

# Needs and satisfaction on palliative care among cancer patients with regard to quality of life during hospitalization

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## Abstract

The study was conducted to explore the experiences of adult cancer patients with regard to meeting their palliative care needs and satisfaction to maintain their quality of life during hospitalization.

Qualitative study design was employed to explore experiences of patients with regard to meeting the palliative care needs and satisfaction. The target population for this study was patients at National Institute of Cancer, Maharagam (NICM), Cancer Home (CH), Maharagama, Shantha Sevana Hospice (SSH) and Ceylinco Oncology Unit (COU), Colombo, Sri-Lanka. Purposive sampling technique was used to select participants. In-depth interviews were conducted using validated interviewer guides. Trustworthiness of the qualitative study was maintained. Data saturation was reached at 16 in-depth interviews with patients. Phenomenological-hermeneutic approach was followed to analyze qualitative data and thematic analysis was performed. Data analysis was done concurrently with data gathering.

The identified main themes were *caring, seeking more information* and *experiencing psychosocial support*.

Palliative care needs of adult cancer patients were well identified by the nurses and the level of satisfaction of patients regarding provision of physical and psychological care was high. However, the study showed that patients need more information, counseling and homely environment to maintain their quality of life.

Key words: Palliative Care, Cancer, Need Assessment, Satisfaction

## Introduction

The Majority of cancer patients worldwide are in advanced stages of cancer when they come to the hospital. At this stage, pain relief and palliative care may be the best realistic treatment options to offer. The basic philosophy of palliative care is to achieve the greatest quality of life for patients even when their illness cannot be cured. Provision of palliative care through comprehensive management of the physical, psychological, social, and spiritual needs of patients (1), while remaining sensitive to their personal, cultural, and religious values and beliefs is a major role of a palliative care nurse. According to World Health Organization (WHO) (2), it is an approach that improves the quality of life of patients and their families facing the 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.

Cancer is one of the non-communicable diseases (NCDs) and according to WHO, Sri Lanka ranks the highest in NCDs in Southeast Asia with a prevalence of 22%. Cancer trend in Sri Lanka appears similar to that observed in Western countries (2) and is steadily on the rise. According to the latest data (2006) gathered by the National Cancer Control Programme (3), the country's cancer incidence rate has doubled since the eighties. Second leading cause of death in Sri Lanka is Neoplasms (4). Out of 25 districts, the second leading cause of hospital deaths was Neoplasms occurring in Colombo, Galle and Mulattivu districts (4). In Sri Lanka there is a rapid rise in adult cancers of all types (3). It is estimated that 18,000 new cases of cancer were reported for the year, 33% of them ending in death within a year (5). Number of newly registered patients at government cancer units in 2014 was 26,341 (4).

Patients with unbearable illnesses, particularly cancer, need special care as they have significantly varied special needs. Palliative care helps hospitals to provide cost-effective, high-quality care in an appropriate level to reduce hospital length of stay, proceed with appropriate treatment, and reduce the use of non-beneficial resources (6). Singh (7) stated that the main focus of palliative care services is to improve patients' quality of life, which he defined as the subjective evaluation of life as a whole. Palliative care has been well researched specially with regards to patients with cancer in many countries; however, there is paucity of research publications on this subject in Sri Lanka. Therefore, this study was undertaken to provide better understanding of the experiences of adult cancer patients with regard to meeting

their palliative care needs and satisfaction to maintain their quality of life during hospitalization.

## **Method**

A Qualitative study design was employed to explore the needs and level of satisfaction of adult cancer patients regarding their experiences while receiving palliative care from nurses. The target population for this study was patients who received care at oncology wards in Sri Lanka. Participants were recruited purposively from the NICM, CH, SSH and COU, Colombo, Sri-Lanka. Validated interview-guides were developed and used to conduct In-depth interviews from consenting participants about their needs, satisfaction and quality of life. Ethical approval for the study was obtained from the ethical review committee of the Faculty of Medical Sciences, University of Sri Jayewardenepura. Approval was obtained from the Ministry of Health to conduct the study at NICM (Which is now known as Apeksh Hospital) and permission was obtained from the Cancer Society and board of management of the COU. According to the inclusion criteria male and female patients who were above 18 years and diagnosed to have cancer were selected. Those who were unconscious, semiconscious, cognitively impaired or could not comprehend Sinhala or English languages were excluded. Each participant provided written consent and selected an identification number that was the only identification used on any documentation related to the study to ensure their anonymity and confidentiality.

Data were collected from February to September 2010 using the semi-structured interviewer guide while the patients were in hospital, to explore the needs and their level of satisfaction on palliative care services provided to them. Ten (10) patients from NICM, two patients from each of CHM, SSH and COU were interviewed.

Data saturation was attained at 16 in-depth interviews with patients (n=16). Interviews were tape-recorded and each interview lasted approximately 30 minutes. All the individual interviews were done after making prior appointment. They were done while the patient was lying on his/her own bed. The ward sister or nurse in charge of each ward was informed before taking each patient for the interview in order to make the patient relax. Phenomenological approach was followed to analyze qualitative data and thematic analysis was performed.

### **Data Analysis**

Thematic analysis was done with the data gathered from in-depth interviews of the patients at the institutions. Patients lived experience on palliative care was collected to come to a fuller grasp of what it means to the human world (8). To ensure the trustworthiness of the qualitative study Guba's model (9) was used. Guba's model is based on identification of four aspects which are credibility, transferability, consistency and neutrality. Rigour was enhanced through these four aspects. The recorded information from the in-depth interviews of the patients were replayed and transcribed verbatim following the completion of each interview with special focus on describing the meaning of the lived experience. This transcription process helped the investigators to become better intimated with the conversations recorded and enabled deeper reflections on what the interviewees had said and how these experiences were expressed. Each written transcript was read several times while listening to the corresponding audio recordings to ensure accuracy of the transcribed record and to come to a better overall understanding of each participant's experience. The significant statements and ideas of the transcripts were highlighted to identify the thematic areas. Themes were identified by manual coding and

thematic analysis was done. Data analysis was done concurrently with data gathering.

### **Results**

Sixteen participants consisting of male (43.75%) and female (56.25%) patients with ages between 26 and 82 years were purposively recruited for informant interviews. The period of hospitalization for these patients ranged between 2 weeks to 16 weeks and they were from five provinces of the country with a diagnosis of different types of cancers such as leukemia, lung, oesophagial, breast, prostate, bone, oral, thyroid, uterus and bowel cancers. Except for the general characteristics three key themes identified out of the above interviews. They were *caring, seeking more information and experiencing psychosocial support*.

#### **Theme 1 – Caring**

Which has four sub categories: feel high satisfaction; motivate to do religious activities, receive individual attention and dedication to nursing profession.

Narratives of the participants at the beginning of the interview provide evidence that patients are receiving appropriate care.

Participant – 1, was from Southern province of Sri Lanka. Before admitted to NICM she was in Colombo North general hospital. When asked **the quality of care they received during hospital stay,**

*“After the surgery I was informed not to go anywhere out of the ward, because it courses to get infection. I think nurses are very concerned about prevention of germs entering in to my body. We need to obey them” (P-05).*

Most of the patients know that they can eat any food to maintain their nutritional status, but they expressed they learnt from nurses about specific food items which give more nutritional value to combat weakness due to the disease condition.

*'They tell us to have bath every day and wear clean cloths always' (P-6).*

*'I have cancer on bones. After the operation nurses ask me to eat foods rich with calcium. They ask to have more yoghurt and more milk' They aware me dairy products have more calcium and having them facilitates to keep bone healthy' (P-2).*

*"There are facilities to read newspapers, watch television to get information and nurses assisted me with religious activities too (smiling)" (P-7).*

*No any short comings we experienced during hospitalization. Care is 200% good. Nurses are excellent.*

Patients revealed that nurses were kind because they understand the patient's situation. Patients believe that nurses thought about their recreational and religious activities too.

*"I thought everything done early because of their kindness. We could not find nurses like them. Nurses informed us that if we have anything to ask from them we can do so any time" (P-7).*

Patients received from the nurses' deeds of kindness and empathy in this oncology institutes. Nurse-patient relationship results in a sense of happiness in the patient. Patients seem trust the nurses; the psychological support they

receive for solving problems such as pain relief, making them feel better in the hospital.

## **Theme 2 - Seeking more information**

It has three sub themes, *need well developed awareness system seeking counseling and receiving inadequate health education.*

Half of the patients (8) desired information on how to live with the disease condition, regardless of their diagnosis and age.

*"Doctors told that I have Leukaemia I like to know about my disease condition fully and whether I can get cured" (P-13).*

*"But I don't know about my disease condition. The day before the operation I was informed that surgery will be done on me. Nurses did not give me information on the surgery. I have heard that this condition gets worse after the operation (Crying). Is it true? I wanted to ask about how to control the disease after surgery and when can I go home" (P-8).*

Patients expressed that they do not receive adequate information about their surgery before the day of operation. However they expect information from nurses.

*"I have heard from my friends that there are some Ayurvedic methods of relieving cancer pain and also I want to know the alternatives other than western medicine to relieve pain, because the pain is not reduced completely with these drugs" (P-2).*

Patients were at an educational level where they could read and listen well. Patients knew that there are some methods to relieve pain other than medicine; however they did not have a clear idea of those methods. They expected appropriate information from nurses.

*“The care we are receiving from the nurses is remarkable with considering the situation of hospitals in our country. They have to look after a large number of patients, how can they pay more attention to us other than fulfilling our basic needs” (P-04)?*

Patients expressed a sense of barrier in communication and lack of desired counseling. Patients also expressed satisfaction with the quality of care received and felt safe in the hospital.

**Theme 3 - psychosocial support** which has eight sub themes as *experience nurse patient relationship, feel trust, sense of happiness and feel better than home, believing religious support, need homely environment, emotional support and experiencing social support.*

Patients expressed their views under two main categories of support.

**Psychological support:** Psychological support is assured to solve health challenges arising from their conditions and is motivated to observe religious activities.

*“They ask us to discuss our needs. Nurses want to discuss with us, but I know that sometimes nurses do not take their meals on time. How can they talk more with us?” (P-09)*

*Even when I have a nap they (nurses) ask why. We are highly satisfied with nursing care here. I do exercises. Nurses asked us to drink more water, stay clean and happily. Certainly, honestly this ward is better than home (P-06).*

Some patients have thought about nurses' well-being too. Patients observed how nurses take care of patients and were satisfied with care provided by nurses. The findings revealed that a majority of the respondents were satisfied with the nursing care provided, while.

*“Definitely, but my family members go for work every day, while I am at home. During that time I am alone. As far as I can handle my activities of daily living its ok, but I am thinking that when I cannot do my work without help what am I to do? (paused and sighed). Therefore I think this ward is better than home” (P – 3).*

Findings from interviews with patients showed that they felt secured and confident about the care received.

**Social support:** Patients expressed their views regarding the nature of interpersonal relationship that existed among them, the nursing staff and the family members. Further they needed to simply express their satisfaction on how they were treated and how the nurses generated a feeling of trust and a sense of happiness among the patients in the hospital.

*“When I say I am tired of my life and dying is better than living, nurses say ‘think positively.’ Further they explained that ‘we can do our maximum to comfort you, so don’t think in a negative manner” (P-5).*

*“We feel no short comings as such. Regardless of their heavy workload sometimes they arrange “pirith chanting”(Religious) in the ward or they allow us to go to the temple (smiling)” (P – 8).*

The participants expressed satisfaction with the encouragement given to perform religious activities. Patients expressed beliefs in conducting religious activities and also acknowledged provision of some form of social support and motivation from the family.

In summary, according to patient's descriptions, perceived threats of patients included, tolerating problems emerging from family, coping with condition, physical weakness, fear of death and emotional reactions towards pain. Perceived

needs of patients were conducive home environment, alternative recreational activities, psychological support and some form of financial support.

## **Discussion**

The study sought to provide better understanding of the experiences of adult cancer patients with regard to meeting their palliative care needs and satisfaction to maintain their quality of life during hospitalization. Quality of life is an important indicator in chronic disease outcomes. As the disease condition deteriorates, the quality of life and perhaps satisfaction of the patients get decrease. Satisfaction is another indicator regarding achievement of needs and this is very essential to meet cancer patients' quality of life. In order to maintain patients' quality of life, need-based care should be seriously considered as this is very essential. The current health care system has a challenge to provide need-based care to fulfill satisfaction of people (10). Analysis of the experiences of the patients has given meaningful insight about palliative care needs and patients satisfaction in the selected institutions. This study has provided evidence that some of the needs of the patients were well identified by the nurses. Most of the patients were satisfied with the basic care they received from the nurses at the selected institutions. The study was able to uncover what the patients expressed as their meaning of caring. According to the results of the current study the meaning of caring as expressed by the patients was the provision of individual attention, high satisfaction, motivation to do religious activities and dedication of nurses.

In a qualitative descriptive study carried out by Liu et al. (11) using semi-structured interviews to explore the meaning of 'caring', they found that patients perceived 'caring' as nurses having professional knowledge, empathetic attitudes and skills in cancer care that was used to provide

information and education, building and maintaining a trusting nurse-patient relationship. The patients' perception on care is important in total management of cancer patients and exploring care providers' knowledge and perception on palliative care in providing quality care. In-depth interviews of patients revealed that they were satisfied with the basic nursing care received. However, when fully operationalizing the definition of palliative care, there are many facets of care patients must have during the period of hospitalization. In the current study it is possible that patients were unaware of the holistic approach of palliative care and as a result, they only expressed satisfaction with the basic nursing care received (12). Palliative care is a new concept to both Sri Lankan cancer patients and to the health care providers. Thus the patients' expectations could have been at a lower level (13). Patients in the current study also hardly knew what palliative care entails.

The study was able to determine that receiving information about their condition and care modalities appeared to be an unmet need of cancer patients who were in the current study. At different times during their illness patients stopped their information seeking because of fearful and contradictory information (14). In contrast, the current study observed that patients tended to request more information about their disease condition which was lacking in their care. The study conducted by Wallberg et al (15) found that patients gave priority to disease-specific information. Lack of information about disease condition can increase uncertainty, anxiety, distress, and dissatisfaction (16). When information about treatment modalities are received by patient from their friends and relatives, particularly about surgery on cancer patients, misconceptions about the prognosis of post-operative period may give rise to unnecessary anxiety. Therefore, providing

required information regarding patients' current situation by professional caregiver is essential for cancer patients. Palmer et al. (17) in their pilot study on unmet needs among adolescent cancer patients reported that information should be provided in a timely manner which allows adequate time to process and re-discuss. The challenge is finding a way of providing information that is applicable for patients who may benefit from it (14).

Providing more information strengthens the nurse-patient relationship. The Nurse-patient relationship is the basis of establishing patients' satisfaction. In Sri Lanka, there are traditional healing methods which are believed to be effective by the community. The study also revealed that information regarding traditional methods was given to cancer patients by the people. Patients reported in this study that they were informed about ayurvedic treatment methods to relieve pain because pain was still remaining with medication they were *receiving and they believed*. Generally nurses do not give information on traditional healing methods, because in the hospitals nurses practice only western methods of caring. However they allow some other methods such as ayurvedic oil treatment, meditation and religious methods to be practiced if they are not harmful to those currently undergoing treatment. These methods are considered as non-pharmacological relieving methods which constitute one of the main aspects of palliative care.

The *psychosocial need* which emerged from the analysis has two facets, psychological and social dimensions. Study participants expressed that they experienced satisfactory nurse-patient relationship. They reported experiencing trusting relationship with the nurses and a sense of happiness which caused them to feel better in hospital than home. Participants expressed their satisfaction with encouragement provided by nurses to engage in religious activities which

facilitated their spiritual well-being. An empirical study conducted by Narayanasamy (18) reported that spiritual issues need to be considered and patients at the end of life or those chronically ill are supported to attain a better quality of life with spiritual support. All the above sub-themes contribute evidence that the patients experience psychological and social need.

According to the patients' views in the current study, nurse-patient relationship was appreciably high. The data from the study provided evidence that nurses are competent to identify patients unmet needs if the nurse-patient relationship is sustained. Health care professionals' point of view on fulfilling social support needs of cancer patients which was studied by Hong et al. (19) reported that patients should be provided informational and emotional support needs. In a study conducted in Iran (19) reported that cancer patients have many unmet supportive care needs, especially in the domains of health system, information, physical, and daily livings. In that study more than half of the participants reported unmet supportive care needs. Similar finding was reported by Michael et al (20).

## **Conclusion**

Most of the adult cancer patients at the selected institutions perceived that most of their needs were well identified by nurses and their level of satisfaction was high. However appropriate information was not received by them. Patients need more information about their disease condition, procedures planned to be done and alternative treatment methods. The study group perceived that the psychological and social support they provided were appropriate to maintain their quality of life. Thus in order to enhance the quality of care it is recommended that the nurses should provide adequate information to patients and their relatives and maintain proper interpersonal relationships in

terms of fulfilling social needs of cancer patients. Continuous in-service education for nurses on cancer palliative care can be recommended by this study to update nurses' knowledge on cancer palliative care and to improve their communication skills in order to provide appropriate information.

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