

# Perceived Palliative Care Needs of Cancer Patients, Nurses and Domiciliary Care Providers at a National Cancer Referral Facility, Sri-Lanka

Lalitha Meegoda<sup>1</sup>, Sharaine Fernando<sup>2</sup>, Sivagurunathan Sivayogan<sup>3</sup>, Nnodimele Onuigbo Atulomah<sup>4</sup>, Jayantha Jayasiri<sup>5</sup>

<sup>1</sup>Department of Allied Health Sciences, University of Sri Jayewardenepura, Gangodawila, Sri Lanka

<sup>2</sup>Department of Physiology, University of Sri Jayewardenepura, Gangodawila, Sri Lanka

<sup>3</sup>Department of Community Medicine, University of Sri Jayewardenepura, Gangodawila, Sri Lanka

<sup>4</sup>Department of Public Health, University of Babcock, Nigeria

<sup>5</sup>Department of Sociology, University of Sri Jayewardenepura, Gangodawila, Sri Lanka

## ABSTRACT

**BACKGROUND:** Cancer is an important cause of morbidity and mortality among all populations and patients need special care while care providers need special skills and resources; all this constitutes a challenge especially in resource limited settings. The study describes the perceptions of cancer patients, nurses and domiciliary care providers (DCPs) with respect to palliative care needs of adult cancer patients and to identify the levels of patients satisfaction with regards to care received at the National Institute of Cancer, Maharagam (NICM), Sri-Lanka.

**METHODS:** The study was a descriptive cross-sectional survey using both interviewer-administered and self-administered validated questionnaires to collect data from 124 patients, 100 nurses and 100 DCPs at the NICM. The level of satisfaction was identified using a rating scale and percentages were computed.

**RESULTS:** We found that 68% of patients reported that their most common need was pain relief followed by interpersonal

relationship (60%) and majority (86%) confirmed that these were adequately met. 70% of the patients expressed full satisfaction with the psychological support they received. Only 54% of nurses surveyed expressed satisfaction with the care they provided. Most nurses (96%) had not attended any educational program on palliative care, and 94% of DCPs expressed the need to improve their knowledge and skills on palliative care. All DCPs thought that patients have care needs other than the treatment, mainly pain relief. DCPs thought that all patients were satisfied with the care they provided.

**CONCLUSION:** Palliative care needs of adult cancer patients were well identified by the nurses and the level of patients' satisfaction was high. However 96% of the nurses had not attended any educational program on palliative care and felt in-service training program can help to improve their knowledge. Although DCPs were satisfied with the services they provided, they too thought that their knowledge was not adequate.

**Keywords:** Palliative care; Cancer; Nurses; Domiciliary care providers

## INTRODUCTION

Cancer is one of the leading causes of death in the world particularly in developing countries [1]. According to the world cancer report, prevalence of cancer is increasing at an alarming rate globally. In 2005, 7.6 million people died of cancer out of 58 million deaths worldwide. More than 70% of all cancer deaths occur in low and middle income countries, where resources

available for prevention, diagnosis and treatment of cancer are limited or non-existent [1]. In Sri Lanka, almost 25,000 new and treated cases of cancer were recorded in 2002, representing more than a 100 per cent increase over the figures for 1992. Presently, cancer ranks fifth in the order of hospital deaths in Sri Lanka [2]. Palliative care is an important aspect of managing cancer patients. It is an approach that improves the quality of life of patients and their

families. Early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems are crucial [1]. Providing such holistic care is known to improve the physical and mental status of patients and their immediate family, thus improving their quality of life and productivity. Palliative care addresses a broad range of issues integrating individual specific needs into care. However, the distribution of services is heavily weighted towards western countries [3]. Only about 6% of all palliative care services are located in Asia and Africa [4], the regions where the majority of the world's population live and die.

Even though there are no published relevant studies on cancer palliative care in Sri Lanka, several related studies have been done in other countries. This study was undertaken to identify the palliative care needs of adult cancer patients and the level of satisfaction expressed regarding care provided from the perspectives of the patients, and caregivers at the National Institute of Cancer, Maharagam (NCIM) Sri Lanka. Further, we explored the perceptions of nurses and domiciliary care providers in terms of facilities and processes available to provide palliative care.

## METHODS

The study was a descriptive cross-sectional survey which used a questionnaire developed to obtain information from participants regarding their perception and satisfaction about care provided after obtaining informed consent from each patient. Test-retest reliability was conducted as well as face validity performed with nursing experts to assure reliability and validate the instruments used. We enrolled 124 patients, 100 nurses and 100 domiciliary care providers using systematic sampling. Male or female nurses who provided palliative care to the cancer patients of the selected institution were included. The study was conducted at the NICM, a national referral centre for cancer. Ethical approval for the study was obtained from the Ethical Review Committee of the Faculty of Medical Sciences, University of Sri Jayewardenepura. Approval was also obtained from the Ministry of Health and NICM. Data were collected from 2009 and 2010.

Male and female patients who were older than 18 years and diagnosed with cancer were selected. The patients who were, unconscious, semiconscious or had cognitive impairment were

excluded from the study. Patients were enrolled into the study by selecting every 12<sup>th</sup> patient on the admission list. Interviewer-administered questionnaire was used to collect data. Measure of interpersonal relationship were asked in the questionnaire through requiring respondents to answer questions regarding their experiences about the extent they trust caregivers, kindness received, timely information conveyed to them by caregivers about their illness, and regular observations of their conditions on a 5-point rating scale (5=highly satisfactory and 1= not satisfactory at all). In order to measure the level of satisfaction received by the patients, questions related to psychological support they received were also asked. Nurses who participated in the study were selected by systematic sampling from a list of nursing staff in the hospital by selecting every 4<sup>th</sup> nurse from a list of all nursing staff in the hospital. A self-administered questionnaire was used to collect data from them. Similarly, DCPs of hospitalized adult cancer patients were selected by systematic random selection of total DCPs present at the time of the study. Self-administered questionnaire was used to collect data from these respondents. DCPs were asked about their patients' needs, facilities available and how they find time to provide care.

## Statistical Analysis

The questionnaires returned were examined for completion, coded and entered into the computer for analysis. The computer-assisted statistical software Minitab version 16 was used to develop descriptive statistics of frequency distributions for all variables analyzed and for continuous variables, data were summarized as mean and standard deviations. Results were also presented as tables and graphs.

## RESULTS

The results showed that the mean duration of hospitalization was 28 days ( $\pm$  35 days) and on average 61 $\pm$ 28 patients received nursing care per day. The mean age of nurses in the study was 29 $\pm$ 5 years and had a mean length of nursing experience in the oncology ward of 3 $\pm$ 2 years. The results in table 1 show the frequency distribution of demographic characteristics of nurses, patients and DCPs who participated in the study. Of the domiciliary care providers, 38% were family members, 32% were neighbors and the rest (30%) were hired. Of the non-related care providers, over 69% did not charge fees for

**Table 1:** Frequency distribution of demographic characteristics of study participants

Variables	Patients (N=124) N (%)	DCPs (N=100) N (%)
Sex:		
Males	50 (40.3)	30 (30)
Females	74 (59.7)	70 (70)
Education:		
Primary	88 (71.0)	91 (91.0)
Secondary	26 (21.0)	7 (7.0)
Tertiary	10 (8.10)	2 (2.0)
Religion:		
Buddhist	105 (84.7)	84 (84.0)
Christian	10 (8.10)	13 (13.0)
Hindu	5 (4.0)	3 (3.0)
Islam	4 (3.2)	1 (1.0)
Ethnicity:		
Sinhala	112 (90.3)	90 (90.0)
Tamil	9 (7.3)	7 (7.0)
Burgher	3 (2.4)	3 (3.0)

the services provided. Only 38% of the domiciliary care providers knew the appropriate care.

#### *Perceptions of patients*

Generally, patients (68%) expressed that pain relief was their commonest need and most readmissions were for pain relief. 52% of patients wanted basic needs like relief from breathing difficulties, personal hygiene, elimination and nutritional requirements to be met. More than 86% of patients were satisfied with the welcome received on admission. Most (86%) said that their needs were well identified; nurses identified the patients' needs before they complained and 89% were fully satisfied with their needs being fulfilled in a timely manner. Wound dressing, nasogastric feeds, provision of meals, attending to personal hygiene and help in elimination were received in a timely manner. Interpersonal relationship between patients and nurses was rated very well by 60% and 70% were fully satisfied with the psychological support they received. More than 90% were happy with the kindness experienced. Although 94% of the patients had the need for health education, only 73% received it.

#### *Perceptions of nurses:*

Pain was the commonest symptom (80%) observed by nurses for hospitalized patients. Most nurses (97%) perceived that palliative care

is more important than curative care. Radiation therapy (82%) and drugs (74%) were the other modes of relieving symptoms. In providing quality care, 76% of nurses totally agreed that psychological support was important. They believed (99%) that the attitude of the patient towards the illness was important in providing palliative care. Nurses perceived that patients have positive attitudes towards the illness and they were motivated for self-care. Only 54% of nurses were fully satisfied on the care they provided and 79% said inadequate time was the main constraint. Nurses realized that they could not provide care in a timely manner (75%). Methods by which nurses updated their knowledge and skills for nursing practice showed that only 32% of nurses in the study group read textbooks and materials from internet on palliative care. Some of them (39%) reported that the knowledge and skills gained during basic nursing education have not been updated during their professional career. Most nurses (96%) did not attend any educational program on palliative care, but they believe the experience they gained through working is more important to provide care for the cancer patients (99%). However, 43% of them said that the current knowledge and skills were not adequate to provide quality care. They (82%) believed that they were able to develop the skills and gain knowledge. Guidelines on palliative care were available to only 37% of nurses.

#### *Perceptions of domiciliary care providers:*

Domiciliary care providers observed that the patients need help and special support in addition to the treatment, to reduce pain (81%), maintain nutritional status (47%), personal hygiene (43%), and elimination (26%), conduct religious activities (33%) and social companionship (14%). DCPs thought that all patients were satisfied with the care they provided and 95% believed that they had to be with the patient always. Domiciliary care providers felt that the most suitable method to relieve symptoms of pain was western medicine (86%) followed by performing religious (22%), Aurvedic (6%) and conducting exorcisms (6%). Majority of DCPs provided care at cancer care institutions as well as at homes. Resources of the patients were adequate (73%) to provide care. Only 11% said that their patient had easy accessibility to cancer palliative care institutions. DCPs were aware of several ways to deliver care to their patients, but 94% of them felt the need to gain more know-

ledge about palliative care and 62% of DCPs had no previous experience in providing palliative care to their patients. Regarding sources of knowledge needed by DPCs to strengthen the care they provided their patients, majority (55%) reported that such knowledge were obtained mainly from medical officers followed by what they were able to gain from experience (39%) and what the nurses (30%) provided. Some of the information about what to do was also obtained from reading literature (19%) and media (14%).

## DISCUSSION

In this study majority of the patients were found to be satisfied with the care they received from the nurses at NICM and the patients felt their needs were well identified by the nurses. The current health care system has to provide need-based care to people [5]. In maintaining patients' quality of life, need-based care is essential and the current study shows that patients' needs were well identified by the nurses.

Nurses have an important responsibility to provide care that fosters good relationships [6]. With meaningful interpersonal relationships, patients must feel bonded and connected to nurses [7]. In this study patients responded that the interpersonal relationship between patients and nurses at NICM was good. Pain was the commonest symptom identified by patients and nurse in this study. It has been reported that greater patient staff communication contributes to a major part for relieving pain [7]. This may have contributed to better needs identification in this group of patients.

Nearly half of the nurses surveyed were not fully satisfied with the care they provided to adult cancer patients. Overcrowding of wards and time constraints to provide quality care may be some possible reasons for this dissatisfaction. Identification of patients' needs or preferences is time consuming because each patient is unique. Similar reasons such as understaffing, inadequacy of time for nurses to provide quality care have been reported by other investigators [8]. Botti et al state that lack of time is one reason for decreased effective communication between patients with cancer and nurses to keep good nurse-patient relationship [9]. However, a higher level of satisfaction with care provided as well as general work satisfaction was reported by nurses with more experience in cancer care and with lower workload [10]. In the current study most nurses believed that psychological support

and the attitude of patients towards the illness was important in providing quality care. Similar observations were made by Isolca et al who said quality of life is not adequate when only the physical needs were met [8].

Although it is believed that the palliative care knowledge and skills can be derived from working with cancer afflicted people [11], the findings of this study suggest that there is a need for further improvements of knowledge and skills of nurses providing care for adult cancer patients. This study also shows that further education is necessary to provide quality care as knowledge and skills on palliative care they gained from the basic nursing education was not updated. Similar findings have been reported by others where many nurses felt that they were inadequately prepared for palliative care [12].

This study reveals that nurses did not have written guidance on how to provide palliative care for adult cancer patients. Use of text books on palliative care was very low among nurses none attended any national or international educational program on palliative care. In this study, the nurses believed that the experience they gained through working was more important to provide care for adult cancer patients. Though there is a big demand for palliative care services, opportunities for Sri Lankan nurses to improve their knowledge and develop attitudes and skills are scarce.

Enhancing nurse's knowledge on palliative care will likely promote their understanding of the needs of the advanced stage cancer patients and will enable them to provide quality care [13]. This is a valuable concept to be taken in to consideration when planning measures for improvement of care. The average educational level of the domiciliary care providers in this study was at primary level. It is a positive feature that the DCPs are willing to acquire new knowledge as they sought from the nurses who provided care to their patients. However it is doubtful that DCPs will search secondary sources for new knowledge. DCP's in this study were well aware of patient's needs and they resorted to local methods to fulfil these needs. Most DCPs were patients' family members and the patients were satisfied with the help given by the DCPs. Although most DCP's were not adequately aware about palliative care and did not have enough experience to provide care to their patients, they did so willingly. The DCP's thought that the best method of treatment for these patients was western medicine with a few believing ayurvedic and religious activities may also be helpful to

relieve patients symptoms.

## CONCLUSION

The adult cancer patients at NICM felt that their needs were well identified by nurses and their level of satisfaction was high. Nurses thought that psychological support and attitudes of patients towards the illness had an impact on the quality of care provided. Knowledge and skills of nurses on palliative care were not updated, but nurses believed that these could be improved and in-service training program is the best method to improve their knowledge. As patients' level of satisfaction on domiciliary care provided by DCPs was high, improving their knowledge on palliative care needs may be a cost effective method of improving care.

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