place of care
3)Therapeutic strategy
4)Hydration at terminal stage
5)Nutrition of the patient
6)Decision regarding blood transfusion
7)Alternative treatment for the patient
8)Terminal sedation of the patient
9)Use of medications

Each audio-recorded interview was transcribed and translated by a native speaker of the local language with adequate knowledge of English. The transcriptions were spot checked by the first author to ensure that they were consistent with the recordings. Confidentiality of the collected data was maintained. Data was analysed using the thematic "Framework Approach"

described by J et al. [6] The analysis was descriptive and was grouped under the relevant codes in the framework. Additional codes were generated as analysis progressed. Subsequently, the data was summarized to derive sub-themes. The sub-themes were then categorized under broader themes describing the data.

RESULTS

Seven nurses working in the palliative care unit participated in this study. They were in the age group of 28-55 years. All the participants were females. Patients who were admitted in this institution were cancer patients, paralyzed patients due to cardio vascular disorders and patients with other chronic illnesses who were terminally ill.

Two primary themes were emerged from the interviews. They were 1) ethical dilemmas faced in encounter with patients and 2) ethical dilemmas faced in encounter with family members.

Ethical dilemmas faced in encounter with patients

Place of care, alternative treatment, hydration and nutrition were the subthemes that were grouped together under the theme.

Ethical dilemmas regarding place of care occurred for many patients. Many of them preferred hospital care and few of them preferred home stay at the end stage of their lives. According to the institution protocol nurses could not take them to the hospital and sometimes hospital admission was not mandatory. Nurses found it difficult to handle the situation. One senior staff said: *“Many patients preferred to go home at their terminal stage; they wanted to spend time with their children and grand children. But children were not willing to take them home....even though institution care was not required”*

Dilemmas concerning therapeutic strategy occurred in the case of some patients and with the use of medication in

few. Few of the patients refused medications at their terminal stage may be out of depression, wherein nurses found it difficult to convince them.

“Sometimes patients will refuse medicines which they were supposed to take....like antihypertensive medications.....diabetic medications.....they say they wanted to die early.....we find it very difficult to convince them and handle the situation.”

Although there was dilemma regarding truth telling for some of the patients during early hospitalization, this gradually resolved with duration of stay. Ethical issues arose regarding hydration and nutrition, wherein patients asked for unnecessary parenteral nutrition, while few patients refused hydration and nutrition at their terminal stage. Conflicts arising from the use of alternative treatment during the hospital stay occurred among a few patients. Many of them preferred Ayurvedic treatment or other modes of treatment for their illnesses.

“Many a time patients insist on other systems of treatment like ayurvedic medicines, massage and sometimes hospitalization which may not be required..... Sometimes even though it is necessary to take them for further diagnosis or treatment, relatives may not be willing for that because of financial constraints.....”

Ethical dilemmas faced in encounter with family members

Place of care, telling the truth, therapeutic strategy and terminal sedation were the subthemes that were grouped together under the theme.

Place of care was a dilemma among health care providers when patients insisted different place of care and the relatives were not willing for the same. Some patients could be taken home, some others had to be taken to other hospitals for further treatment, but the relatives were not able to do so because of financial constraints and

unavailability of human resources. One staff nurse said:

“We come across difficulty regarding place of care when the relatives refuse to take back the patients after relief of symptoms as we have shortage of beds in our centre we prefer home based care once the patient is stable...and does not require medical assistance....but at times relatives may not take back to their houses.....”

Few of the family members and relatives insisted on not revealing the truth to patients.

“We found that the intention and process of telling the truth were often interrupted by relatives.... although this could be gradually resolved through continuing communication.”

The most commonly observed problems with medication were: using herbal treatment instead of prescribed medicine; misunderstandings about the purpose of morphine, and worry about its untoward effects. This created dilemma when relatives insisted on alternative system of medicines and discontinued the routine medications. It added to the dilemmas when patient's families requested curative treatment rather than palliative care at the terminal stage also. Staff nurses also came across dilemmas regarding terminal sedation. Staff said:

“Few relatives insist for sedation even though it was not required....so that patient does not have to suffer.”

DISCUSSION

In our study we tried to assess various ethical dilemmas faced by nurses working in a palliative care unit. Telling the truth was a conflict among them. In Indian culture, it is common practice not to disclose the truth of the illness especially to a terminal ill patient, on the basis of nonmaleficence. This mutual pretence prevails because both sides are unwilling to hurt each other and lack of knowledge of

how to communicate with each other. Nevertheless, evidence suggests that a “good” death is easier to achieve if patients have enough time to arrange their affairs.^[7] However, the nurses reported that the intention and process of telling the truth were often interrupted by relatives. Another ethical dilemma encountered was the demand for hydration and nutrition. Because patients with terminal illness often develop anorexia or dysphagia, parenteral fluids and nutrition are usually requested by the patients. However, inappropriate hydration and nutrition may further increase patients' distress by aggravating conditions such as ascites, limb oedema and gastrointestinal secretions.^[8,9] Meanwhile, use of parenteral hydration and nutrition too early may replace the family's care and make the relationship between the patient and the family more aloof. Improving the quality of life by encouraging more interaction between patient and family is an essential part of palliative care. Some of patient's relatives experienced difficulty in deciding on the appropriate goal of treatment between “cure” and “pursuing better quality of life” and this was not resolved by a longer period of hospitalization. Emphasis on the need for communication appeared to be the only useful strategy in resolving this issue. Staff felt the need of counselors in the institution to handle these dilemmas. A study conducted in Taiwan found that 81% of patients had used alternative treatments such as herbals (51.4%), anti neoplastic diets (34.8%), faith healing (18.1%) and acupuncture (5.1%) during the course of disease.^[10]

The dilemmas not only puzzled the nurses, but also impeded the pursuit of better quality of life and a meaningful and peaceful death. Further investigations are needed to establish guidelines suitable for dealing with these dilemmas.

CONCLUSION AND RECOMMENDATIONS

In conclusion, many ethical dilemmas were encountered in caring for the terminally ill which troubled the staff nurses. Ethical dilemmas faced in encounter with patients were regarding place of care, alternative treatment, hydration and nutrition. Ethical dilemmas faced in encounter with family members were place of care, telling the truth, therapeutic strategy and terminal sedation.

Effective communication between the medical staff and patients and family is essential if attitudes towards these ethical dilemmas are to be improved. Supportive supervision and mentoring is crucial for appropriate decision making and resolving ethical dilemmas in palliative care. Professional development based on good research evidence may help to solve these dilemmas. Education which focuses on medical ethics is crucial for appropriate decision making in palliative care. It is also important to emphasize that relieving the suffering of the terminally ill and providing them with adequate support, is an essential part of the health care system.

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Conflict of interest

The authors have no competing interests to declare.

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