



Research Article

QUALITY OF LIFE OF PATIENTS UNDERGOING PALLIATIVE CARE

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Abstract :

The whole world is experiencing a health transition, with a rapidly rising burden of chronic and incurable diseases. Long Term Care for patients with chronic and incurable disease is emerging as the major healthcare issue in countries like India. Cancer patients in India seek health care only in their last stages when it is incurable and too late to improve the quality of life of patients. Palliative care is a specialized medical care for people with major health care issue such as cancer. This study is done to find the change in quality of life of patients before and after undergoing palliative care. 60 patients were included in the study. WHOQOL-BREF (WHO Quality of Life) questionnaire was used as a tool to assess the quality of life of patients. It assesses four major domains: physical, psychological, social relationships and environmental domain. It is a self-administered questionnaire. The statistical analysis was performed using SPSS version 16.0. The mean domain score at admission for psychological domain was 9.6 ± 2.3 and after 2 weeks was 10.6 ± 1.7 which was statistically significant ($p = 0.04$). The mean domain score at admission for environmental domain was 9.9 ± 2.2 and after 2 weeks was 11.4 ± 1.6 which was statistically significant. This shows that there was an improvement in quality of life in both psychological & environmental domains after palliative care. Quality of life of a patient can be enhanced greatly by incorporating palliative care early in the course of the illness, perhaps even from the day of the diagnosis.

Key words: Cancer, Palliative care, Quality of life, WHOQOL-BREF questionnaire

INTRODUCTION

The whole world is experiencing a health transition, with a rapidly rising burden of chronic and incurable diseases. Even as infections and nutritional deficiencies are one of the leading contributors to death and disability; cardio-vascular diseases (CVDs), cancers, diabetes, respiratory diseases, neuropsychiatric ailments, and other chronic diseases are becoming major contributors to the burden of disease. India too illustrates this health transition, which positions Non-Communicable Diseases (NCDs) as a major public health challenge of growing magnitude in the twenty-first century. In India, chronic diseases accounted for 53% of all deaths and 44% of disability-adjusted life-years (DALYs) lost in 2005.^[1,2] Long Term Care for such patients is emerging as the major healthcare issue in countries like India. The complex nature of physical and psychosocial problems faced by these patients demand good medical and nursing attention, but such system of care alone is not adequate. The present medical establishment, with its hospital centre services, is geared basically to look after patients with acute illness. Patients suffering with a disease like cancer require not only physical control of disease and symptoms but also need help to cope up with other elements caused by disease. The physicians and the institutions where they go address the physical



needs as a “Default” approach, but, the patient’s psychosocial and spiritual problems and needs are not brought to light.

Palliative care is aimed at improving the quality of life.^[3] World Health Organization defines palliative care as an interdisciplinary team approach that improves the quality of life of patients and families living with a life-threatening illness through early identification, assessment, and treatment of pain and other physical, psychological, and spiritual problems.^[4, 5, 6]

Palliative care should not be confused with end-of-life and hospice care. Palliative care can be initiated while curative or disease modifying treatments are still being utilized.^[6] Palliative care specialists are often called as “good stewards of resources,” mainly because of the time they spend in identifying various systems of care, products available, and venues of care giving. They promote communication between various care providers on behalf of the patient and family. The palliative care team includes physicians, nurses, home health aides, nurses, social workers, health councillors and spiritual counsellors, psychiatrists and psychologists, pharmacists, nutritionists, and physical, occupational, speech, massage, recreation, and respiratory therapists.^[7]

In India, palliative care is relatively a new concept. Due to various reasons, like illiteracy, poverty, negligence, etc., cancer patients in India seek health care only in their last stages when it is incurable. Being a new concept, research is needed in this area to improve quality in palliative care. Very few researches have been done on palliative care in India. This study is done to find the change in quality of life of patients before and after undergoing palliative care.

MATERIALS AND METHODS

A cross sectional study was done during the period of May 2010 to September 2010 (5 months), in Jeevodaya Hospice Care Centre, Manali, Chennai. Jeevodaya is a nonreligious, charitable and a non-profit Palliative Care Organization, founded in 1990, and has, so far, helped about 3250 (Institutional record statistics till Sept 2010) fellow human beings to live and die with human dignity. During the data collection period 135 patients were admitted and of which 75 patients were very ill, not able to talk comfortably and had poor mental state (as per the mini mental state examination) and were excluded from the study. The remaining 60 patients were included in the study after obtaining written informed consent. The information provided by the study subject on their illness was confirmed with hospital and laboratory (biopsy) reports possessed by the individual. WHOQOL-BREF (WHO Quality of Life) questionnaire was used as a tool to assess the quality of life of patients admitted in Jeevodaya. This tool was administered twice to the same patient once during admission and second after 15 days of palliative care.

The WHOQOL-BREF is a short version of WHOQOL-100. The WHOQOL-BREF contains a total of 26 questions. It assesses four major domains: physical, psychological, social relationships and environmental domain. It is a self-administered questionnaire and has been validated in many languages. The four domain scores denote an individual perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean and standard deviation of the domain



scores were computed and the mean of the domain scores before and after palliative care were compared using the paired-t test. The statistical analysis was performed using SPSS version 16.0.

RESULTS

60 patients were included in this study conducted at Jeevodaya Hospice Care Centre. Among the study subjects the males and females were equally distributed. The age and sex distribution, educational status, last occupation, religious background and marital status of the patients in the study are shown in Fig 1. Disease profile of patients included in this study is shown in Fig 2.

The WHOQOL-BREF tool was administered twice to each patient. It contains a total of 26 questions. It assesses four major domains: physical, psychological, social relationships and environmental domain. Mean domain scores were calculated at admission and after 2 weeks in palliative care (Table 1, Fig 3). Increase in domain 2 (psychological) and domain 4 (environmental) score was observed which is statistically significant. Table 2 (Fig 4) shows the patient domain score after palliative care.

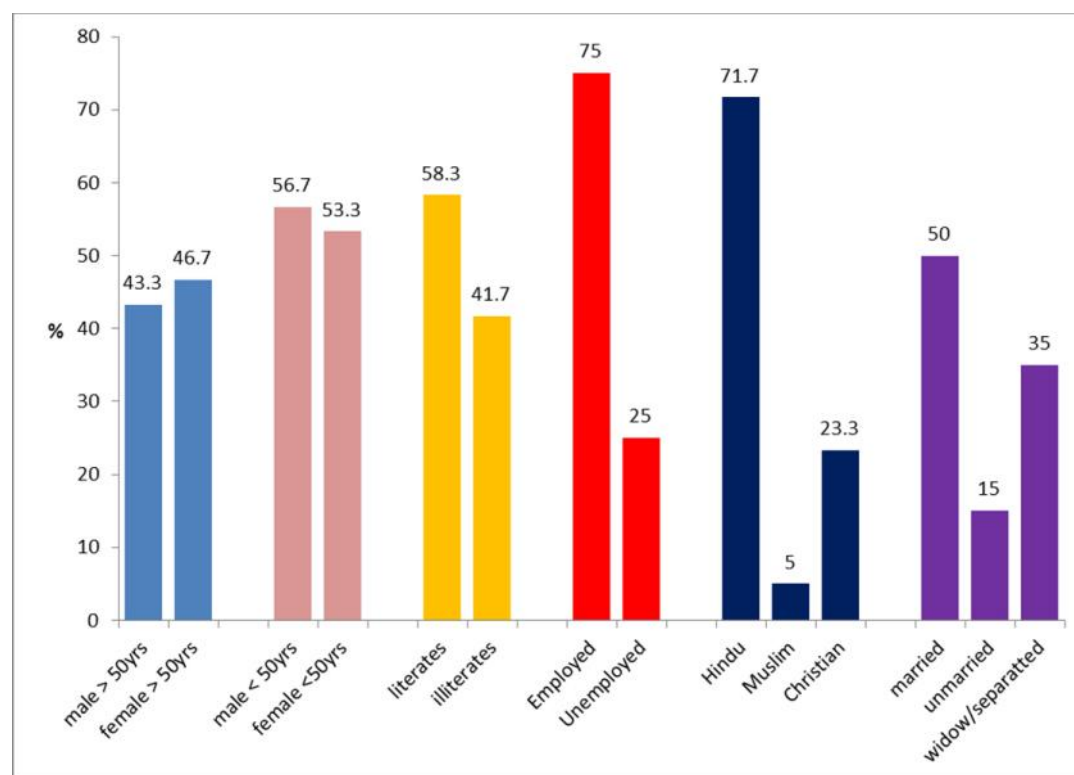


Fig 1: Demographic profile of patients in the study.

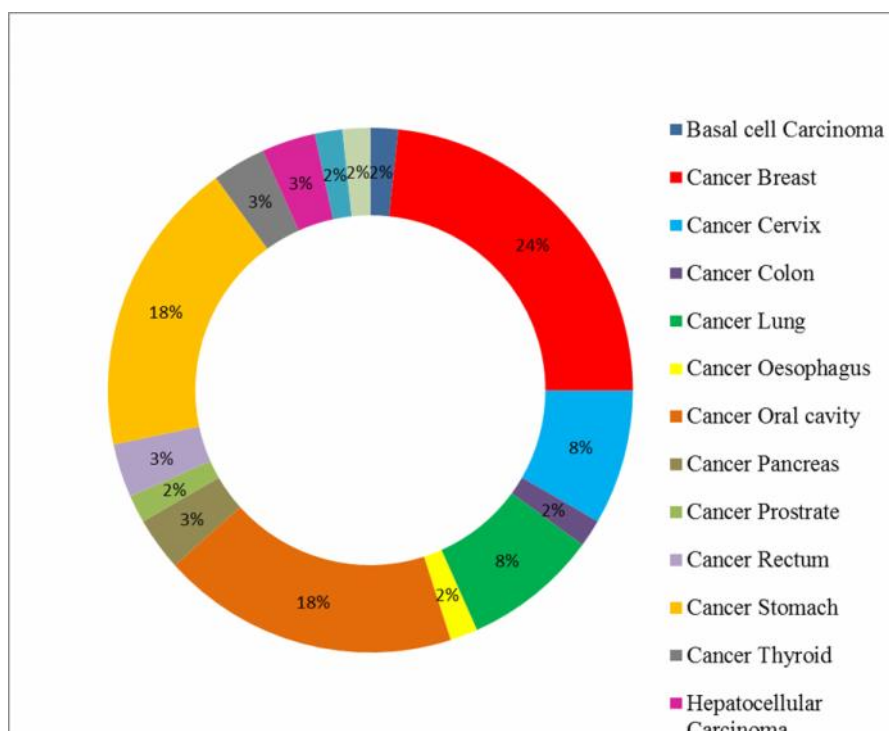


Fig 2: Disease profile of palliative care patients

Table 1: Quality of life Domain scores at admission and after 2 weeks of palliative care:

Domains	Mean \pm (SD) [At admission]	Mean \pm (SD) [After 2 weeks of palliative care]	p-value
Domain 1	9.7 \pm 1.8	9.3 \pm 1.9	0.277
Domain 2	9.6 \pm 2.3	10.6 \pm 1.7	0.041
Domain 3	9.5 \pm 3.6	9.1 \pm 3.6	0.056
Domain 4	9.9 \pm 2.2	11.4 \pm 1.6	0.007

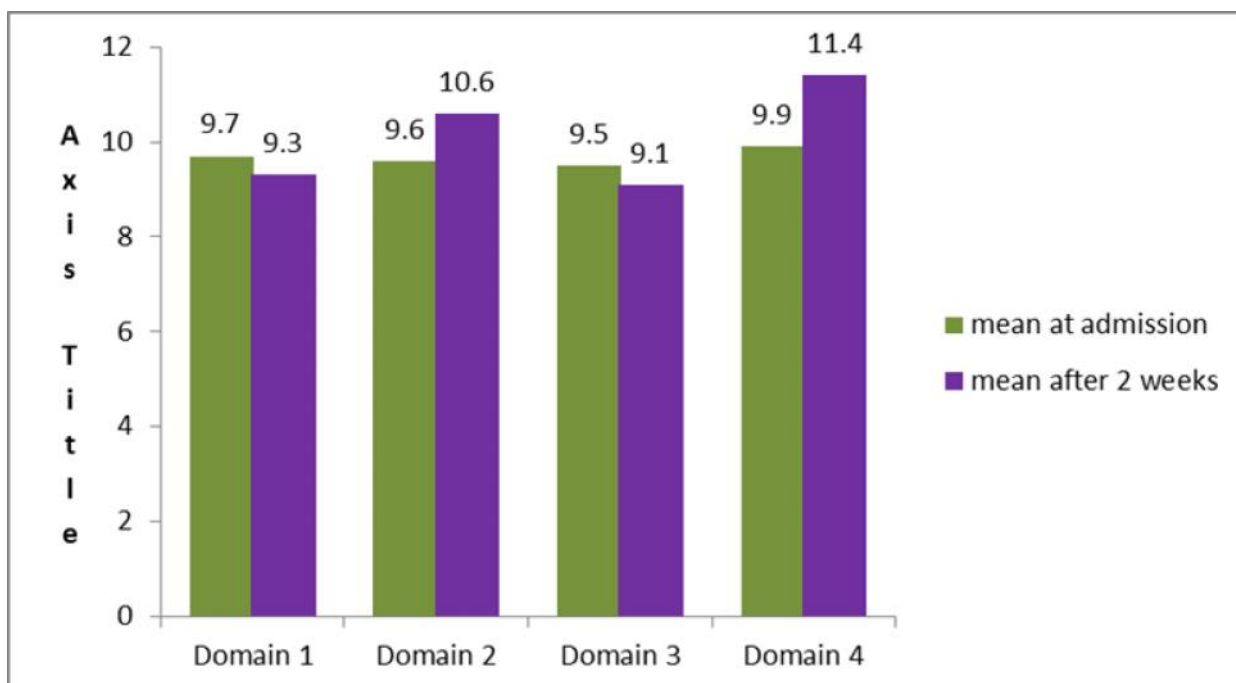


Fig 3: Effect of palliative care

Table 2: Patients domain scores after palliative care:

Domains	Improved (%)	No change (%)	Decreased (%)	Total
Domain 1	5 (27.8)	4 (22.2)	9 (50)	18
Domain 2	11 (61.1)	3 (16.7)	4 (16.7)	18
Domain 3	-	14 (77.8)	4 (22.2)	18
Domain 4	14 (77.8)	-	4 (22.2)	18

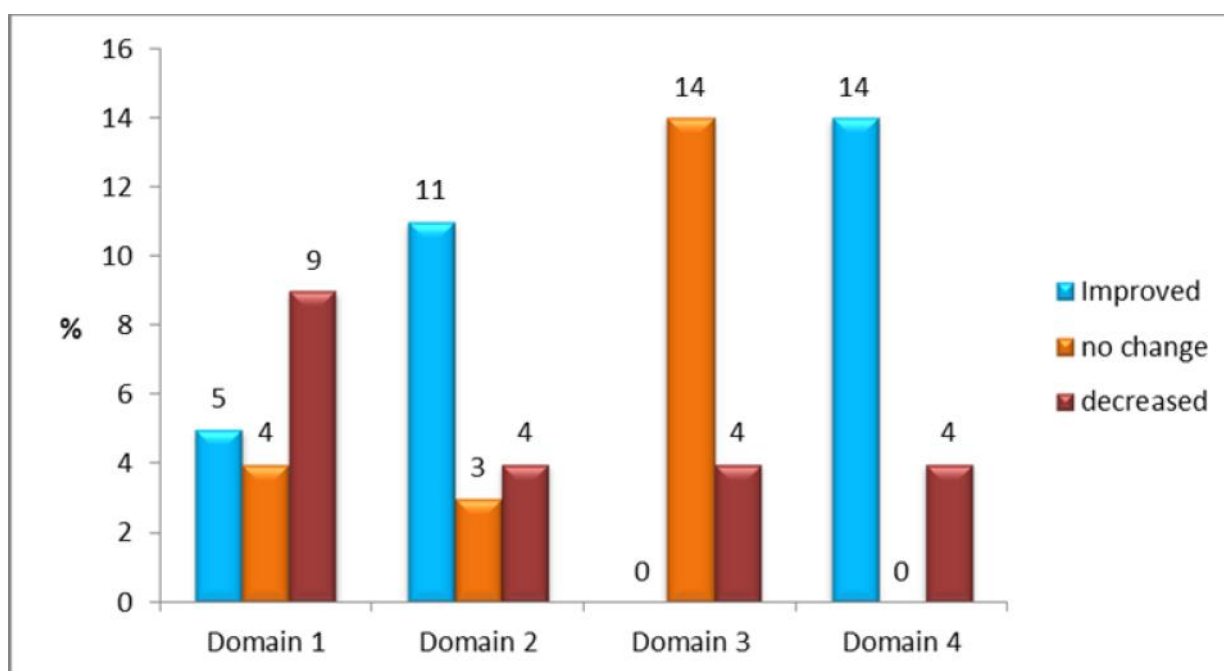


Fig 4: Effect of palliative care

DISCUSSION

Palliative care is aimed at meeting physical, psycho-social and spiritual needs by early identification of needs and threats, thus, preventing and alleviating suffering and supporting families during illness of a loved one. The aim is to improve the quality of life. Thus evaluation of quality of life of patients in Palliative Care centre is an important procedure in identification of a patient's overall condition, as well as, in the evaluation of the quality of service provided. WHO defines the quality of life as "the way individuals perceive their living position in a cultural context and value system in which they live and in relation to their tasks, expectations and standards set by environmental determinants".³ There are various instruments to measure quality of life. In this study we have used WHOQOL-BREF questionnaire to describe the quality of life of patients. It consists of quality of life items that are concerned with different aspects of life of patients' and how satisfactory or problematic is their experience of them. It is based on a four domain structure: physical, psychological, social relationships and environmental domain.

The Noble prize winner for peace 'Mother Teresa' in 1979 said "The greatest disease today is not leprosy or tuberculosis, but rather the feeling of being unwanted, uncared for and deserted by everybody. A caring touch or a loving word can help the suffering patients to take out their sorrows. Communication skills, empathy, body language, listening more than talking etc., are some of the core principles in interviewing palliative care patients. In this study, initially a good rapport was developed with the patients by just listening to their



sorrows. Care was taken on the choice of words which were used and the body/ facial gestures in order to prevent hurting patient's feelings.

The male and female patients in this study were equally distributed. Fig 1 shows, 58.3% of patients in this study were literates, 75% were employed (before being admitted in palliative care), 71% belonged to Hindu religion and 50% were married. 24% of patients in this study had cancer breast, 18% of patients had cancer oral cavity and cancer stomach each (Fig 2).

In this study there was an increase in domain 2 (psychological) and domain 4 (environmental) score (Table1, Fig 3). The mean domain score at admission for domain 2 was 9.6 ± 2.3 and after 2 weeks was 10.6 ± 1.7 which was statistically significant ($p = 0.04$). The mean domain score at admission for domain 4 was 9.9 ± 2.2 and after 2 weeks was 11.4 ± 1.6 which was statistically significant ($p = 0.007$). This shows that there was an improvement in quality of life in both psychological & environmental domains after palliative care. Other studies also show an increase in quality of life among cancer patients undergoing palliative care. According to a study done in Massachusetts General Hospital in Boston, on introducing palliative care early, after diagnosis of metastatic non-small-cell lung cancer, an improved quality of life and mood, reduced aggressive end-of-life care, and increased survival in patients was observed.^[8] In another study done by Milan et al on patients with incurable cancer, they found that patients' quality of life improved in the physical, psychological, medical and global areas after designation to a palliative homecare team.^[9]

Patients attending palliative care seem to have a better quality of life, but problems related to the progression of the illness constantly challenges and changes quality of life. These changes seem to at some points improve or diminish quality of life, which are distressing to patients and their families. 9% of patients in this study showed a decrease in domain 1 scores whereas, 5% showed an increase in domain 1 score after palliative care (Table2, Fig 4). 14% of patients in this study showed no change in domain 3 score and 4% showed decreased domain 3 scores (Table 2, Fig 4). The decreased scores are seen since the disease process cannot be halted also the patients cannot revert back to his/her normal social functioning like social support, sexual activity etc.

There are prospective studies that demonstrate the effects of concomitant palliative and oncology care. One such study by Bakitas et al, investigated routine cancer care with or without regular advance practice nurse-coordinated psycho-educational sessions aimed to empower patients in approaching palliative and end-of-life needs to their physicians.^[10, 11] Another Randomized controlled study conducted at Lebanon on 322 patients newly diagnosed with advanced cancer from November 2003 through May 2008 revealed that the patients received palliative care interventions along with oncology care had higher scores of quality of life and mood compared to the patients received only oncology care.^[10, 12] Indeed, early referral to palliative care not only facilitates timely diagnosis and treatment of symptoms, but also minimizes care giver distress and aggressive measures at the end of life.^[13]



With this increasing availability of beneficial palliative services, optimizing delivery and improving access to palliative care for the neediest cancer patients has become a current priority. Despite this, misconception about palliative care still exists in developed and in most developing countries-even among the medical professionals. It is believed that palliative care indicates that treatment has failed and the patients who are receiving or attending to palliative care facilities are considered “TERMINAL.”^[12] This leaves the patient and the family confused and often unwilling to receive the care and would often resist the offer of the team to visiting the patient at home. Thus, referrals to palliative care often come too late to improve quality of life for patients with cancer. A new study carried out in Japan, on family members of people who have died of cancer found that nearly half of respondents believed that referrals to palliative care were given late in the course of the illness.^[13, 14] A study conducted at several sites in Australia regarding late referral or non-referral to palliative care for people with life-limiting disease states that lack of knowledge about palliative care services and its benefits was the over-riding reason among all health care providers, patients and families.^[15]

The introduction of palliative care early in the disease together with curative treatment is essential. When the patients are faced with serious illness, they feel that they need a special kind of care – care that focuses on pain relief, symptom management and improving quality of life. Palliative care provides the best possible quality of life for people facing pain; symptoms and stresses of serious illness, including those undergoing treatment for curable illnesses; and those living with chronic diseases, as well as patients who are nearing the end of life.

Further research is needed to investigate ways of optimizing the use of advance directives and maximizing the advance care planning process in general. Palliative oncology is the multidisciplinary, active, and total care of the cancer patient that must start at diagnosis disclosure and continue well after cure or death. Evidence demonstrates the ability and efficacy of integrating symptom control, communication and quality care delivery early and often into the care of cancer patients and their families, leading to an improvement in their quality and length of life. The future of palliative oncology will depend on the continued generation of research into individualized palliative care delivery and public policy that rewards evidence-based patient-centred care.^[11]

There is no doubt that the quality of life of a patient can be enhanced greatly by incorporating palliative care early in the course of the illness, perhaps even from the day of the diagnosis. Oncologists and primary care physicians must be sensitized to the role of palliative care team and must be encouraged to take them as partners early in the disease if they are to give a comprehensive and total care to the patients, to help them go through the treatment and to support them till the very end.

Death and dying is never an easy process to go through. However, humans have found ways & tools to help ease this part of life. As health care professionals it is our responsibility to utilize them fully and to use them promptly. “There is end to cure but there is no end to care.”

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