

Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Short Communication

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Cultural Challenges in Implementing Palliative Services in Emerging Countries

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ABSTRACT

Palliative Care is Unique: It is a new specialty that helps patients and their families as fully as possible when faced with a life-threatening illness. The population is aging which means more people will need Palliative Care (PC) services in the future. Palliative care responds to the population's health needs and helps to build a bridge for better understanding amongst all people. Palliative care involves the belief that no life is disposable or dispensable and that each and every human being deserves to be heard and helped. The scope of palliative care is the quintessential scope of the culture of peace.

Background: We have to respond to the needs of public health and provide services of optimal care. To establish a palliative care system in Palestine, it is necessary to identify barriers to provide palliative care service to the patients who are suffering with cancer or chronic illness during treatment or at end-of-life.

Aim: The aim of this study is to identify barriers against providing palliative care in Palestine from nursing perspective.

Methods: Family questions, staff and informal discussion, communication, attitude, psychosocial and emotional needs have been noted as per author's direct observation and experience. The study was done at Pediatric Intensive Care Unit (PICU) at Makassed Hospital, East Jerusalem between February 2014 to February 2017. The study is prospective and descriptive in design.

Results: The findings of this study are based on views and perceptions of patients as well as the health professionals regarding the challenges of providing palliative care which include lack of government strategies, lack of awareness among the professionals, insufficient training for physicians and nurses, family concerns about cost and inadequate financial coverage from health insurance. To establish structured palliative care services, we need to meet the challenges and remove barriers by enhancing knowledge and awareness of healthcare professionals, educate professionals and develop updated standards and treatment protocols.

Conclusion: In Palestine, there are no palliative care services or any other related services or support towards patients and families, especially in case of life-threatening conditions in case of emergency.

KEY WORDS: Palliative care (PC); Barriers; Culture; Quality; Education; Chronic.

INTRODUCTION

Palliative Care (PC) services in the healthcare system in Palestine still remains undefined, with inexistent home care, lack of rehabilitation program and inefficient insurance. The healthcare system in Palestine is unable to meet the needs of its population, forcing patients and their families to rely on international aid in order to receive medical attention. The healthcare system is not equipped to confront many of the devastating illnesses from which the population suffers. Most of the time, the only solution for patients is to request a referral to a Jerusalem hospital, which is only possible if the necessary permission is granted by the Israeli Government.

As a Head Nurse in the Pediatric Intensive Care Unit (PICU) at Makassed Hospital East Jerusalem, I have observed the economic challenges, the patient's efforts, and the suffering of the families. They are unwilling to discuss and accept issues related to death due to the lack

of family health services and adequate methods of pain relief. This situation should be improved by introducing an awareness of a holistic approach to patient and family needs. Caring for a critically ill patient is always stressful and difficult.¹ Planning must be made for end-of-life that should be dignified. Because of increased mortality rates and the admission of adults as well as children with life-threatening illnesses to the Intensive Care Unit (ICU), palliative care is essential. We need to have a palliative care team that offers referral services to community agencies for practical services and provides community resources to help meet family needs and strengthen coping strategies for family members assisting in the treatment and care of their loved ones. Untreated pain leads to greater suffering and further complications, resulting in longer hospital stays and greater costs to families.

BARRIERS TO PALLIATIVE CARE

Barriers to the provision of palliative care is a major problem. Governmental health ministries and non-governmental organizations (NGOs) have to standardize and coordinate palliative care services and educate healthcare providers.² Palliative care services do not exist because of a lack of Government strategies.³ Cancer incidence and death rates are rising, and unfortunately many patients are diagnosed in advanced stages of their illnesses.² Palliative care is an important public issue due to aging of the population.⁴ The increase in the rate of cancer in Palestine is partly due to lifestyle factors such as heavy smoking and less physical activity levels, which increase the risk of cancer.⁵ One barrier is a general lack of awareness among the professional caregivers and the general public about what palliative care is.⁶ They think that palliative care is for people close to death. Healthcare providers are influenced by their own cultural and personal values; patients rely on physicians to guide them in end-of-life care, but this care is usually requested by relatives. Unfortunately, there are numerous problems in making early diagnosis because many patients become late in their checkup and have advanced stage of cancer.⁷

There aren't enough adequately equipped public hospitals because of limited resources. In our culture, decision making is family centered.⁸ Illness is shared with the family and is linked with not losing faith in a cure.⁹

LIMITED PROFESSIONAL TRAINING IN PALLIATIVE CARE

Physicians and families often feel that withholding information is in the best interests of the patient.⁹ The family is responsible for managing the information and patient treatment during illness.⁹ Medical professionals focus on curing the disease, which limits palliative care development.² Many patients with chronic diseases suffer unnecessarily during treatment and at their end-of-life.¹⁰ All patients should have a right to get palliative care services.¹¹ Our challenge is to provide a healthcare service that is equivalent and accessible to all individuals in the country. The family is concerned with the cost of treatment and worried about

inadequate financial coverage by health insurance, insufficient training of physicians and nurses and a lack of familiarity with various prognostic tools.¹² Additionally, there are strong cultural and social attitudes against talking about death; some family's view on discussions about end-of-life and are just limited to not giving up hope, and are not comfortable with end-of-life conversations with physicians.¹³ However, the family wants the physicians to be accessible and to provide honest and complete information, and not to give prognostic information to patients, which may lead to false hope and feelings of anger.

Barriers to palliative care are a major health issues. The Makassed Islamic Charitable Society Hospital is considered one of the leading medical institutions in Palestine. Currently, it has a staff of 750 employees, which includes 48 specialized doctors and consultants, 74 residents working in the training program sponsored by the hospital, 3 emergency doctors, 344 nurses, 77 technicians, 146 administrators and 40 hired employees. As the Head Nurse of the PICU which cares for children with a chronic life-limiting illness, the work can be emotionally and physically challenging. Just as families struggle with whether they are making the right decisions or not, care providers struggle as well. Increase in advanced medical technology and in dealing with chronic diseases in children prolong the dying process. Palliative care is thus essential in the PICU because of the increased mortality rate and the presence of life-threatening conditions in patients admitted to this unit. Palliative care helps patients and their families as fully as possible when faced by a life-threatening illness. It is a human right for everyone to receive pain relief and have access to pain treatment. Palliative care is essential in the PICU to provide relief to the children as well as their families from suffering.

WHAT NEEDS TO BE DONE?

As there is no organized structure for palliative care services in Palestinian hospitals, we need to develop teamwork to provide high quality care, to provide a support system, and to provide the best quality of life (QoL) for all individuals. We must focus on the ways that must help to decrease physical and emotional suffering throughout the life and to achieve the best mode of treatment for the patients and their families. We have to strive to make palliative care available for all.

From direct observation and experience as a Head Nurse in the PICU in Makassed Hospital, I believe that all family questions, staff and informal discussions, communications, attitudes, and psychosocial and emotional needs must be noted. Families are confused about trying to cure the patient's disease or just managing pain. There are no support services for the patients and family, especially in the case of an emergency life-threatening condition.

SUFFERING

I have observed how the patients and families suffer in different

ways. For example, they are unwilling to discuss the economic costs and efforts that must be made, and the issue of death due to the lack of family health services and adequate pain relief. The patient gets support from family members, not from professionals. We need a palliative care team to provide family education and to develop and strengthen coping strategies for family members assisting in the treatment and care of their loved one. Families and friends need a reliable support system to provide the best QoL possible for the patients at end-of-life.

Makassed Hospital is a referral hospital from the West Bank and Gaza Strip as well as East Jerusalem. The PICU that I lead at Makassed Hospital provides comprehensive services for a variety of critically ill medical and surgical young patients with acute life-threatening diseases or injury such as when an infant or a child becomes critically ill and requires complex surgery, or is in need of very close medical attention for any reason, the beds in the ICU are available to them. The PICU has 9 beds for medical and surgical trauma. It is a multidisciplinary unit which admits all children from newborns up to and including 14.5 years of age. Most of the time we also care for the family who accompanies the child. Because of the advances that have been made in medical treatment, more children with life-threatening conditions survive for a longer time and require a longer period of palliative care. In Palestine, it is common to get help from the extended family in caring for both healthy and ill children.

No patients' representative is available to help families, cope effectively with difficulties that may be present, or to help alleviate tensions. There is no training in palliative care at the undergraduate level; palliative care has not been integrated in their professional training programs.¹⁴

WHAT WE HAVE IN MAKASSED HOSPITAL

Previously, patients with chronic conditions failed to receive adequate care because of the poor quality of health services. Typically, the healthcare providers struggled and were left wondering if they did all they could, they feared death, and being confused. Nurses, too, struggle with difficult decisions that parents and families often have to make. Caring for the critically ill patient is always stressful: and,

Mostly we offer: Post-operative care for patients, pain control and management (as much as possible, but not enough), and recreational activities; support; however, mostly by family members.

What we have to do: We must respond to the population's health needs and provide insights into healthcare services and the needs of palliative care for parents, children and extended family. Palestinian hospitals lack palliative care. We need to provide a support system for family and friends to achieve the best QoL for patients and their families with a concern for comfort rather than cure.

CULTURAL AND RELIGIOUS BELIEFS

There is an increasing prevalence of chronic disease, with advanced medical technology prolonging the dying process. As technology improves, sick people are able to live longer, but this requires more effective pain and symptoms management at the terminal stage. Traditional families treat illness as a top secret. Parents and medical providers refuse to talk about issues of death and dying with children who have a life-threatening disease, although children are usually aware that they are dying.¹⁵ Thus, caregivers need training in understanding the psychosocial aspects of children and death, and the techniques of counseling. For example, the patient's siblings are often forgotten members of the family during the time that their parents focus their attention on the ill child. With services in place this could be prevented.

BENEFITS OF PALLIATIVE CARE

If we have Palliative Care Teams, large number of families will come to know easily about how to get involved in patient's care properly. Team members provide family education to develop and strengthen coping strategies for family members assisting in the treatment and care of their loved ones.¹⁶ This improves QoL by reducing or eliminating pain and supporting the patient, which also builds staff confidence and satisfaction.¹⁷ People with life-threatening diseases will live more comfortably. After looking at other models of palliative care, team members will offer referral services to community agencies for practical services and community sources to meet the family's needs. It will effectively manage and coordinate the care of the critically ill patients by maintaining high standards of care in the ICU. Services will improve for patients by continually evaluating the effectiveness of nursing intervention, by learning new skills, and by having families help loved ones to deal with issues of grief. Parents of chronically ill children will be involved early in discussions of daily scheduling and behavioral expectations to help establish realistic goals.

CONCLUSION

Doctors and nurses should have awareness and skills in the area of palliative care. When the physical condition of patient deteriorates, he/she needs palliative care and we must strive to make palliative care available to them. It must be available to all populations and be given by a team of people knowledgeable in end-of-life care. They should provide the best QoL for individuals, with a focus on life, not on death. Therefore, nurses and doctors need proper education and training to provide palliative care.

RECOMMENDATION

Palliative care is essential to relieve suffering in children, adult and families. We must try to do our best to improve access of palliative care in Palestine.

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