

NEEDS AND CARING BEHAVIOURS OF NURSES IN PROVIDING QUALITY CARE TO TERMINALLY ILL CANCER PATIENTS IN ONCOLOGY UNIT OF A PUBLIC HOSPITAL IN KUALA LUMPUR, MALAYSIA

By

SANTHNA LETCHMI PANDURAGAN

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CHAPTER 1

INTRODUCTION

This chapter presents the background of the study, statement of the problem, purpose of study, significance of the study and definition of terms used in the study.

1.1. Background of study

Nursing as a professional discipline places the greatest demands on the development and the refinement of the caring concept of nursing. Historically a nurse's role consisted of only providing care and comfort to the needy (Craven and Hirnle, 2003). Today with the advancements in technology, health promotion and prevention, nursing has widened the functions of the nurses

1.1.1. Nursing in the present times

At present, just as the health system is continually evolving, so are the community of nurses; it is necessary for them to remain effective in the patient community they serve. Nurses integrate community involvement and knowledge about the entire population with personal, clinical understanding of health and illness experience of individuals and families within the population (Allender, Rector & Warner, 2010). Modern nursing has expanded and emphasizes not only on treating the disease but also preventing illness, restoring optimal wellness through rehabilitation, and educating the patient and the family (Cooper & Gosnell, 2015; Harkreader & Hogan, 2004). This aspect of nursing also includes assisting patients with terminal illness to maintaining comfort and dignity in the final stage of illness.

The primary goal of the community of nurses is to ensure optimal physical, mental, and social well-being of the patient (Cooper & Gosnell, 2015) by engaging in several important roles, which not only develop patients but also ensure that the surrounding community is educated to understand about their illnesses and be more careful about their problems. Nursing as a whole promotes health and assists patients to move to a higher level of wellness (Cooper & Gosnell, 2015).



1.1.2. Caring for terminally ill patients

Lately the issue of terminally ill cancer patients have been repeatedly discussed, and it has been suggested that nurses lack the skills and competencies required to care for these patients (Arantzmendi, 2012),).The International Agency for Research on Cancer had estimated that there were 12.7 million new cancer cases in 2008 worldwide and according to WHO, 2014, 14 million new cases of cancer are diagnosed around the world yearly (THE STAR, 12thAugust, 2015). All these people would eventually require palliative care (Ferlay, Shin, Bray, Forman, Mathers, & Porkuus (2010). In Malaysia, approximately 40,000 people are been -diagnosed with cancer each year, (MAKNA, 2007) and as a consequence, experience a variety of psychosocial and emotional responses.

Thornton, 2012; Berg and Danielson (2007) explain that "caring" in the nursing profession means providing holistic care to patients; however in the oncology context, caring generally focuses on patients with chronic and life threatening illness and mainly entails providing emotional and psychological support to both patients and their families. Davis (2004) asserts that people with cancer especially terminal cancer suffer significant emotional morbidity and psychological distress and face physical issues related to their cancer treatment, end of life issues (EOL) and survival issues.

The prevalence of psychosocial distress in the patient ranges from 20% to 60% (Zabora, BrintzenhofeSzoc, Curbow Hooker & Piantadosi, 2001) and evidences suggest that 12% to 30% will experience clinically significant anxiety problems. Kruijver, Garner, Visser and Kuijer (2006) point out that life threatening disease such as terminal cancer are traumatic events and demand a great deal of adaptability from patients, caregivers and their environment.

Nursing involves interaction with patients on various levels which usually depend on the unique set of circumstances and the patient's individual personality. Patients expect quality nursing care from nurses and to them quality nursing can only be provided by nurses who are competent, caring, supported by professionalism and deliver care with an appropriate demeanor (Izumi, Baggs & Knafi, 2010).

1.1.3. Caring behaviors expected by terminally ill patients

Cancer care especially for terminally ill patients require special skills and qualities from nurses and other health professionals. Active listening skills help nurses to establish a relationship and helping patients cope can reduce distress due to illness (Green et. al, 2005). What nurses do and how they communicate with patients will make a difference in the management. It is important that the

nurses develop trust and rapport to create a supportive relationship between themselves, the patient and caregivers. Nurses need to spend sufficient time with dying patients to create an environment that is conducive for a peaceful and dignified death. Assisting dying patients with functional ability and the hygienic status of the body are fundamentals of nursing care. Achieving adequate symptom control is another important issue.

Most of the time, in the cancer units, the patients' major problems are caused by the initial shock of diagnosis, particularly when the cancer has been diagnosed rather late and patients may be on the final stages of the disease. Ross (1969) describes in detail the psychological changes that occur with great intensity in cases where diagnosis comes as a shock for patients. Some go into denial and do not recover from this stage, while others may deny that there has been any alteration to their bodily condition, which may affect them emotionally. Still others will take a while to accept what has happened to them. Very few patients are usually able to maintain psychological balance and face the situation bravely.

Miller (2009) describes the experience of cancer as a combination of physical, emotional and social challenges that occur in phases. Support is also needed financially which also means providing practical help such as transport to medical appointments or assistance with finding information about a particular type of cancer. The failure by a health care provider to address these needs of cancer patients and their caregivers is a failure to the effective treatment of the patient's illness.

Krishnasamy, 1996; Wortman & Conway (1985) explain that people who are physically ill, especially cancer patients may find that their social relationship not only fail to buffer them from the stress of the illness, but actually constitute an additional source of distress. This conflict results in behavioral responses which are damaging to the patient and results in the inability to discuss about the disease with nurses or doctors (Wortman & Dunkel-Schetter, 2010). Sometimes the patients may try to avoid the health care professionals and nurses may experience negative behaviors among patients (Wortman & Dunkel-Schetter, 2010).

The patients have to make a variety of complex decisions as a result of the cancer diagnosis and usually they are emotionally and physically unable to tackle these problems. The emotional support provided by health professionals in relation to decision making usually focuses on positive health outcomes; thus, nurses are usually the ones in the best position to support the patients throughout the disease process.

Krishnasamy (1996) highlights that nurses continuous support to patients can prevent patients from suffering inferiority complex or feelings of low self-worth and helplessness. Many providers of health services, including those in oncology and those who deliver health care for other complex health conditions recognize that psychosocial problems can have both direct and indirect effects on health. The provision of optimal care for patients with cancer involves both physical and psychological aspects (Botti, Endacott, watts, Cairns, Lewis & Kanny, 2006). Health care professionals can help reduce patient and family distress by means of physical care in the form of interventions and strengthening of the patient's own coping resources.

Terminally ill patients have very special needs which can be fulfilled if nurses can take the time to sit and listen to them and understand what these needs are. It is important for nurses to let patients and family know that the nurses are ready and willing to share some of the concerns. Providing clear and accessible information is important and necessary; therefore, (Krimshtein, Luhrs, Puntillo & Cortezet, Livote, Renrod, & Nelson, 2011; Corner et al. 2003) insist that nurses develop their communication skills.

Communicating effectively means patients are able to receive and interpret information and are in a position to clearly express their needs for assistance (The National Academias, 2008). Schuster and Nykolyn (2010) posit that nurses use communication 24 hours a day and failure to communicate may lead to patient harm. Patients should be comfortable in enquiring about their care and in deciding the best choice of treatment for them and nurses should be equally prepared to provide the appropriate information. A study carried out by Herbert, Moore & Rooney, 2011; Kwekkeboom, Vahl & Eland (2005) reveal that nurses often feel ill-equipped to provide psychosocial care, communicate and deal with patients' questions due to limited knowledge on palliative care. This was due to the fact that, the basic curriculum did not prepare them adequately to provide end-of-life care to patients. The authors continued to say that due to these deficiencies, end-of-life dilemmas and barriers to provide quality care to terminally ill patients are common in nursing practice.

1.1.4. Challenges faced by nurses as caregivers

According to The National Academies (2008), numerous cancer survivors and their caregivers report that cancer care providers did not understand their psychological needs and in fact did not consider psychosocial support to be an integral part of quality cancer care. Rodin (2008) posit that the provision of effective psychosocial care improves the outcome for cancer patients. Nurses need to attend to the different needs of the patients while helping them to recognize these differences. However providing care for cancer patients can place a specific burden on health professionals. The effectiveness of the care provided depends on the training, skills, attitude and beliefs of the health care staff (Botti et al., 2006).

Caring for dying patient is emotionally trying and challenging for nurses. When nurses are present in the face of suffering, they need to find ways of using themselves therapeutically when medical and curative limits have been exhausted. In fact, this task can provide deep professional satisfaction (American Board of Internal Medicine, 2008); nevertheless, the question arises as to whether nurses are knowledgeable enough and readily available when the patients need them.

Ganz (2009) posits that cancer survivors face many unique challenges which they need to cope. In the short term, the patients require to have an understanding of the type of treatments they will undergo and the type of followup that is necessary. It is generally recognized that cancer presents the nurses and other health practitioners with a unique and dramatic set of challenges. She further states that providing cancer care leads to characteristic behavior changes among nurses including arrogance, irritability, rigidity, emotional distance and avoidance.

As far back as 1966, Saunders pointed out that the nurses tried to avoid being with the dying patients by hurrying, by talking about superficialities and giving no space for patients to talk further. She pointed out that it was crystal clear that "Don't ask me too much" attitude was obvious in these nurses, and that the confidence to stand alongside dying patients no matter what happened to them depends on the nurses having the necessary knowledge, skills and support to understand the patients' needs and respond to them.

Hodgkinson and Gilchrist (2006) explained that a demanding work schedule, limited support from higher authorities and lack of confidence in talking about sensitive and personal issues with the patient can contribute to stress and burn out among nurses. In turn, this can negatively affect the quality of psychosocial care provided to patients.

As a summary, nurses as part of the health community have to play an important role in educating and caring for patients and more importantly for terminally ill patients who need special attention.

1.2. Statement of the Problem

Life expectancy in Malaysia is on the increase due to improvements in health care services (Ministry of Health, Malaysia, 2011) In turn, this has resulted in an increase in the number of Malaysians suffering from chronic illnesses such as cancer, organ failure and neurodegenerative diseases (Palliative Care Services Operational Policy, 2010). Dr. Richard Lim (2010), National advisor for Palliative Medicine services, states that "Palliative Care is an important area to develop if we want our health services to be of good standard". He also emphasized that palliative care is a service that must be fulfilled as a basic human need to comfort people who suffer from their illnesses. Life threatening illness especially cancer in particular, may require complex physical intervention; however this can also involve complex emotional issues for both patient and nurses (Steward, 2003) even more so if the nurses are not able to provide the care needed.

Healthcare professionals encounter an increasing number of patients with advanced terminal illness and in fact should be prepared to provide reasonable options to them. Terminally ill patients should be able to receive high quality palliative care throughout the illness trajectory, health care providers should seek not only to minimize patients' suffering, but also to ensure that patients receive good-quality care at all times (Palliative Care Services Operational Policy, 2010). The nurses' role in caring for the terminally ill cancer patients differ from that related to general patients, due to the complexities of each person's illness and its effects on the individual.Mellon, Northhouse and Weiss (2006) explained that it is not only the patients but those closely connected to the patients during the phases of uncertainty are impacted both emotionally and psychologically. Halldorsdottir and Hamrin (1996)too explain that people suffering from terminal cancer experience tremendous changes involving the lived experiences of uncertainties, vulnerabilities, isolation, pain and other symptoms which affects not only the patient but also others around them, as roles have to be redefined due to health deterioration.



Very little empirical research has been carried out by nurses on care for terminal ill patients in Malaysia. A study conducted by Pathma, Lee, O'Connor & Barnett (2013) in Malaysia indicated, that to enable nurses to provide effective and quality care to the terminally ill patients and the family, formal palliative care education is necessary. This had also being informed by Oliver (2014) that to prevent obstacle in the provision of end of-life-care, nurses need to be educated on various aspects of quality EOL and be properly informed regarding the process and treatment possibilities.Gordon (2006) states that to gain the respect of the patients and other health care professionals, nurses should be able to communicate the knowledge and skills required for professional care. This is only possible through education and training.

Most of the time, not much importance was provided to terminally ill patients because nurses usually considered dying as a normal part of a patient's life. A study conducted by Santhna and Zaidah (2007) in one of the hospitals revealed that nurses did not show much interest in caring for the terminally ill patients and the nurses failed to understand their needs. According to Sahlsten, Larsson, Plos & Segeston (2005) the disregard for patient care could be due to lack of theoretical or practical knowledge required for the management of terminally ill patients. There was indications that quality care was lacking, as there were many complains that nurses do not know how to manage patients' problems. This could be due to the fact that, nurses considered terminal illness as something normal in adults (Gardiner, Cobb, Goh & Ingelton (2010). This was due to lack of knowledge on terminal illness. The gap could be due to the lack of formal education on EOL in both the basic and bachelor's nursing curriculum.

The present study was conducted to better understand on how nurses in this public hospital manage the terminally ill cancer patients and what they were lacking in knowledge and also other problems that hindered quality care to the terminally ill patients.

The main problem that the study sought to address is that there are some indications that quality care towards terminally ill patients is lacking and a study needs to be conducted to better understand the problem. This curiosity urged the researcher to read in depth on literatures of nurses working with terminally ill patients and this later transpired the researcher to sought solution for this crucial problem especially in the local setting. As the elderly population in Malaysia is increasing (Ministry of Health, Malaysia, 2011) it is even more crucial that the community of nurses are educated and developed towards providing quality services to terminally ill patients. The other important aspect is that, by critically analyzing the care provided by the nurses, it will help to scrutinize the nursing curriculum to add in components related to care for the terminally ill patients.

1.3. Purpose of the study



As health care services improve in Malaysia, so does the life span; this means in the coming future more nurses will be caring for increased number of dying patients. Thus, the general purpose of the study is to explore and better understand the practice of nurses towards terminally ill patients in a public hospital in Malaysia. To this end, a case study analysis of nurses, the head nurse, patients, caregivers and a doctor was carried out in an oncology unit to contribute to a more complete understanding of the type of care provided by the nurses to the terminally ill patients. Other intervening factors like demands on the nurses from the patients, families, doctors and management were considered as well, since this may also be contributing factors to nurses' behavior towards providing care to terminally ill cancer patients. This case study was carried out in an oncology unit in a public hospital. A qualitative method was used to get an insider view of the nurses, patients, head nurse, caregivers and doctor of the overall situation related to the needs and caring behaviors of the nurses towards the patients in the ward. To guide the research, the following questions were posed:

1.4. Research questions

- 1. What are theeducational needsof nurses to provide quality care to the terminally ill cancer patients? Is there a need for nurses to be re-trained?
- 2. What does "quality care" for terminally ill cancer patients mean to the nurses in the oncology ward?
- 3. What type of caring behavior do patients expect from thenurses?
- 4. What are the barriers affecting caring behaviors of the nurses towards patients?

1.5. Significance of the Study

ii.

The significance of the study can be summarized as follows:

- i. The findings will provide data on how nurses can provide quality care to patients and contribute to the existing knowledge by addressing the gaps in the knowledge on care provided by the nurses working with terminally ill cancer patients and the care received by the patients. The study attempts to contribute to the existing knowledge by drawing on individual accounts of the experiences of nurses, a head nurse, terminally ill cancer patients, doctor and caregivers. It will also help to identify the needs and caring behaviors of nurses towards the patients' families.
 - The four year Bachelor of Nursing Curriculum in public universities in Malaysia offers a module on Oncology Nursing (4 credits) in year 3. The findings of this study will augment information on teaching and learning related to the care and management of terminally ill patients. The findings are expected to indicate a need for greater emphasis on clinical exposure in order to practice psychological aspects of care.

iii. This study may provide insight into how to improve existing educational programs for nurses serving in cancer units or palliative care units. The study may also trigger the establishment of a palliative care program at a postgraduate diploma or master's level.

The health industry has always been dynamic and constantly evolving and healthcare professionals must stay current in order to remain relevant to an industry with an increasing number of elderly patients with chronic diseases (Naughton, Bennett & Feely, 2006). With the increasing cancer population, the demand for EOL care is also increasing; thus, the provision of palliative care programs is no longer optional. The issues presented and discussed in this study may help incite serious focus on quality care.

iv. Quality care is the ultimate goal of any services related to patients. The findings of this study will enable the researcher to formulate a framework for quality care that can be applied to any setting that provides health care to patients. The framework explains that, it is not only the needs and caring behaviors of nurses but the combined effort of the management, multidisciplinary teamwork and with high standards of nursing by utilizing the nursing process, the community of nurses can be developed to provide the care. This will eventually assist nurses to provide quality nursing care to the terminally ill patients and also to educate and develop the community towards better care.

1.6. Limitation of the study

The purpose of the study is to understand the educational needs and the caring behavior of nurses in providing care to terminally ill patients in an oncology unit, in a public hospital in Kuala Lumpur. The study relies heavily on the nurses as the primary source of data, data provided by patients, caregivers, head nurse and doctor was also taken into account as it was supposed to add on to enhance data provided by the nurses. The opinion of any individual are biased by the position from which they observe. It is quite difficult to determine that all the individuals involved as participants are knowledgeable and have the ability to articulate their thoughts well.

Another limitation is the generalizability of the findings. The researcher makes no claims that the data from the study will reflect the experience of all nurses, patients and caregivers in other oncology units. The findings are better understood as a conceptual way of thinking about experiences of nurses, patients, caregiver, head nurse and doctor in an oncology unit.

1.7. Operational definition of terms

The meanings are clearly explained for the key terms used in the study as necessary for the study.

Caring behaviors

Caring behaviors are actions that are characteristic of concern for the well-being of a patient, such as sensitivity, comforting, attentive listening, honesty and nonjudgmental acceptance (Mosby's Medical Dictionary, 2009). This includes the close relationship that a nurse creates when interacting with the patients and the caring attitude of a nurse towards the dying patient and the family. In this sense, the nurse provides holistic, palliative care that focuses not only on patients' physical needs but also their social and psychological needs.

Care giver

The term family caregiver and informal caregiver refer to an unpaid family member, or friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing and taking medications to tube feeding. (Reinhard, Given, Petlick & Bernis, 2008). He/she too sometimes require needs support from the health care staff as the as he/she too are emotionally drained by the burden of caring.

Competent nursing community

The legal capacity of a nurse to perform an act and understand its impact. It is a community of nurses working with terminally ill cancer patients who possess the knowledge, skills and attitude (appropriate behaviors) to provide care and are able to identify and manage problems encountered by the terminally ill cancer patients and the significant others.

Needs

Nurses have to be properly equipped with the necessary knowledge, skills and caring attitude to manage patients who are suffering from cancer and terminal illness. In the present study, needs refers to, what nurses actually require in order to cater to the needs of the terminally ill cancer patients. For instance, do the nurses have the knowledge and experience to deal with the psychosocial needs of the patients and families who are emotionally and physically drained? What else is needed by nurses to be able to provide the best care to the patient?

Oncology Unit

This is the unit that serves patients ranging from young adult to older adults in the diagnosis and management of a variety of acute or chronic malignancies. The present study will be conducted on an oncology ward where patients with malignant tumors are placed. Some patients may have multiple cancers and specialized care is provided to these patients. This ward caters to both oncology and terminally ill patients because a special palliative ward is not available in the present public hospital.

Palliative care

This describes an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."(WHO, 2009). This is care provided to persons who are in the final stages of their life and is also known as supportive care or hospice care.

Psychosocial support

Psychosocial support involves the culturally sensitive provision of psychological, social and spiritual care (Hodgkinson & Gilchrist, 2008). It is a specialized care given to patients undergoing a great deal of distress due to the strain arising from cancer and its symptoms and is given to terminally ill cancer patients who are facing imminent death. The psychological care of a person with cancer begins from the time of initial diagnosis and continues through to the patient's death and the period of bereavement and involves all members of the treatment team, from family to caregivers.

Psychological problems

Are issues such as excessive anxiety, depression which may be due to the cancer experienced by the terminally ill patients and which the nurse must identify and solve according to patient's need.

Quality care

Quality care is the degree of excellence observed in nursing care delivery to patients (Leinonen, Leino-Kilpi & Stalberg, 2001); that is, in the present study, the holistic care provided was as needed by the terminally ill patients. It meets not only physical but also the emotional, psychological, cultural and spiritual needs of the patients.

Staff nurse

Staff nurses are registered nurses who may or may not have undergone training in the care of the terminally ill patients or rely on experience gained in the course of working with the terminally ill patients.

Support

Support is basically giving assistance. It relates to aspects of care that are psychological in nature wherein nurses actively listen to patients, or perhaps hold the hands of someone who is dying. Sometimes support is also given to the family members of a dying patient because the family also bears the burden of the dying patient.

Terminally-ill patients

A patient is considered terminally ill when their estimated life expectancy is six months or less, under the assumption that the disease will run its normal course (Wikipedia). Cancer patients who are in the final stage of illness and awaiting death where treatment may slow down disease's progression for some time but will not cure or have any substantial impact on the patient.

Therapeutic relationship

Therapeutic relationship involves a situation in which the nurse is willing to create a relationship with the patient in order to provide the healing care as needed by the patient. This relationship forms the basis for caring which is the hallmark of nursing practice. The therapeutic relationship is based on a belief that a person has a natural drive towards health (Watson, 2005).

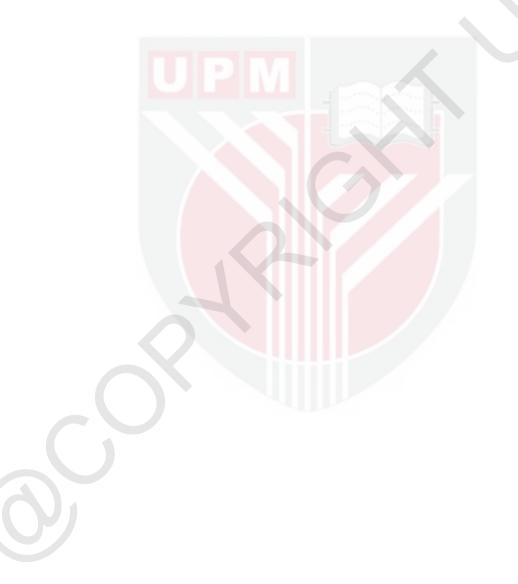
Ward management

The management responsibilities of the head nurse are primarily concerned with activities to ensure the work in the ward runs smoothly. The function of the head nurse involves delegating duties and responsibilities according to qualification and abilities. The head nurse also overlooks activities of nurses and works towards ensuring quality care for the patients.

1.8. Summary

The chapter provides a brief history on nursing in the present times, the challenges faced by the community of nurses to provide care to terminally ill patients. The chapter also describes the problem statement, purpose of the study, significance of the study and concludes with the operational definitions.

The following chapter provides a comprehensive review of literature surrounding caring theories and terminally ill patients.



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