A COMPARATIVE STUDY ON THE EFFECTIVENESS OF HOME BASED PALLIATIVE CARE AND HOSPITAL BASED PALLIATIVE CARE IN IMPROVING THE QUALITY OF LIFE

Project report submitted in partial fulfillment
Of the requirement for the
Masters of Social Work degree

Submitted by

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CERTIFICATE

This is to certify that this project study entitled "*A study on the effectiveness of Home based palliative care and hospital based palliative care in improving the quality of life.*" submitted by Job K. Joseph (11JJAS407) of master of social work course of Kristu Jayanti college is a bonafide work based on the findings of the study conducted by the candidate.

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Place:

Date:

DECLARATION

I hereby declare that the entire work embodied in this dissertation entitled *"A study on the effectiveness of Home based palliative care and hospital based palliative care in improving the quality of life."* Submitted in partial fulfillment of the requirement for Master degree in Social Work, Bangalore University is based on the result of the research work carried out by me under the supervision and valuable guidance of Ms. Gayathri G. Lecturer department of social work, Kristu Jayanti College.

This dissertation or any part of this study has not been previously used for any other university or institution.

BANGALORE

DATE:

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CHAPTER – I

INTRODUCTION

INTRODUCTION

Caring of sick people has been a key part of many societies in the world. Since the 4th century, the rest house, sarai, sanatorium and hot springs were developed as special places to attend to their needs. The diagnosis of cancer and understanding of its incurability in a majority of patients, in the first half of 20th century, appeared as new challenges to the medical community. The pioneering works of Dame Saunders in the United Kingdom drew the attention of the medical community and the public to the evolution of the palliative care in the 1960s. From the 1980s rapid progress was made in developing palliative care as a discipline in the health care delivery. In the 21st century, many countries have recognized the importance of palliative care (Mohantti KB, 2011). However, in the 21st century fifty percent of the cancer patients are cured and those identified with the advanced stages of cancer lives for many more years so it is critical challenge to provide them with palliative care to improve their quality of life (Mohanthi, 2013).

WHO defined palliative care as "an approach that improves the quality of life of patients and their families facing the problem 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, psychological, and spiritual. DivyaKhosala further explains that Palliative care is a health care specialty that is both a philosophy of care and an organized, highly structured system for delivering care to persons with life threatening or debilitating illness from diagnosis till death and then into bereavement care for the family. Palliative care improves the health care quality in three domains: the relief of physical and emotional suffering; improvement and strengthening of the process of patient-physician communication and decision making; an assurance of co-ordinate continuity of care across multiple health care settings such as hospitals, home, hospices, and long term care."

Hence, Palliative care has been widely recognized as a medical specialty with a special emphases on education, training, clinical practical skill, man power and structured setting (Mohanthi, 2013).

1.1 Palliative Care in India

The concept of palliative care is relatively new to India. Together with input from UK, Indian health care professionals have taken up the enormous challenges of delivering appropriate palliative care in India. The first palliative care facility was a western-style hospice founded by an Indian cancer surgeon inspired by St. Christopher's hospice in London. Subsequent initiatives included support by WHO to hospital-based clinics wishing to include pain and symptom control in their cancer centers. Thus, following the western model palliative care was started in India in the mid-1980s (E, L, & M, 2008).

Although, the history of palliative care in India has the history of more than three decades, the growth of palliative care in India has been very slow and does not cater to the needs of the growing population of our country. In consistent with this Kumar (2013) finds that less than 3% of the advanced cancer patients and 1% of the patients with all incurable disease have any access to any palliative care in India. And there is a very limited provision for palliative care in India when taken as a whole. In India where recently initiated National Program for Heath care of Elderly(NPHCE)aims to develop infrastructure and built capacity of health care providers for elderly health care, around the world , there is growing concern to achieve sustainable quality of life.

The concept of "active aging" has also fostered interest in the well being and life satisfaction dimension; however, the definition of quality of elderly life and its determinants remained a concern. The poor under poor understanding of elderly life under changing economic and social norms in India has led to a weak care and support for them. Majority of elderly in India are lives and work in the unorganized agricultural sector in rural area.(Dongre AR, 2012)In addition to this Kumar reports that there are less than 130 palliative care units in our country which includes hospices, hospital based units, out patients' clinics, home care programs and community based programs. In a multi method review McDermott finds that the development of palliative care service in India was uneven and there are 19 states and union territories where palliative care provision was nominal. Moreover, the palliative care facilities in India are mostly concentrated in larger cities. He also identified that the major hurdles of palliative care in India were poverty, population density, geography, workforce development, and limited national palliative care policy. And he concluded that the adoption of western model of hospices and palliative care in

India cultural context largely failed to cater the need of Indian health care scenario (Seamark, 2000).

Although, the palliative care service in India is very poor, the small southern state of Kerala stands different to this. Kumar S reports that more than 50% of all the palliative care units in India is concentrated in this small state which habitats around 3% of its total population. Kerala has put a bench mark in the history of palliative care delivery by its experiment of Neighborhood Network in Palliative care characterized by massive community participation and thus ensuring 60% to 80% of palliative care coverage. For the first time in India, a pain and palliative care policy was declared by the Kerala State government to guide and facilitate the development of community based home care initiatives under the leadership of local self-governments (LSGs). The ArogyaKeralam palliative care project was formulated in consonance with the policy that has been quite successful in initiating such services with community participation in a large number of LSGI in all parts of Kerala(Jayakrishnan Thayyil, 2012).

The Pain and Palliative Care Society (PPCS) a nongovernmental organization (NGO) began at Calicut in 1993. An outpatient clinic was set up at the Calicut Medical College. Subsequently, a memorandum of understanding was signed with the government of Kerala. The government gave permission to the NGO to work in the premises of the medical college and also agreed to provide a few non medical staff and medicines and finding the remaining expenses to run the establishment had to be met by PPCS. Today there are 57 palliative care units spread across the six northern districts of Kerala which are evolved in the NNPC. These 6 districts have 11 million people, roughly a third of the state's population. The three districts of Malapuram, Kozhikode and Wayanad are almost fully covered. The remaining three, Kannur, Palakkad and Thrissure are covered.(Anil Paleri, 2005)

Since the inception, it was clear to the founders of PPCS that professionals alone would not be able to carry the entire weight of the task of looking after chronically ill people but also need the support of community. The clinic itself began with one volunteer and a part time doctor. Other volunteers were encouraged to join the initiative, and at that time they were seen as people to help with the nursing tasks. A volunteer could work in a clinic or home care program only during the hour in which these programs were run. Hence almost all the volunteers worked in the clinics, which often were far from their place of residence, and they often worked in isolation as there were few other volunteers from their locality. The first link center of the PPCS was established in 1996 at Manjeri in the neighboring district of Malappuram. The method of setting up a new link center was to train a doctor, preferably a team of doctor and a nurse and to encourage them to set up a palliative care clinic in their area.

MC Dermott identified 138 organizations currently providing hospice and palliative care services in 16 states or union territories. These services are usually concentrated in large cities and regional cancer centers, with exception of Kerala, where services are more wide spread. The Kerala net work has more than 60 units covering a population of greater than 12 million and is one of the largest networks in the world. In April 2008, Kerala became the first state in India to announce a palliative care policy.

The Calicut model has also become a WHO demonstration project as an example of high quality, flexible and low coast palliative care delivery in the developing world and illustrating sound principles of cooperation between government and NGOs. Can support has 11 home care teams, each consisting of doctors, nurses and counselors trained in palliative care to cover the different part of Delhi and national capital regions. The majority of the doctors, nurses and paramedical professionals working in these centers have rendered exemplary services to deliver palliative care of cancer and other terminally ill patients, raise awareness about palliative care practice and educate others.

1.2 Who Provides Palliative Care?

Palliative care can be provided by a number of different health professionals depending on the illness and the needs and resources of the patient, their family and caregivers. Together, professionals involved in delivering palliative care generally work in a multidisciplinary team and may include:

- Specialist palliative care doctors and nurses
- General practitioners
- Specialist doctors – oncologists, cardiologists,
- Neurologists, respiratory physicians
- Nurses
- Allied health professionals – pharmacists, occupational

- Therapists, physiotherapists
- Social workers
- Grief and bereavement counselors
- Pastoral care workers.

Patients and their families and caregivers should have access to the level of care and support they need provided by health professionals, trained volunteers and their own communities. A small number of people experience severe or complex problems as their illness advances. These people may be referred to a specialist palliative care service where a team of specialist professionals will work to meet their need (Palliative care Australia).

Palliative care can be provided:

- In the home
- In a hospital
- In an aged care home
- In a hospice.

Most people prefer to receive palliative care in the home, but this will depend on many factors including:

- The nature of the illness
- How much support is available from the patient's family and community
- Whether the patient has someone who can care for them(palliative care Australia)

1.3 Home Based Care and Institutional Based Palliative Care

The rise of hospice and palliative care in its distinctly modern guise is generally traced to the late 1950s and early 1960s when there is evidence in many countries of a new interest in the improvement of care for dying people. In the wake of developments at the local level and as hospice and palliative care services began to establish in individual settings, there quickly emerged a range of international association to consider promote and develop the work of hospice palliative care, along with the cognate field of pain medicine. These organizations focused on professional development, education and training; on clinical innovation and research; on lobbing and advocacy. It is estimated that hospice or palliative care services now exist or are under development, on every continent of the world-in around 100 countries. The total number of hospice or palliative care initiatives is in excess of 8,000 and these include inpatient units, hospital based services, community based teams, day care centre and other modes of delivery. There is much to celebrate about these achievements, in many cases development has been hard won and have required enormous efforts for their realization. (Clark, 2003).

The studies conducted by Jayakrishnan Thayyil and Jeeja MC suggest that the interface between institutional based care and home care needs more exploration and prospective study. According to the World Health Organization (WHO) home based palliative care refers to the provision of health services by formal and informal caregivers within the home. The aim of home based care is ultimately to promote restore and maintain, a person's maximum level of comfort, function and health including care towards a dignified death. The WHO foresees home based care as an integral and integrated aspect of health care. In essence, home based care can be considered as an alternative to traditional institutionalized care, focusing on palliative care in the home. The training that care givers received was very much sufficient to help them to provide excellent services under the circumstances. Refresher course is needed for new personnel, and management skills are necessary for supervisor to be able to organization properly.

Home based care models in general adopt a holistic approach to care. Physical, social, psychological, emotional, economic and spiritual factors are all taken in to account and considered collaboratively with and within the community setting. Home based care modals also aim to offer basic and essential components of primary health care adhering to basic principles in health care and development (Moetlo GJ, 2011). Home based palliative care services are becoming increasingly popular with care being taken to the doorstep of the patient. Ideally, this is where people are most comfortable at the end of their lives, surrender by their loved ones.

It is also well suited to conditions in India where a family member is usually available and willing to nurse the sick person. It is also coast effective as it does not entail doctors and nurses' fees and travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments. MC Dermott identified 88 home care programs rather than services that provide occasional visits (Divya Khosala).

1.4 Integrated Home Based Care

This model works by linking all service providers with patients and their families in a continuum of care .the aim is to embrace mutual support between the different systems: patient, family, home based carer, hospital, clinic, and NGO. This system allows for referral between all partners as trust and capacities among these partners develop. The patient and family are the focus of the care and support. The small group is supported by a larger network of services (home based carers, clinics, hospital), and the larger community (Uys and Cameron, 2003). The care given is based on home based care and palliative care standards. Its primary purpose is the prevention of illness, and related complications, by increasing openness and understanding among participants, hereby changing behavior (Louden, 1999). An early review of the impact of home care found that there was no effect on mortality and that it may reduce entry to long-term residential care. However, the review contained few randomized controlled trials (Hedrick et al. 1989).

1.5 Home- Based Palliative Care Program Goals

The home-based program is designed to improve care for patients with advanced complex illness in these ways:

- Improve symptom management and quality of life
- Help patients clarify their values to direct care decisions
- Avoid unnecessary hospitalization through care coordination and medical management
- Develop strong linkages with the PCP to ensure a collaborative approach

1.6 Models of Home Based Care

Thus far, most home based care services have been established through unsystematic, needs-based efforts (Uys and Cameron, 2003). Home based care organizations recognize the importance of providing home based carers with adequate training

These training should include:

- General basic nursing care
- Training primary caregivers in home based care
- Counseling services of patients and families
- Assessments of basic needs (food, shelter, cloths etc)

A number of different systems on home based care have been reported on in the literature namely Uys and Cameron (2003); Louden (1999); and Defilippi (2005):

1.6.1 Single service home based care

In this model, one service provider (a hospital, a clinic, a NGO, or a FBO) organizes home based care by recruiting volunteers, training them, and linking them to patients and their families at home (Uys and Cameron, 2003). While this is largely how most home based care initiatives started out, it soon became evident that networking with other stakeholders was crucial if the intention was to provide holistic and adequate home based care.

1.6.2 Informal home based care

In this model, families are helped to care for their sick members in their own homes, with the informal assistance of their own social network. Nobody has any specific training or external support, and there is no structured or organized intervention (Uys and Cameron, 2003). Informal home based care is very strenuous because those home based cares have to deal with the burden of lack of necessary skills, training, knowledge and emotional tenacity to care and support their patients.

1.7 Benefits of Home-Based Care

As discussed by Uys and Cameron (2003), the benefits of home based care may be summarized as follows:

- It affords the patient and the family time to come to grips with the illness, and the impending death of the patient.

- It is less expensive for the family because problems with transport to the hospitals/ clinics, time spent on hospital visits, and other related costs are reduced. Relatives can care for the patient while doing other chores.
- Care is more personalized, and the patient is likely to feel less isolated from family and friends.
- People prefer to face ill health and death in familiar surroundings rather than a clinical hospital ward.
- Home based care is less expensive for the country than institutional options (hospitals, hospices) since periods of say at those institutions are reduced.

Kaiser Permanente developed a home-based model of palliative care that uses an interdisciplinary team of providers to manage symptoms and pain, provide emotional and spiritual support, and educate patients and family members on an ongoing basis about changes in the patient's condition. One randomized controlled trial and one comparison-group study showed that the program increases patient satisfaction, increases the portion of patients dying at home rather than in the hospital, and reduces emergency department visits, inpatient admissions, and costs.

1.8 Hospital- Based Palliative Care

Hospital-based palliative care comes into play following a patient's hospital admission, and prior to discharge. It is important to remember that hospitals are acute facilities that strive to restore patients to optimum function. Very simply, this means that they focus on therapeutic, rehabilitative measures. When that is not a viable option due to a patient's terminal or life-limiting disease, the hospital-based palliative care team can assist the physician in structuring a plan of care that strives to maximize quality of life while managing pain and symptoms. In this situation, the palliative care team might suggest an early hospice referral, as the patient would be leaving the hospital setting. Generally, while the patient's doctor and the hospital-based palliative care team make the referral, the patient and family also participate in the decision, so that the outcome best benefits and supports the patient's desires.

The physician must be confident the hospital-based palliative care team incorporates holistic care at its very base, including ensuring the patient's physical comfort, providing emotional and psychological support, and supporting shared decision-making. In addition, the patient's physicians should also be confident that the hospital-based palliative care team coordinates the care across different care settings and involves the patient and family as appropriate.

The physician should expect the following from the hospital-based palliative care team:

- Evidence-based symptom palliation and psychological support
- Shared decision-making that supports both the patient and the family or caregiver
- Dignity and respect regarding the patient's cultural values
- Practical, financial and legal assistance for patients and families

Coordination of care across the health care setting that helps patients move from one setting to another (e.g., from hospital to home) in a seamless fashion The hospital-based palliative care team can work closely with the local hospice agency once patients have completed all therapies and have a prognosis of six months or less. I have found that when working with physicians, patients and families who are considering hospice care in the last months, everyone appreciates a coordinated health care approach, which helps guide the patient to navigate the system, providing appropriate care at each stage. A hospice nurse on the hospital-based palliative team can advise as to when the patient would benefit more from hospice services, and advocate for the patient and his or her family regarding those services.

The hospital-based palliative care team offers very important services for the patient, but those services vary from hospital to hospital, and not all hospitals have such teams. Hospice services and team members are the same, however, from hospice agency to hospice agency, as mandated by Medicare. Both hospital-based palliative care teams and hospice agencies strive to provide an interdisciplinary approach to care that takes into account the patient's physical, social, psychological and spiritual well-being. Whether a patient receives care from the hospital-based team or the hospice team, both must strive to provide patient and family-centered competent and compassionate care. This allows for a life closure with dignity and respect—hallmarks of all palliative care.

SUMMARY

The palliative care movement is one example of how health services can go well beyond the biomedical model of health and be seen as an affirmative act of living with dignity even whilst accepting that death is an inevitable part of life. Health related quality of life is increasingly used in health care research, particularly in palliative care. An objective of present study is to evaluate effectiveness of palliative care service and to compare the effectiveness of services receiving through home based and hospital based palliative care in Thrissur district. Palliative care has been recognized as essential health care which should be comprehensive, accessible and appropriate to the community they serve. Family is the most cherished social institution in India. The majority of the patients like to spend their last years of life with their family members. Social, psychological, religious and spiritual net works are strongest at home. If it is lacking in that family home based palliative care is essentials. At the same time hospital based palliative care also play major role in caring of sick people. So the researcher would like to conduct a comparitative study on home based palliative care and hospital based palliative care.

CHAPTER – II

REVIEW OF LITERATURE

REVIEW OF LITERATURE

The review explores the definition of home based care and the history of this model of care. An overview of the different home based care models is highlighted and a comparison is made of home based care and hospital care.

PALLIATIVE CARE

Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support to from diagnosis to the end of life and bereavement. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO).

When there is no cure for an illness, palliative care tries to make the end of a person's life as comfortable as possible. This is done by attempting to relieve pain and other distressing symptoms while providing psychological, social and spiritual support. Carers and family are also offered emotional and spiritual support. This is called a 'holistic' approach to care.

Some of the literatures collected from reliable sources and relevant to study mentioning below:

1. **Kerala state adopts palliative care in Primary Health Center; Express health care ; article(September 2009)**

In a study done in Malappuram district of Kerala, it was found that around 40 per cent of those people who are dying would have benefited from applying the principles of Palliative Care (PC) in their management. In Kerala, with a population of 32 million and a crude death rate of 6.3 (Reference: Census 2001) around 80,000 dying patients and their families would be benefited each year. To this, if we add the number of people living for years with chronic conditions the total number will be much more. Taking cue of this, in a revolutionary decision, the Kerala Government has issued an order that integrates PC with the primary healthcare system run by the Health and Family Welfare Department.

This step is a follow-up on the PC policy issued by the Government in 2008. "The Government of Kerala has probably become the first Government in the whole world to officially integrate PC into primary healthcare," commented Dr Suresh Kumar, Director, Institute of Palliative Medicine, Kerala. The circular has laid down a series of guidelines for the delivery, administration and review of PC from the PHC to the Directorate of Health Services.

At present, there are around 100 palliative care units in Kerala. The guidelines stress the role of PHC, as the epi-centre of the actual delivery of PC. An elaborative reporting system has been put in place. It also establishes the procedures for fixing responsibilities. The PHC will play a strategic role in PC management. At the PHC, there will be an outpatient clinic atleast once a week, medicines will be issued to the patients for upto six weeks (unlike three-five days for ordinary patients), and a trained field staffer would go on home visits, on rotation-basis. The PHC will also liaise with the local panchayats or municipalities.The District Medical Officer (DMO) will ensure that doctors, nurses and the field staff are adequately trained in PC.

2. Research focus in palliative care ; Bidhu K. Mohanti, Indian Journal of palliative care, medknow publication 2011, January

Research in health care has always fascinated the mankind. The benefits ofpenicillin, safety of surgery under anesthesia, global eradication of small pox by vaccination, discovery of X-rays, and our recently unfolding human genome project are some of these examples of medical research. Advances in palliative care are made with a focus to address the quality of medical practice and commercial establishments who have a stake in the palliative care practice.

Challenges in practicing palliative care

The reasons to conduct research in palliative care are that there at many levels within our health system.

Fifty percent of the patients with cancer are not cured of their disease. However, with improved treatments, even those with advanced stage may live for many years. Providing palliative care for those who are incurable, and for patients in advanced stage concurrent with anticancer therapy, has been proposed to improve their quality of life.

The limited availability of palliative care service structures within a hospital or outside make it difficult for the patients and their families to go through the terminal phase of disease and dying. This is further compounded by the lack of an adequate number of health professionals trained to deliver the palliative and end-of-life care. These infrastructure and personnel deficits are observed even recently in many developed countries like the USA and Germany.

The physicians and nurses who deliver community health care are not educated and trained in the domains of palliative care, whereas a large part of managing the patients with life-threatening diseases like cancer and other end-stage conditions require medical attention nearer to their homes.

Availability and procurement of morphine, an essential drug in palliative care, is often an obstacle in many countries. Although relief from pain, distressing symptoms and dignity in death is considered as rights of patients with advanced cancer and other end-stage diseases, recent reviews and observational studies describe considerable dissatisfaction, indicating that there are still opportunities for improvement.

3. Home-based palliative care in Kerala, India: the Neighbourhood Network in Palliative Care.

Libby Sallnow, Suresh Kumar, Mathews Numpeli, Neighbourhood Network in Palliative Care, Institute of Palliative Medicine, Calicut, Kerala, India

The Initiation of the Neighbourhood Network in Palliative Care.

In 1993, the Pain and Palliative Care Society (PPCS) was set up in the grounds of a medical college in northern Kerala, a clinic committed to relieving the pain and suffering of patients with advanced disease.

Although a home-care service was offered as an extension of the out-patient clinic, it became apparent that this model was not adequate to reach all those in need, and working within a biomedical paradigm of disease meant important aspects of patients' suffering were not being addressed. It was this recognition that resulted in the formation of the NNPC in 2001.Kerala has a long tradition of social activism and many groups already involved in community service were interested in helping deliver palliative care services in their area. With the support of the medical and nursing teams from PPCS and link centers, community owned units were set up in rural areas. The community embraced the new services and the training courses to become a volunteer quickly developed waiting lists. The rights and needs of the terminally ill were taken on by community members. In the words of one community volunteer: 'In many gramsahbas (local government meetings) they have begun to hear raised voices not only about the state of the roads and electricity, but of the care for the terminally ill'.

Palliative care in Kerala has now become a social movement. A regional Palliative Care Day was created on 15 January 2004, marked with functions at local and regional level.

The media have been quick to endorse the movement. The local language newspaper, *Malayala Manorama*, the largest circulating regional newspaper in India with an estimated readership of over 9 million, has run a 3-month campaign in collaboration with the Institute of Palliative Medicine entitled 'Njangalundu Koode' (We are with you). The response was overwhelming, with over 50,000 calls in the first 3 weeks of the campaign alone.8 The campaign has recently won national awards for developmental journalism. Palliative care has become an advantageous movement for politicians to support and many local political candidates include support for the local centre as part of their manifesto. Due to this public endorsement, the Government of Kerala has pledged to support the movement. In 2008, the Government announced the first national policy on palliative care for Kerala. This was written in discussion with leaders of the NNPC and placed home care at the centre of the policy.

4. Impact of a home-based social welfare program on care for palliative patients in the Basque Country (SAIATU Program), BMC Palliative Care *2013.*

Emilio Herrera Molina, **Roberto Nuño-Solinis**, **Gorka Espiau Idioaga**, **Silvia Librada Flores**, **Naomi Hasson** and **Juan F Orueta Medía**.

In the developed world, some 10,000 people per million population die every year. Some 70% of the total population lives through a period of terminal illness lasting several months before their eventual death, whether it be a type of cancer (2,500 cases per million population) or the final stage of deterioration of non-oncological illnesses (approximately 4,500 cases per million population). It has been accepted internationally that the largest proportion of healthcare costs incurred by a citizen are generated in the final months of life. We are therefore discussing the largest source of costs to the healthcare system, an issue to which insufficient attention has been paid. In these cases, both the symptoms themselves and the complexity of accompanying circumstances cause a high degree of suffering in the patient and a social and family crisis in his immediate environment, as well as incurring the largest share of healthcare expenditure in the life of each respective patient.

Palliative Care (PC) has been scientifically demonstrated as a truly effective tool in both welfare and organizational terms, complementing appropriate medication and medical care with psychological, social and spiritual support for patients and their careers.
The SAIATU in-home care program is a social innovation project launched in February 2011 in Guipúzcoa, with the aim of providing a set of in-home social support services to complement clinical palliative care, in order to improve comprehensive care for people with advanced and terminal illness and their families. This has entailed widening the scope of the classic model of primary care in palliative patients, expanding the traditional model to a cross-cutting action framework.

Currently, the program provides care in complex social situations, or in cases requiring attendance by clinical teams to provide appropriate symptom control, which requires the assistance of a social support network to facilitate the interventions of Osakidetza palliative care teams.

This new care model for Palliative Care patients forms part of an innovative approach, which aims to co-ordinate social services and healthcare in the field of palliative care. This approach is currently thriving in other health systems internationally, including the Canadian and British health systems, and seeks to provide both the best possible comprehensive care and efficiency in the provision of complementary health and social services .
SAIATU has been the first such experience in Spain, and the first internationally which combines the quantification, analysis and impact assessment of the reduction of healthcare resource usage by end-of-life patients, based on a pilot study of in-home social care for palliative care patients in the Basque Country.

The evaluation of the program, conducted in January 2012, has attempted to compare the difference in the intensity of health care provided to end-of-life patients in traditional services and in specialised Palliative Care services, but, for the first time, adding to the second group the effect of a social service trained in Palliative Care.

SAIATU could become a benchmark for an innovative model of home-based palliative care, focusing on the complementary aspects of healthcare; namely, social welfare and companionship. It is the first program to define a specific portfolio of services directed at the social welfare and support of end-of-life patients. This will allow the creation of new professional profiles to carry out this type of work, as well as clarifying which capabilities should be fostered in the training of in-home support staff, so that in the future they will be able to care for patients with advanced disease and high levels of dependency (a basic tool to cope with the socio-demographic changes we are currently undergoing).

The current project could be a graphic demonstration of an important solution to improved efficiency in the health system, through investment in resources outside the health system; in this case, in the social sector. Should the current hypothesis be confirmed, the creation of a reserve of appropriately trained home care professionals would lead to a more community-based model of healthcare, resulting in a more economical expenditure of the total resources used in the integrated care process.

5. Home-based functional walking program for advanced cancer patients receiving palliative care: a case series. Published on May 11, 2013.

Sonya S Lowe, Sharon M Watanabe, Vickie E Baracos and **Kerry S Courneya**

Among the most common distressing symptoms facing patients with advanced cancer is loss of physical function. Its underlying etiology is multifactorial, with increasing fatigue, muscle wasting and generalized debility all contributing to this phenomenon. Loss of physical function impedes the patient's ability to perform activities of daily living, and increases dependence on caregivers leading to additional emotional and psychological burden The importance of keeping mobile is linked to maintaining independence and overall quality of life [QoL] in patients with advanced cancer. Increasing attention has been given to physical activity as a QoL intervention in cancer patients. Physical activity interventions can improve cancer-related fatigue and physical functioning in early stage cancer patients. However, these benefits have not been confirmed for patients at later stages of cancer. There is preliminary evidence that select patients with advanced cancer express willingness to participate in a physical activity intervention, with positive benefit on some supportive care outcomes.

The aim of this study was to examine the initial development and pilot testing of a physical activity intervention in patients with advanced cancer receiving palliative care. Based on our pilot survey data, there was a majority preference for home-based, solo interventions, with walking being the most preferred activity. Therefore a modified home-based functional walking program was designed to incorporate the specific physical activity preferences of this sample, and a similar recruitment strategy was adopted.

There are a number of feasibility issues deserving of attention from this study. From our pilot survey study, we were able to recruit 50 patients over a 7 month period. using the same eligibility criteria and local recruitment strategy, however, we were only able to recruit 9 patients over a 6 month period. A total of 504 patients were screened through the RPHCP and CCI outpatient radiotherapy units on behalf of all palliative care research studies that were open for accrual during that 6-month period, however only 15% (96/504) consented to being contacted with regards to this particular study. In both RPHCP and CCI settings, the first contact was such that the patient's interest in being contacted by the study coordinator took precedence over obtaining physician-estimated survival; those patients who refused, therefore, may not have fulfilled all eligibility criteria at the time of initial screening of the 96 patients who consented to being contacted by the study coordinator, 53% (51/96) fulfilled all eligibility criteria for this study. Therefore of all patients who consented to being contacted by the study coordinator and who met all eligibility criteria for this study, our accrual rate was 18% (9/51). Locally, this accrual rate is comparable to Hutton et al.'s study of dietary intake in 151 patients with advanced cancer, wherein the authors reported an estimated 21% accrual rate from both the CCI and RPHCP. Elsewhere, Porock et al. reported a recruitment rate of 46% (11/24) in their pilot study of 4-week home-based exercise program in home hospice care patients, with incomplete information as to attrition rates and reasons for withdrawal. Oldervoll et al. reported a recruitment rate of 58% (231/400) in their recent RCT, however the reasons behind refusal to participate were not reported; 36% of the intervention group, versus 23% of the control usual care group, were lost to follow-up primarily due to disease progression. Compared to the 104-day median survival of our pilot survey sample the median survival of the 9 consented participants in this study was 92 days. It is therefore likely that our participants were further along the cancer trajectory than those of Oldervoll et al. Untimely attrition over a 6-week period in this population with such limited prognosis is not unexpected.

From our pilot survey, the majority felt willing and able to participate in a physical activity intervention. The ability to participate in a physical activity program, however, may fluctuate depending on patient-reported symptoms: 69% (35/51) of eligible patients declined consent to the study because of severe symptoms, with fatigue being the most common reported symptom. These findings concur with Mercadante et al.'s prospective study of 400 palliative home care patients with a mean survival of 52 days, wherein there was an increase in fatigue scores over time, with a peak in symptom intensity and frequency at the lowest levels of Karnofsky performance status of the 9 patients who enrolled in our study, 6/9 dropped out with the most common reason being admission to acute care for severe symptoms. This rate of attrition is higher when compared to large palliative care trials; Oldervoll et al's recent RCT reported that 36% of the intervention group, versus 23% of the control usual care group, were lost to follow-up, primarily due to disease progression. In contrast, 5/6 dropouts occurred within 4 weeks of starting our physical activity intervention. Given the shorter median survival of our pilot survey sample, consideration was given to maintain the intervention as long as it was feasible and safe for the patients.

6. Innovative models of home-based palliative care

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Palliative care means patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and [facilitating] patient autonomy, access to information, and choice. At its core, palliative care is a field of medicine aimed at alleviating the suffering of patients. As a "philosophy of care," palliative care is appropriate for various sites of care at various stages of disease and all ages of patients. While hospice care is defined by the provision of palliative care for patients at the end of life, not all palliative care is hospice care. Rather, palliative care is an approach to care for any patient diagnosed with a serious illness that leverages expertise from multidisciplinary teams of health professionals and addresses pain and symptoms.

Palliative care addresses suffering by incorporating psychosocial and spiritual care with consideration of patient and family needs, preferences, values, beliefs and cultures. Palliative care can be provided throughout the continuum of care for patients with chronic, serious, and even life-threatening illnesses.1 to a degree, all aspects of health care can potentially address some palliative issues in that health care providers ideally combine a desire to cure the patient with a need to alleviate the patient's pain and suffering.

Many Medicare-certified home health agencies also operate Medicare-approved hospice programs. Home health agencies have a heightened perspective on patients' palliative care needs. Because of the limited nature of the Medicare hospice benefit, home health agencies have built palliative care programs to fill unmet patient needs. Home health agencies often provide palliative care to patients who may be ineligible for the hospice benefit or have chosen not to enroll in it. These programs are particularly attractive to patients who would like to pursue curative treatment for their serious illnesses or who are expected to live longer than 6 months.

Home health patients with advancing or serious illness or chronic illness are candidates for a palliative care service. For these patients, the burden of their illness continues to grow as distressing symptoms begin to more regularly impact their quality of life. As they continue curative treatment of their illness, they would benefit from palliative care services that provide greater relief of their symptoms and support advanced care planning. Palliative care interventions become an integrated part of the care plan for these patients. Home health agencies serving patients with chronic or advancing illnesses will see care benefits from incorporating palliative care into their team's skill set.

Two innovative examples of home health–based programs that include a palliative care component have been reported in peer-reviewed literature to date: Kaiser Permanente's In-Home Palliative Care program and Sutter Health's Advanced Illness Management (AIM) program.

7. Hospital-Based Palliative Care Consultation: Effects on Hospital Cost

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Context: Palliative care consultation teams in hospitals are becoming increasingly more common. Palliative care improves the quality of hospital care for patients with advanced disease. Less is known about its effects on hospital costs.

Objective: To evaluate the relationship between palliative care consultation and hospital costs in patients with advanced disease.

Design, setting, and patients: An observational study of 3321 veterans hospitalized with advanced disease between October 1, 2004 and September 30, 2006. The sample includes 606 (18%) veterans who received palliative care and 2715 (82%) who received usual hospital care. October 1, 2004 and September 30, 2006.

Main outcome measures: We studied the costs and intensive care unit (ICU) use of palliative versus usual care for patients in five Veterans Affairs hospitals over a 2-year period. We used an instrumental variable approach to control for unmeasured characteristics that affect both treatment and outcome.

Results: The average daily total direct hospital costs were $464 a day lower for the 606 patients receiving palliative compared to the 2715 receiving usual care ($p<0.001$). Palliative care patients were 43.7 percentage points less likely to be admitted to ICU during the hospitalization than usual care patients ($p<0.001$).

Comments: Palliative care for patients hospitalized with advanced disease results in lower costs of care and less utilization of intensive care compared to similar patients

receiving usual care. Selection on unobserved characteristics plays an important role in the determination of costs of care.

Palliative care during hospitalizations for advanced disease was associated with significantly lower direct hospital costs, including costs for pharmacy, nursing, laboratory, and radiology compared to costs for usual care patients with advanced disease. Our findings are consistent with a recent multicenter randomized controlled trial (RCT) showing that patients with life-limiting illness randomized to an inpatient palliative care service had fewer ICU admissions on readmissions and lower costs compared to patients randomized to usual hospital care.42 Our results also fit with a large multicenter observational study by Morrison and colleagues43 demonstrating significantly lower overall hospital, ICU, and laboratory costs for patients receiving palliative care consultation compared to propensity score matched usual care patients.

8. Palliative Care: A Long-Term Care Perspective

by Bridget Wohlers, MSN, GNP-BC, ACHPN, Karen Roth, MSN, ANP-BC, ACHPN, & Linda Janelli, RN, BC, EdD

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Demographics demonstrate that the fastest growing segment of our society are those who are 85 years or older. While most older adults would acknowledge that given the choice they would prefer to die in their own home, many will die in long-term care facilities. The prediction is that by 2020, 40% or 2 out of 5 older adults will die in a nursing home. Numerous studies have demonstrated the failure and/or the inability of these facilities to meet the palliative and end-of-life needs of the residents they serve.

Palliative care, which is often confused with hospice care, is a philosophy of care with a unique set of interventions intended to improve and enhance quality of life in order to provide a "good" death. The World Health Organization defines palliative care as "an approach to care which improves quality of life of patients and families facing life-threatening illness, through prevention, assessment and treatment of pain and other physical, psychological, and spiritual problems." One of the fastest growing trends is hospital palliative care. According to data collected by the Center to Advance Palliative Care, the National Palliative Care Research Center, and the American Hospital Association, about 63% of hospitals now have palliative care teams. Less is known about palliative care in the nursing home environment. Many long-term care facilities are beginning to view palliative care as a subspecialty that needs to be included in their provision of care. Currently, federal regulations often emphasize, and reimburse for curative efforts rather than for end-of-life interventions. This has promoted a strong, ingrained culture of aggressive medical treatment in the nursing home environment. In the future, the hope is that long-term care residents with a life expectancy of six months or less can navigate a seamless transition from palliative care strategies to hospice services.

In February 2011, New York became the second state to enact a law requiring health care providers to disseminate information on end-of-life options to terminally ill patients. The Palliative Care Information Act (PCIA) states that "If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including .. prognosis, risk and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management". The goal of PCIA is clear, but what is still unclear is the interpretation of the law - is it enforceable, and will it be effective. If nothing else the PCIA has focused attention on the need for an open and honest discussion about end-of-life. The purpose of this descriptive study was to determine the knowledge, practice, and attitudes of nursing homes in New York State regarding the implementation of the Palliative Care Information Act.

9. COMPARISONS BETWEEN HOSPITAL-BASED CARE AND HOME BASED CARE (BEECHEY, J.2004:76)

Hospital-Based Care	**Home-Based Care**
High costs to set up and run	Low cost in comparison to hospitals
Focus of care is on the disease	Focus is the whole person
Quality of medical care is good	Quality of medical care is good
Non-medical care is not available	Non-medical care is available
Relationships exists with medical staff only	The patient is part of a web of relationships including medical staff and volunteers
Awareness and prevention are regarded as separate activities	Awareness and prevention are integrated

Patients are referred to outside organizations to access long-term, holistic care.	Patients are helped to access hospital treatment when needed.

10. BENEFITS OF HOME-BASED CARE: Uys and Cameron (2003)

- It affords the patient and the family time to come to grips with the illness, and the impending death of the patient.
- It is less expensive for the family because problems with transport to the hospitals/ clinics, time spent on hospital visits, and other related costs are reduced. Relatives can care for the patient while doing other chores.
- Care is more personalized, and the patient is likely to feel less isolated from family and friends.
- People prefer to face ill health and death in familiar surroundings rather than a clinical hospital ward.

Kaiser Permanente developed a home-based model of palliative care that uses an interdisciplinary team of providers to manage symptoms and pain, provide emotional and spiritual support, and educate patients and family members on an ongoing basis about changes in the patient's condition. One randomized controlled trial and one comparison-group study showed that the program increases patient satisfaction, increases the portion of patients dying at home rather than in the hospital, and reduces emergency department visits, inpatient admissions, and costs. Home based care is less expensive for the country than institutional options (hospitals, hospices) since periods of say at those institutions are reduced.

CHAPTER – III

RESEARCH METHODOLOGY

RESARCH METHODOLOGY

TITLE OF THE STUDY

A comparative study on the effectiveness of home based palliative care and hospital based palliative care in improving the quality of life

STATEMENT OF THE STUDY

The goal of palliative care is to improve the quality of both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psycho-social and spiritual support. There is relatively little formal knowledge about patients needs. It may include caring out inmates' task such as washing, helping people to dress and go to toilet, or heavy task such as lifting. This kind of caring is usually performed by people with close kinship ties, often living in the same house and motivated by love and a desire to keep an older person out of an institution. Palliative care is provided by a team of doctors, nurses, counselors, social workers, and volunteers. So the researcher trying to evaluate the effectiveness of home based palliative care and hospital based palliative care. Home based care models in general adopt a holistic approach to care. Physical, social, psychological, emotional, economic and spiritual factors are all taken in to account and considered collaboratively with and within the community setting. Home based care modals also aim to offer basic and essential components of primary health care adhering to basic principles in health care and development .so though this research the researcher evaluating the effectiveness of home based palliative care and hospital based palliative care.

SIGNIFICANCE OF THE STUDY

Everyone has the right to security in the event of unemployment, sickness,, disability, widowhood, old age or other lack of livelihood in circumstances beyond his or her control.(Article 25 united nations universal declaration of human rights,2011). Through this study evaluating the effectiveness of home based palliative care and hospital base palliative care. The main aim of palliative care is to improving the quality of life of patients and supports them in all the levels of life. Home based palliative care and hospital based palliative care improving the quality of life. Palliative care aims to help the patient live as well as possible. Palliative care offers support to help family and caregivers manage during the patient's illness and in bereavement. As a person receiving palliative care, the patient is an important partner in planning their care and managing their illness. When people are well informed, participate in treatment decisions and communicate openly with their doctors and other health professionals, they help make their care as effective as possible. People can continue treatment aimed at curing illness. The focus of palliative care is maintaining quality of life and meeting the needs of the patient, their family and caregivers. In Thrissur district there are 14 palliative care centers including both home based palliative care and hospital based palliative care. In this situation understanding the quality of life of palliative care patients is very significant.

OBJECTIVES

GENERAL OBJECTIVE

- To evaluate the effectiveness of home based palliative care and hospital based palliative care.

~~SPECEFIC~~ OBJECTIVES

- To study the socio-demographic details of the patients under palliative care
- To understand the quality of the life of the patients in home based palliative care.
- To understand the quality of the life of the patients under hospital based palliative care.

- To compare the quality of life of the patients under home based palliative care and hospital based palliative care.
- To understand the socio-demographic correlates of the quality of life of the patients under home based palliative care and hospital based palliative care.

HYPOTHESIS

Hypotheses are usually considered as the principal instrument in research. Its main function is to suggest new experiments and observation. In social science where direct knowledge parameters is rare, hypothesis testing is often used as strategy for deciding whether a sample data offers such support for a hypothesis so that generalizations can be made. Thus testing the hypothesis enables us to make probability statements about population parameters. The hypothesis may not be proved absolutely, but in practice it is accepted if it has withstood a critical testing (Kothari, 1990). The following were the hypothesis formulated for the present study.

H1: There is a significant difference between the quality of life experienced by the patients under home based palliative care and hospital based palliative care.

H2: Home based palliative care is more effective in improving the quality of life of the patients than the hospital based palliative care.

H3: There is a significant relationship between the socio-demographic variables and the quality of life experienced by the patients in home based palliative care and hospital based palliative care.

DEFINITIONS

THEORITICAL DEFINITION

➢ **Palliative care**

The WHO defined palliative care as "an approach that improves the quality of life of patients and their families facing the problem 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, psychological, and spiritual."

- **Home based palliative care**

According to the World Health Organization (WHO), home-based care refers to the provision of health services by formal and informal care givers within the home. The aim of home based care is ultimately to "promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death."

- **Hospital Based Palliative Care**

Hospital based palliative care refers to the provision of health services by formal care givers within the hospital. The aim of hospital based care is ultimately to "promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death."

- **Quality of Life**

Quality of life (QOL) in the context of advanced, progressive, incurable illness, is defined as the subjective experience of an individual living with the interpersonal, psychological and existential or spiritual challenges that accompany the process of physical and functional decline and the knowledge of impending demise (Byock and Merriman,1998).

OPEEATIONAL DEFINITION

- **Palliative care**

In this study palliative care is a type of care given to the terminally ill persons. It is a treatment given to the patients from the hospital, clinic or home. The age group of patients is between40 to 80 especially in the area of Thrissur district.

- **Home based care**

In this study home based care is a care given to the patients from their own home .It improves the quality of life of terminally ill persons. The aim of home based care is ultimately to “promote, restore and maintain a person’s maximum level of comfort, function and health, including care towards a dignified death.”

- **Hospital based care**

Hospital based care is a type of care giving to the patients from the hospital or clinics. The age group of patients is between40 to 80 especially in the area of Thrissur district.

- **Quality of life**

In this research quality of life refers to the subjective experience of palliative care patients in five dimension mainly symptoms, function, interpersonal, well-being, and transcendence. Both under the home based palliative care and hospital based palliative care patients.

PILOT STUDY

The researcher visited the centers of palliative care to know the feasibility and scope of the study in terms of availability of respondents, finalizing tools and methods of data collection and official permission to undertake study.

UNIVERSE OF THE STUDY

In this research the universe of the study is the palliative care patients in Thrissur district

UNIT OF THE STUDY

In any research studies unit is very important to clearly define the set of objects technically. The unit can be finite or infinite, homogeneous and heterogeneous in nature. In the current study, all the terminally ill patients who receive palliative care either at home or at hospital consists the universe of the study.

SAMPLE SIZE

Sample of the study consist of 80 terminally ill patients who presently receive palliative care either at hospital or at home. Forty patients were selected from home based palliative care and forty patients were selected from institutional based palliative care.

SOURCES OF DATA

- **Primary data**

The primary data collected from the home based palliative care patients and hospital based palliative care patients in Thrissur district

- **Secondary data**

The secondary data for the study collected from various books, journals, magazines, palliative care centers, news papers and internet

DESIGN OF THE RESEARCH STUDY

After the research problem having been formulated in clear cut terms, the next step would be preparing research design. In this, the researcher would have to state the conceptual structure within which research would be conducted. The research design has to be structured to collect the relevant evidence with minimal cost effect like - expenditure, effort, time and money. This can be achieved mainly on the research purpose. Research purpose can be divided into four categories, according to Kothari, 1990 categorized as exploratory, description, diagnosis and explanation.

In the present study a descriptive cum explanatory design was adopted. The descriptive design was adopted to understand the socio-demographic detail of the respondent and the quality of life experienced by the respondents.

Measurement Tools

Socio-demographic data schedule: The socio-demographic data for the present research is elicited using a semi-structured, pre-formatted schedule. This is a detailed schedule which was designed to collect data on the age, sex, education, religion, family income, marital status, duration of illness and the education of the patients. The purpose of administering this schedule was to gather as much data as required for statistical, descriptive and analytical purposes. The main purpose these questions are mainly to know the socio-demographic background of the patients and to better understand the influence of these socio-demographic variables on the quality of life experienced by them.

The Missoula-VITAS Quality of Life Index (MVQOLI): The Missoula-VITAS Quality of Life Index (MVQOLI) is an assessment instrument that gathers patient-reported information about quality of life during advanced illness. Maintaining optimal quality of life is a core goal of palliative and hospice care, and information gathered via the MVQOLI assists health care professionals in identifying and addressing patient concerns that affect quality of life. The MVQOLI has been used in many different healthcare settings including hospice, hospital, home health, long-term care (including assisted living), outpatient palliative care, disease management and pre-hospice programs. The MVQOLI was developed in 1995 by Ira Byock, MD, Melanie Merriman, PhD, and Barry Kinzbrunner, MD (Chief Medical Officer at VITAS Healthcare Corporation), and revised in 2004.The MVQOLI asks patients about 5 dimensions or domains of quality of life: symptoms; function; interpersonal; well-being; and transcendence.

PRE-TEST

Pre-test is the trail administration of a newly developed instrument to identify flaws or assess time requirements (Pliatet al, 1999). Socio-demographic data schedule and The Missoula-VITAS Quality of Life Index were administered to four respondents who received palliate care from hospital and home based care. All items were closely understood by the respondent and they answered well

DATA COLLECTION

The researcher has collected the data through the questionnaire from palliative care patients in Kannur district. The researcher collected data from 80 respondents; 40 respondents from the hospital based palliative care and 40 respondents from the home based palliative care.

EDITING CODIG AND TABULATION

The data processing is an important stage of work between data collection and interpretation. After collecting the data was edited by the researcher. Then it was classified and gave codes to each respondent. Researcher tabulated the data by using SPSS. Statistical computation is used for further interpretation.

ANALYSIS AND INTERPRETATION

The analysis and interpretation are based on the responses given by the 80 respondents. Processed data is presented in the analysis part with the help of tables and charts.

INCLUSION CRITERIA

- Age group of patients is above 40
- Patients should live with the family
- Physically and verbally responsive

EXCLUSION CRITERIA

- Patients with any psychiatric and neurotic disorder
- Age group of patients should not be below 40
- Patients should not use any day care facilities

DATA PROCESSING AND STATISTICAL ANALYSIS OF DATA

Test applied for the study	**Purpose of the test**
Descriptive statistics Frequency, Mean, Median, Mode, S.D, Range	• This test was used to find the frequencies of demographic variable measured at nominal level • This test was used to examine the pattern of central tendencies in individual variables and continues variables. • This test also described quality of life of the patients in home bases palliative care and institution based palliative care.
Chi-square	• This test was done to compare the variables which are categorical in nature. • To find out the association between the socio-demographic variables and quality of life experienced by them • Example: Educational grade achieved and type of marriage
Independent sample t-Test	• This test was used to find out statistical difference between independent groups (two) mean scores on the quality of life scale.
Karl pearson's correlation matrix	• The test measures the degree of association between two variables. A positive value for the correlation implies a positive association. A negative value for the correlation implies a negative or inverse association. • This was used to find the relationship between various continuous variables. • In this study, all the sub-domains of the scales were used to find out positive and negative association among the sub-domains.

Limitations

1. Geographically the scope of the study restricts its self to particular area only.

CHAPTERISATION

I. Introduction

The first chapter of the study includes the introduction palliative care, history, models of palliative care; home based and institutionalized palliative care and brief summary.

II. Review of literature

The second chapter deals with the review of literature related to study which was collected from books, article, magazines and website.

III. Research methodology

The third chapter deals with research methodology. It contains the Introduction, title of the study, statement of the problem, objectives of the study, universe, pilot study, research design, and tools of data collection, sources of data, pretesting, definitions, data processing and statistical analysis of data and limitations of the study.

IV. Analysis and interpretation

The fourth chapter consists of data analysis and interpretation

V. Findings and suggestions and Conclusion

The fifth chapter deals with the major findings of the study, suggestions and conclusion.

Annexure

- Bibliography
- Appendix

CHAPTER –IV

ANALYSIS AND INTERPRETATION

ANALYSIS AND INTERPRETATION

The present chapter deals with the analysis and interpretation of the data based on the interview schedule. The analysis and interpretation is designed along with the direction of the aim and objectives of the study. The objectives of the study were:

- To study the socio-demographic details of the patients under palliative care
- To understand the quality of the life of the patients in home based palliative care.
- To understand the quality of the life of the patients under hospital based palliative care.
- To compare the quality of life of the patients under home based palliative care and hospital based palliative care.
- To understand the socio-demographic correlates of the quality of life of the patients under home based palliative care and hospital based palliative care.
- To achieve the above said objectives in the present study the researcher used the following tools:

    1. Socio demographic data schedule (prepared by the researcher).
    2. The Missoula-VITAS Quality of Life Index (MVQOLI) (Ira Byock et al, 1995).

Objective 1: To study the socio-demographic details of the patients under palliative care

Table – 4.1

Gender of the Patient

Gender of the Patient		
	Frequency	Percent
Male	44	55.0
Female	36	45.0
Total	80	100.0
Religion of the respondent		
	Frequency	Percent
Christian	2	2.5
Hindu	62	77.5
Muslim	16	20.0
Total	80	100.0

The table no 1 shows the gender, religion, and marital status of the respondents. There are 44 (55%) male respondent and 36 (45%) female. Majority of the respondents were belonging to the Hindu religion. Among 80 respondents 62(77.5%) were identified as Hindu and 16(20%) respondents were identified as Muslims. Only 2 (2.5%) respondents were identified as Christians.

Figure – 4.1

Religion of the respondent

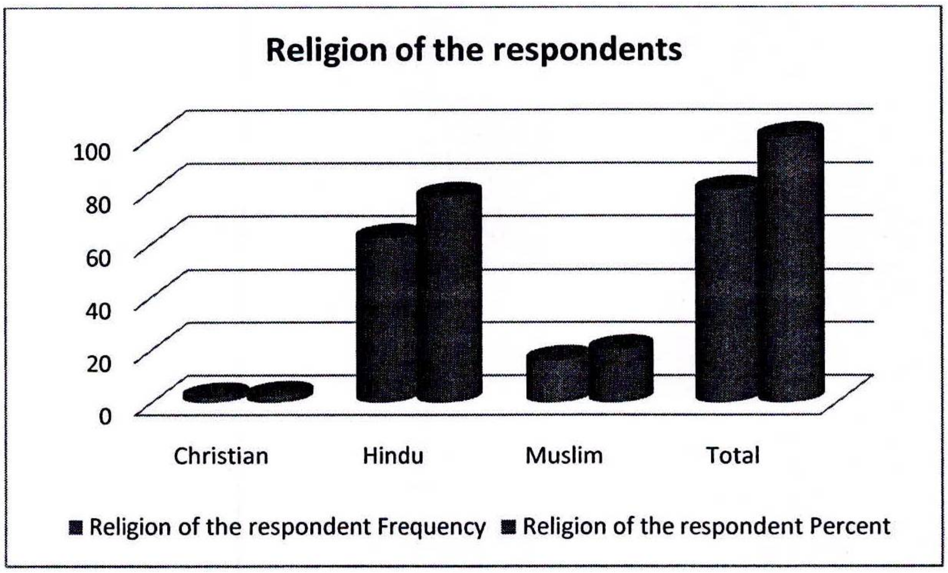

Table -4.2

Marital status of respondent

Marital status of respondents		
	Frequency	Percent
Single	3	3.8
Married Couples	67	83.8
widow/widower	10	12.5
Total	80	100

Table no 2 shows the marital status of the respondent. The marital status of the palliative care patients among 80 respondents 67(83.8) were married couples. The respondents leading single life was 3(3.8%). 10(12.5%) respondents were identified as widow or widower.

Figure -4.2

Marital status of the respondents

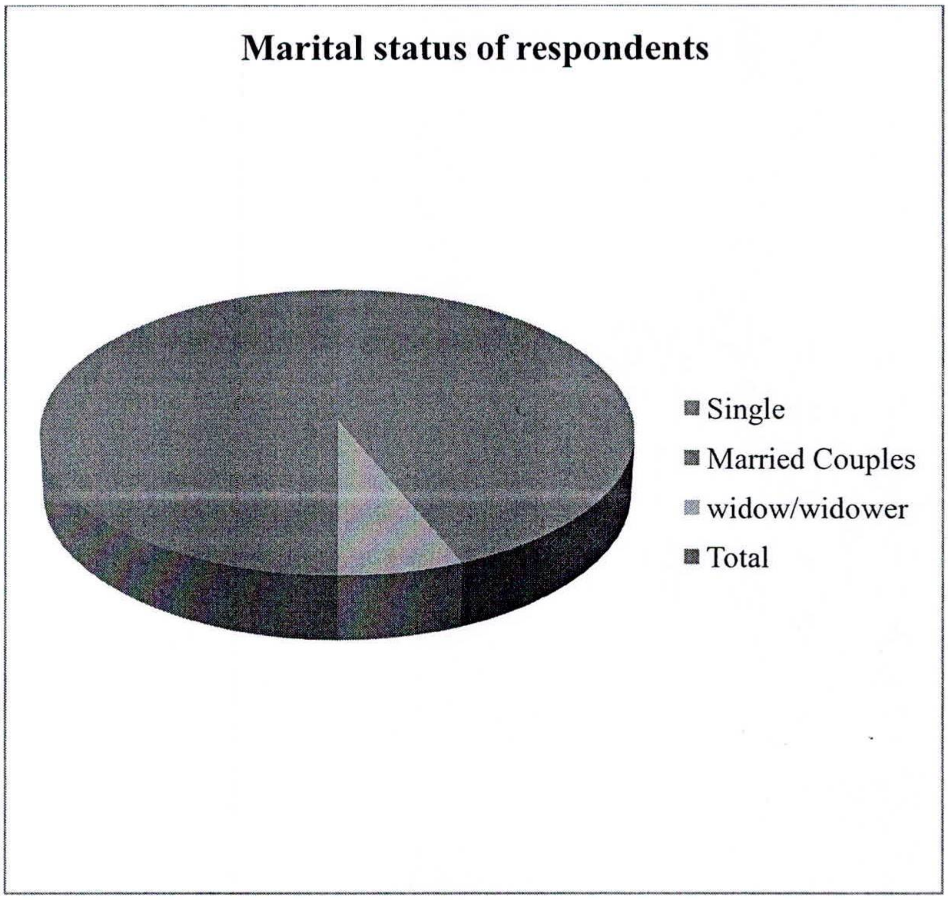

Table -4.3

The type of disease of the respondent in the palliative care

Type of disease		
	Frequency	Percent
Cancer	43	53.8
Cholesterol, sugar	19	23.8
Heart disease	18	22.5
Total	80	100.0

This table no 3 shows the type of the disease of the respondents in palliative care. There were 43(53.8%) respondents with cancer. Among the respondents19 (23.8%) were experiencing high level of sugar and cholesterol and 18 (22.5%) respondents were suffering from heart disease.

Total	80	100.0

This table no 4 reveals that the respondents relief from the treatment. Among 80 respondents 59(73.8%) were getting relief from the treatment. At the same time 21(26.3%) respondents were not experiencing relief from the treatment.

Table -4.5

How did the respondent come to know about palliative care?

How did the respondent come to know about palliative care		
	Frequency	Percent
Volunteers	38	47.5
Hospital	12	15.0
Relatives	8	10.0
Doctor	16	20.0
Others	6	7.5
Total	80	100.0

This table indicates that how respondents came to know about the palliative care. The majority of the respondents 38 (47.5%) came to know through volunteers; 15 %(12) of the respondent came to know about palliative care through hospital. ; 8 (10%) came to know through relatives; 20% (16) respondents came to know about palliative care through doctor; and 6 (7.5%) respondents came to know through others.

Figure-4.3

Figure showing the type of disease of the respondents in palliative care

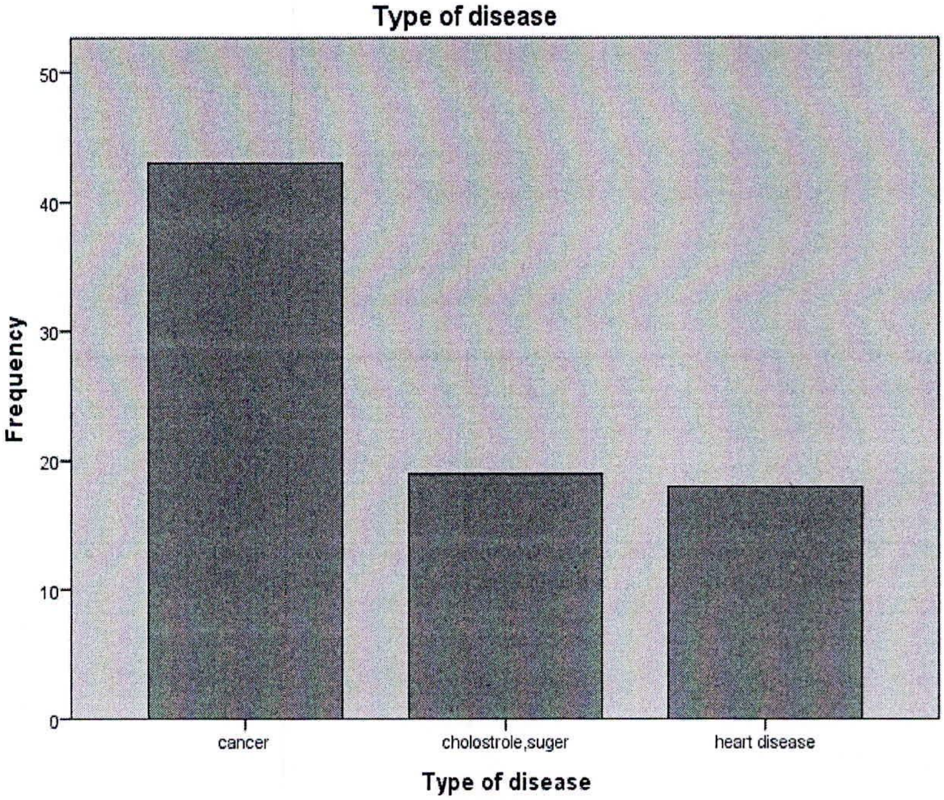

Table -4.4

The respondent's relief from the treatment

The respondent's relief from the treatment		
	Frequency	Percent
yes	59	73.8
No	21	26.3

Figure – 4.4

Figure showing how did respondents come to know about palliative care

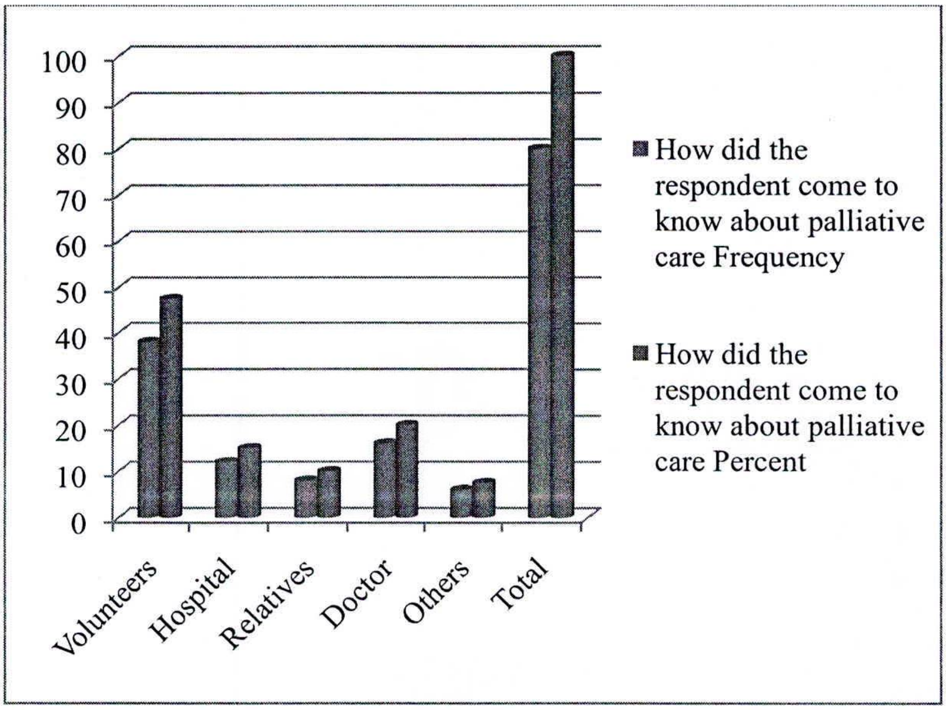

Table -4.6

Age of the patient

Age of the respondents		
	Frequency	Percent
40-50	7	8.8
51-60	15	18.8
61-70	28	35

71-80	29	36.3
80 above	1	1.3
Total	80	100

Above table reveals that the majority 36.3% (29) of the patients are the age group between 71-80. Among the 80 respondents 35 % (28) of the respondents were the age group between 61-70; 18.8% (15) respondents identified as the age group between 51-60. The age group between40-50 identified as 7(8.8) and there were only one identified as above the 80.

Figure – 4.5

Age of the respondents

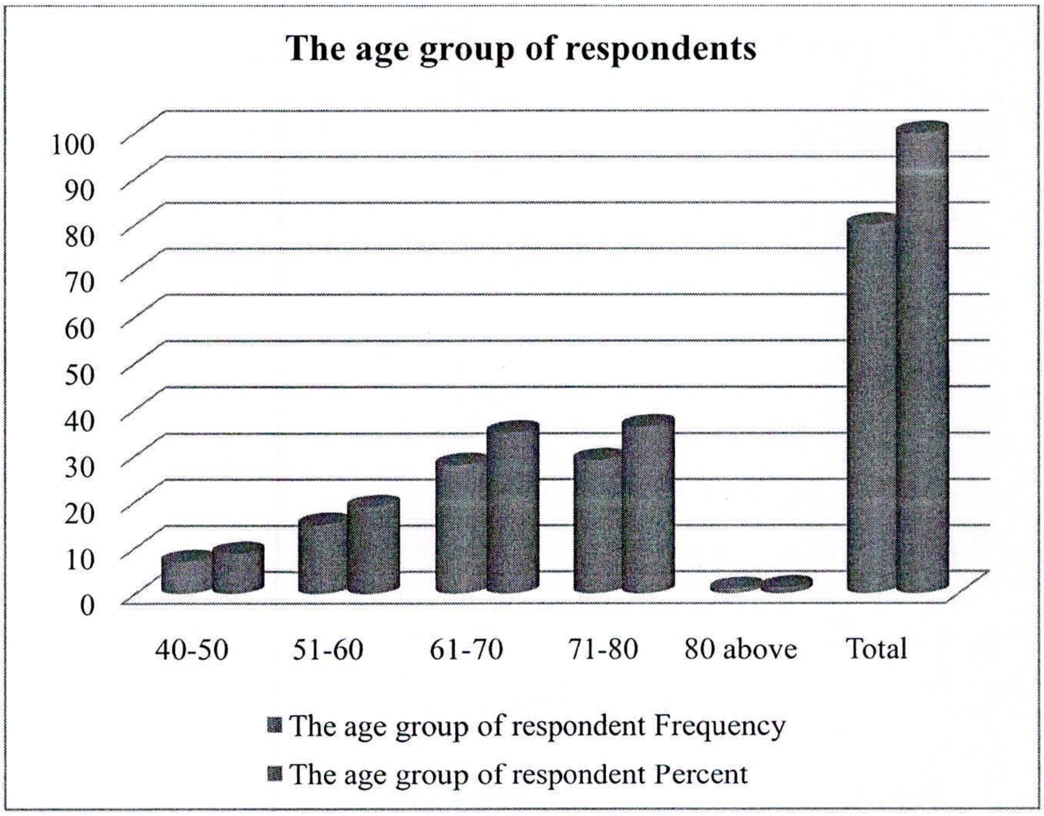

Table -4.7

The respondent's need for the care other than the care provided by the unit

The respondent's need for the care other than the care provided by the unit		
	Frequency	Percent
Yes	22	27.5
No	58	72.5
Total	80s	100
Specifying the care needed by the patients		
	Frequency	Percent
Counseling	6	7.5
More visits	11	13.8
Speech therapy	2	2.5
No opinion	59	73.8
Financial support	2	2.5
Total	80	100

This table shows the respondents need for the care other than the care provided by the palliative care unit.58 (72.5%) respondents were answered that they are satisfied with all they receive.22(27.5%) identified that they have desire to get little more services by the palliative care unit. Among the 22 respondents there were 6(7.5%) respondents who were in need of counseling; and there were 11(13.8%) respondents who were in need of the frequent visit and care of the personals in the palliative care; there were 2(2.5%) respondents who were in need of speech therapy; and there were 2(2.5%) respondents who were in need of financial support.

Figure-4.6

Figure showing the patients need other than the care provided by palliative care unit

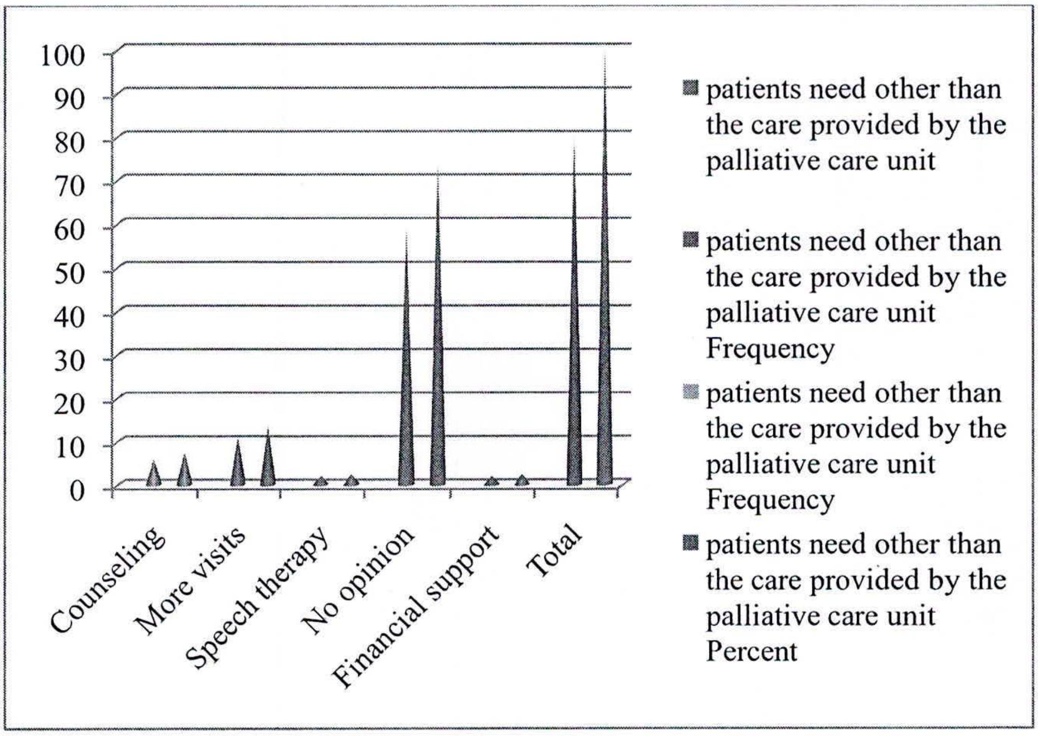

Table -4.8

Duration of respondents undergoing palliative care

Duration of respondent undergoing palliative care		
	Frequency	Percent
Less than 6 months	23	28.8
6-12 months	6	7.5
12-18 months	28	35
18-24 moths	7	8.8
24 months and more	16	20
Total	80	100

Table number 7 shows the duration of the respondent undergoing the care provided by the palliative care unit. There were 23(28.8%) respondents who were attending the treatment in a duration of less than 6 months; there were 6(7.5%) respondents who were getting the service of palliative care unit in time period of 6-12 months; there were 28 (35%) respondents who were given service in a time period of 18-24 months; there were 7(8.8%) respondents who were given service in a time period of 18-24 months; there were 16(20%) respondents who were given service in a time of 24 months and above.

Figure -4.7

Duration of respondents undergoing palliative care

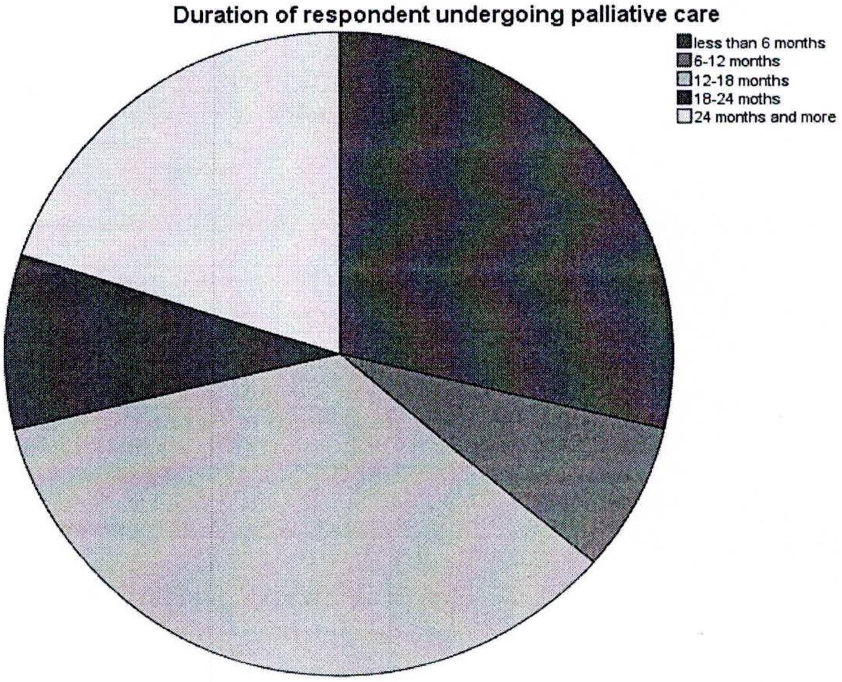

Table -4.9

Type of care receiving the patient

Type of care receiving the patient		
	Frequency	Percent
Home based care	40	50
Hospital based care	40	50
Total	80	100
Receiving home based care is more effective than receiving hospital based palliative care		
	Frequency	Percent
yes	80	100

Table number 8 shows the type of care received by the patients. There were 40(50%) respondents who were receiving home based palliative care and there were 40(50%) respondents who were receiving hospital based palliative care; the 80 (100%) respondents were desired to get or respondents thinking that home based palliative care will be more effective.

Figure – 4.8

Type of care receiving the patients

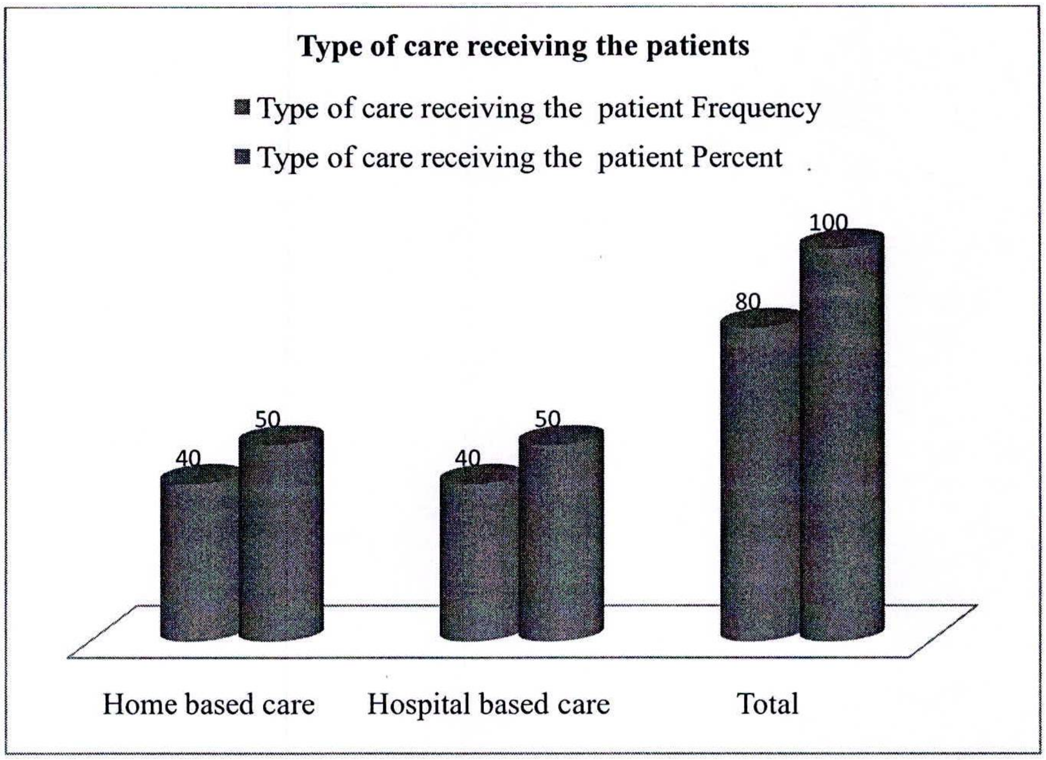

Table -4.10

The respondent's satisfaction of services provided by the doctor of palliative care unit

The respondent's satisfaction of services provided by the doctor of palliative care unit		
	Frequency	Percent
Highly satisfied	29	36.3
Satisfied	46	57.5
Not satisfied	5	6.3
Total	80	100

Table no 9 shows that the satisfaction of the respondents by the services of palliative care givers mainly by doctor. There were 29(36.3 %) respondents highly satisfied with the service of doctor in palliative care unit; and 46(57.5 %) respondents were satisfied; 5 (6.3%) respondents were not satisfied with the care provided by the doctor in palliative care unit.

Figure – 4.9

The respondent's satisfaction of services provided by the doctor of palliative care unit

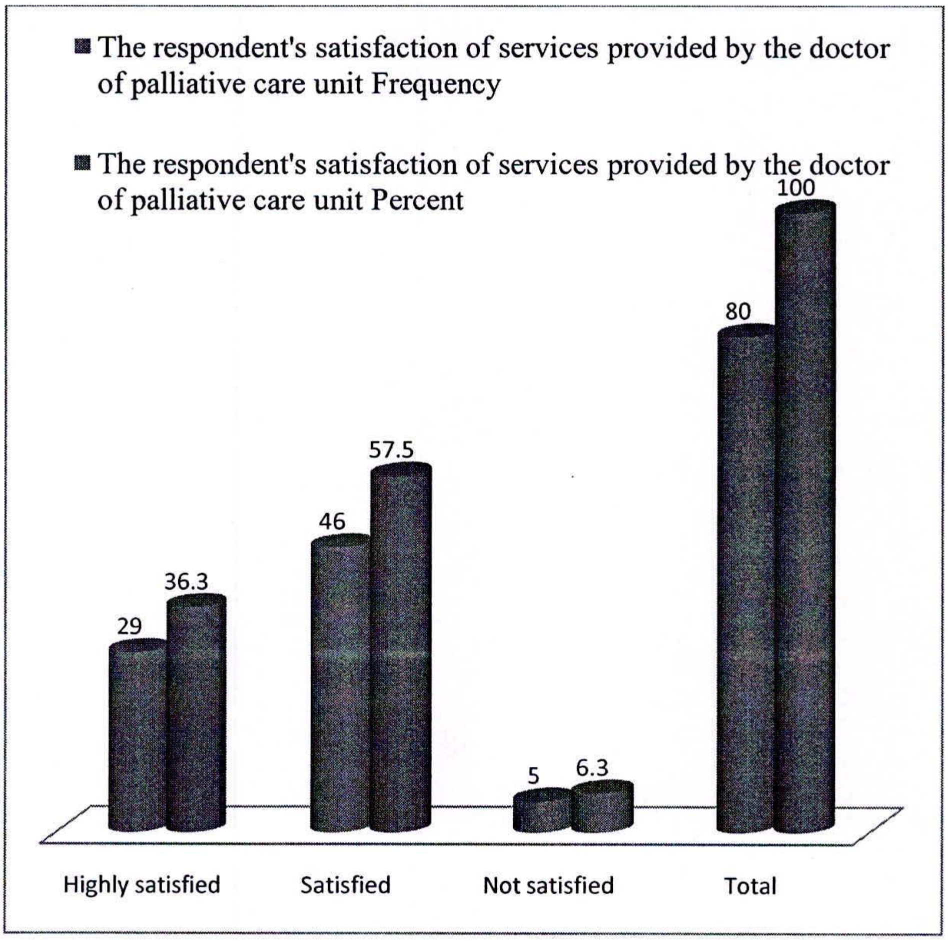

Table -4.11

The respondent's satisfaction of services provided by the nurse of palliative care unit

The respondent's satisfaction of services provided by the nurse of palliative care unit		
	Frequency	Percent
Highly satisfied	31	38.8
Satisfied	49	61.3
Total	80	100

The table no 11 shows the respondent satisfaction in the service provided by the nurse of palliative care unit. Among the 80 respondents 31 (38.8%) respondents were highly satisfied with the care provided by the nurse in palliative care unit. Majority of the respondent 49 (61.3%) were satisfied with the care provided by the nurse.

Table -4.12

The respondent's satisfaction of services provided by the volunteers of palliative care unit

The respondent's satisfaction of services provided by the volunteers of palliative care unit		
	Frequency	Percent
Highly satisfied	31	38.8
Satisfied	45	56.3
Not satisfied	4	5
Total	80	100

The table no 12 shows the respondent satisfaction in the service provided by the volunteers of palliative care unit. Among the 80 respondents 31 (38.8%) respondents is highly satisfied. 45(56.3%) were satisfied with the care and 4 (5%) respondents were not satisfied with the care of the volunteers in palliative care.

Objective 2: To understand the quality of the life of the patients in home based palliative care.

Table-4.13

Quality of life of patients receiving home based palliative care

Quality of life of patients receiving home based palliative care				
	N	Mean	Std. Deviation	Std. Error Mean
Symptoms	40	15.88	6.8987	1.0908
Function	40	12.463	11.332	1.7918
Interpersonal	40	18.288	9.4258	1.4903
Well-being	40	7.475	11.008	1.7405
Transcendent	40	12.175	6.7154	1.0618
Total	40	21.543	2.4668	0.39

Table no 13 shows the quality of life among the home based palliative care patients under 5 dimensions namely symptoms, functions, interpersonal, well-being and transcendent. The possible range of total score is 0 to 30 .the mean total score of quality of life is 21.5425 (SD=2.67) which means that the patients experienced fairly high level of quality of life. The possible range of sub scales are -30 to +30, there the mean score in symptom was 15.88 (SD=6.89); which means the Experience of the physical discomfort associated with progressive illness; perceived level of physical distress of patients in home based palliative care is fairly well. The mean score of function is 12.46 (SD=11.33); which means thefunctions and activities of daily living; experienced in relation to expectations are fairly well. The mean score of interpersonal dimension was 18.28 (SD=9.45); which means that they were able to invest more time in their personal relationships and they experience better quality of life. The mean score of well-being was 7.47 (SD=11.007); which means Self-assessment of an internal condition; subjective sense of wellness of home based care patients was less comparing to other dimension. The mean score of transcendent was 12.17 (SD=6.71).which means theexperienced degree of connection with an enduring construct; degree of experienced meaning or purpose in life is fairly well.

Objective 3: To understand the quality of the life of the patients under hospital based palliative care.

Table no-4.14

Quality of life of patients receiving hospital based palliative care

Quality of life of patients receiving hospital based palliative care				
	N	Mean	Std. Deviation	Std. Error Mean
Symptoms	40	1.525	14.80859	2.3414
Function	40	-5.8	23.41674	3.7025
Interpersonal	40	4.15	18.40645	2.9103
Well-being	40	-11.5	12.44938	1.9684
Transcendent	40	0.03	10.89637	1.7229
Total	40	14.263	5.00581	0.7915

Table no 14 shows the quality of life among hospital based palliative care patients under 5 dimensions namely symptoms, functions, interpersonal, well-being and transcendent. The possible range of total score is 0 to 30. The mean total score of quality of life is 14.2625 (SD 5.00581). This means that the patients experienced low level of quality of life. The possible range of sub scales are -30 to +30, there the mean score in symptom was 1.5250 (SD=14.808); which means the Experience of the physical discomfort associated with progressive illness; perceived level of physical distress of patients in hospital based palliative care is very low. The mean score of function is -5.80(SD=23.416); which means thefunctions and activities of daily living; experienced in relation to expectations are not functioning well. The mean score of interpersonal dimension was 4.15 (SD=18.406); which means that they were not able to invest more time in their personal relationships and they experience lower quality of life. The mean score of well-being was -11.500(SD=12.449); which means Self-assessment of an internal condition; subjective sense of wellness of hospital based care patients was very less comparing to other dimensions. The mean score of transcendent was .03 (SD=10.89).which means theexperienced degree of connection with an enduring construct; degree of experienced meaning or purpose in life is very

Objective 4: To compare the quality of life of the patients under home based palliative care and hospital based palliative care.

Table – 4.15

Quality of life of patients receiving home based and hospital based palliative care

Quality of life of patients receiving home based and hospital based palliative care							
	Type of care receiving the patient	N	Mean	SD	T	Df	Sig. (2-tailed)
SYMPTOMS	Home based care		15.88	6.89865	5.557	78	0
	Hospital based care	40	1.525	14.8086			
FUNCTION	Home based care	40	12.4625	11.332	4.44	78	0
	Hospital based care	40	-5.8	23.4167			
INTERPERSONAL	Home based care	40	18.2875	9.42575	4.324	78	0
	Hospital based care	40	4.15	18.4065			
WELL-BEING	Home based care	40	7.475	11.0075	7.222	78	0
	Hospital based care	40	-11.5	12.4494			
TRANCENDENT	Home based care	40	12.175	6.71541	6.001	78	0
	Hospital based care	40	0.03	10.8964			
TOTAL	Home based care	40	21.5425	2.46682	8.25	78	0
	Hospital based care	40	14.2625	5.00581			

The above table shows the comparison of the quality of the patients from the home based palliative care and the hospital based palliative care. The comparison in the symptom dimension of the quality of life scale shows that the patients from the home based palliative care experience better satisfaction in the symptom dimension (M= 15.88; SD=6.898) than the patients from the hospital based palliative care (M= 1.525; SD= 14.8086). The independent sample t-test shows that these difference were significant (t= 5.557; DF= 78; p<.0001). The comparison in the function dimension the quality of life scale shows that the patients from home based palliative care experience better satisfaction in the function dimension(M= 12.462; SD= 11.33) than the patients from the hospital based palliative care (M= - 5.8;SD=23.416). The independent sample t-test shows that these difference were significant (t= 4.44o; DF= 78; P<.001). In the interpersonal dimension the quality of life scale shows that the patients from home based palliative care experience better satisfaction (M= 18.287; SD= 9.425) than the patients from hospital based palliative care (M= 4.15; SD= 18.40). The independent sample t-test shows that these difference were significant (t= 4.324; DF= 78; p<.0001). In the well-being dimension of the quality of life scale shows that the patients from the home based palliative care experience better satisfaction (M= 7.475; SD=11.007) than the patients from the hospital based palliative care (M= -11.5; SD= 12.449). The independent sample t-test shows that these difference were significant (t= 7.222; DF= 78; p<.0001). In the transcendent dimension of the quality of life scale shows that the patients from the home based palliative care experience better satisfaction (M= 12.175; SD=6.715) than the patients from the hospital based palliative care (M= -0.03; SD= 10.896). The independent sample t-test shows that these difference were significant (t= 6.001; DF= 78; p<.0001).The overall score of the life satisfaction scale shows that the patients from home based palliative care experienced better quality of life (M=21.54; SD=2.46) than the patient from hospital based palliative care (M=14.26; SD=5.005). The independent sample t-test shows that these difference were significant (t= 8.250; DF= 78; p<.0001).

Objective: 5

To understand the socio-demographic correlates of the quality of life of the patients under home based palliative care and hospital based palliative care.

Table – 4.16

Correlation matrix of quality of life and duration of palliative care and duration of illness

Correlations

		1	2	3	4	5	6	7	8
		Duration of disease	Duration respondent undergoing palliative care	Symptoms	Function	Interpersonal	Well-being	Transcendent	Total
1	Duration of disease	1							
2	Duration undergoing palliative care	.372**	1						
3	Symptoms	-.306**	-.485**	1					
4	Function	-.328**	-.419**	.534**	1				
5	Interpersonal	-.343**	-.429**	.503**	.341**	1			
6	Well-being	-.354**	-.457**	.576**	.494**	.490**	1		
7	Transcendent	-.221*	-.345**	.500**	.364**	.467**	.541**	1	
8	Total	-.412**	-.547**	.784**	.631**	.790**	.796**	.726**	1

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

The above table shows that there is a negative correlation between the duration of illness and quality of life in symptom dimension which means that the duration of illness increases the quality of life in symptom dimension($r = -.306$; $p<.001$). Duration of the palliative care and quality of life in symptom dimension shows the significant correlation ($r = -.485$; $p< 001$). Correlation between the duration of illness and quality of life in function dimension ($r = -.328$; $p<.001$) shows the negative correlation. The duration of illness increases the quality of life in interpersonal dimension ($r =-.343$; $p<001$) Duration of the palliative care and quality of life in interpersonal dimension shows the significant correlation($r = -.429$; $p< 001$). It is interesting to note the significant positive correlation between the function dimension and symptom dimension ($r=.534$; $p<.001$). A significant inverse correlation between the wellbeing dimension and duration of palliative care ($r = -.457$; $p<001$) the correlation is significant.

Table – 4.17

Independent sample t-Testcomparing the difference between female and male respondent receiving palliative care

Group Statistics							
	Gender of the Patient	N	Mean	Std. Deviation	t	df	Sig. (2-tailed)
Symptoms	Male	44	8.6591	14.50893	-.031	78	.975
	Female	36	8.7556	12.51033			
Function	Male	44	.3295	24.22831	-1.461	78	.148

	Female	36	7.0000	14.08292			
Interpersonal	Male	44	10.3295	16.19393	-.541	78	.590
	Female	36	12.3056	16.31970			
Well-being	Male	44	-4.9545	14.61634	-1.963	78	.053
	Female	36	1.5833	15.06012			
Transcendent	Male	44	4.5455	11.13961	-1.425	78	.158
	Female	36	8.0056	10.37351			
Total	Male	44	17.2000	5.34257	-1.300	78	.197
	Female	36	18.7611	5.34243			

The above table shows that the different level of quality of life experienced by male and female respondent in palliative care. In symptom dimension there is only slight level of difference between male (M =8.6591; SD =14.50) and female (M =8.755; SD =12.510). Independent t test (t= -.031; df = 78) shows that the difference is not significant (NF=.975). In function dimension there is only slight level of difference between male (M =.329; SD =24.22) and female (M =7.00; SD =14.08). Independent t test (t= -1.46; df = 78) shows that the difference is not significant (NF=.148).In well-being dimension there is difference between the quality of life of male (M= -4.954; SD =14.61) and female (M =1.58; SD =15.06). The independent test (t= –1.96; df = 78) shows that the difference is significant (053). In transcendent dimension there is only slight level of difference between male (M = 4.54; SD =11.13) and female (M =8.005; SD =10.37). Independent t test (t= -1.425; df = 78) shows that the difference is not significant (NF=.158).overall expect well-being dimension is not significant. This shows that there is no difference between the quality of life experienced between male and female respondents.

Descriptives							
		N	Mean	Std. Deviation	df	F	Sig.
SYMPTOMS	cancer	43	8.2488	13.79435	2	.296	.744
	Cholesterol, sugar	19	10.7632	8.01798			
	Heart disease	18	7.6111	17.60645			
	Total	80	8.7025	13.56179			
FUNCTION	Cancer	43	1.7326	13.83893	2	2.141	.125
	Cholesterol ,sugar	19	11.3947	10.80455			
	Heart disease	18	-1.3611	35.29489			
	Total	80	3.3313	20.45804			
INTERPERSONAL	Cancer	43	9.2442	16.87820	2	1.054	.353
	Cholesterol, sugar	19	15.7105	12.70096			
	Heart disease	18	11.1944	17.58353			
	Total	80	11.2188	16.17758			
WELL-BEING	Cancer	43	-4.4186	14.29199	2	3.602	.032
	Cholesterol, sugar	19	5.8421	13.41646			
	Heart disease	18	-4.5556	16.47537			
	Total	80	-2.0125	15.08247			
TRANCENDENT	Cancer	43	3.7907	11.46747	2	3.878	.025
	Cholesterol, sugar	19	11.8158	10.06812			
	Heart disease	18	5.5944	8.17791			
	Total	80	6.1025	10.87286			
TOTAL	Cancer	43	16.8174	5.17987	2	3.405	.038
	Cholesterol ,sugar	19	20.5526	4.29785			
	Heart disease	18	17.6972	6.08925			
	Total	80	17.9025	5.36581			

CHAPTER V

FINDINGS, SUGGESTIONS, AND CONCLUSION

FINDINGS

- The important findings of this study entitled evaluating the effectiveness of hospital based palliative care and home based palliative care to improve the quality of life of the terminally ill persons are following.
- 77.5% of the palliative care patients were identified as Hindu
- Among the 80 respondents 43(53.8%) respondents were suffering from cancer.
- The majority of the patients under the palliative care 59(73.8%) are getting relief from the treatment.
- The majority of the respondents 38 (47.5%) came to know about palliative care through volunteers; 15 %(12) of the respondent came to know about palliative care through hospital. ; 8 (10%) came to know through relatives; 20% (16) respondents came to know about palliative care through doctor; and 6 (7.5%) respondents came to know through others.
- In this study the majority of the respondents 38 (47.5%) came to know about palliative care through volunteers; 15 %(12) of the respondent came to know about palliative care through hospital. ; 8 (10%) came to know through relatives; 20% (16) respondents came to know about palliative care through doctor; and 6 (7.5%) respondents came to know through others.
- The age groups of patients undergoing palliative care in this study discover that 36.3% (29) of the patients are the age between 71-80. Among the 80 respondents 35 % (28) of the respondents are the age group flanked by 61-70; 18.8% (15) respondents identified as the age group flanked by 51-60. The age group between40-50 identified as 7% (8.8) and there were only one identified as above the 80.

- 72.5% of the respondents are satisfied with the care provided by the palliative care unit. 22(27.5%) identified that they have desire to get little more services by the palliative care unit. Among the 22 respondents 6(7.5%) respondents who are in need of counseling; and 11(13.8%) respondents are in need of the frequent visit and care of the personnel's in the palliative care; there are 2(2.5%) respondents who are in need of speech therapy; and there are 2(2.5%) respondents who are in need of financial support.

- Among the 80 respondents 31 (38.8%) respondents are highly satisfied with the care provided by the nurse in palliative care unit. Majority of the respondent 49 (61.3%) are satisfied with the care provided by the nurse.
- Among the 80 respondents 31 (38.8%) respondents highly satisfied with the care provided by the volunteers in palliative care; 45(56.3%) are satisfied with the care and 4 (5%) respondents were not satisfied with the care of the volunteers in palliative care.
- The patients from the home based palliative care experience better satisfaction in the symptom dimension (M= 15.88; SD=6.898) than the patients from the hospital based palliative care (M= 1.525; SD= 14.8086).
- The patients from home based palliative care experience better satisfaction in the function dimension (M= 12.462; SD= 11.33) than the patients from the hospital based palliative care (M= - 5.8; SD=23.416).
- In the interpersonal dimension the patients from home based palliative care experience better satisfaction (M= 18.287; SD= 9.425) than the patients from hospital based palliative care (M= 4.15; SD= 18.40).
- In the well-being dimension the patients from the home based palliative care experience better satisfaction (M= 7.475; SD=11.007) than the patients from the hospital based palliative care.
- In the transcendent dimension the patients from the home based palliative care experience better satisfaction (M= 12.175; SD=6.715) than the patients from the hospital based palliative care (M= -0.03; SD= 10.896).

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Internet Resources

- http://www.ccjm.org/content/80/e-Suppl_1/e-S30.abstract
- http://www.ncbi.nlm.nih.gov/pubmed/14622451?log$=activity
- http://www.ncbi.nlm.nih.gov/pubmed/20642361?log$=activity
- http://www.ncbi.nlm.nih.gov/pubmed/19615625
- http://healthcare.financialexpress.com/200909/market13.shtml
- http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140078/
- http://palliumindia.org/cms/wp-content/uploads/2010/01/Palliative-Care-Policy-Kerala.pdf
- http://www.instituteofpalliativemedicine.org/download.php
- http://books.google.co.in/books?id=YmMwVnGTNiYC&printsec=frontcover&dq=palliative+care&hl=en&sa=X&ei=aSXMUbXAL4qHrgefroD4CA&ved=0CDIQ6AEwAA#v=onepage&q=palliative%20care&f=false
- http://www.instituteofpalliativemedicine.org/index.php

APPENDIX

	SOCIODEMOGRAPHIC QUESTIONAIR	
SD1	Name of the patient	
SD2	Name of panchayath	
SD3	Gender of the patient	1.Male 2. Female
SD4	Age of the respondent	1.30-40 2.41-50 3.51-60 4.61-70 5.Above 70
SD5	Religion of the respondent	1. Christian 2. Hindu 3.Muslim
SD6	Marital status	1.single 2. Married 3 Divorced/separated 4.widow/widower
SD7	Type of disease	
SD8	How long have you been	1.Less than 6

	suffering from this disease?	months 2. 6-12 months 3. 12-18 months 4.18-24 months 5.24 Moths and more
SD9	Do you get pain relief from treatment	1.Yes 2.No
SD10	How did you come to know about palliative care?	1. Volunteers 2. Hospital 3. Relatives 4. Doctor 5. Others
SD11	Please specify the type of care you get:	1.Home based care 2.hospital based care
SD12	Are you satisfied with the present medical treatment provided by pain and palliative care	1. Highly satisfied 2. Satisfied

	unit?	3. Not satisfied 4. No opinion
SD13	Are you satisfied with the present medicines of pain and palliative care unit?	1. Highly satisfied 2. Satisfied 3. Not satisfied 4 No opinion
SD14	Are you satisfied with the overall services of the Unit?	1. Highly satisfied 2. Satisfied 3. Not satisfied 4. . No opinion
SD15	Do you need any care other than the care provided by the unit?	1.Yes 2. No
SD16	If yes, please specify the care needed by you	
S	Do you think that pain	1. Absolute

D17	and palliative care is essential for patients suffering from terminal illness or old age problems?	ly Essential 2. Essential 3. Some what essential 4. Not essential 5. No opinion
SD18	How long have you been undergoing palliative treatment?	1. Less than 6 months 2. 6-12 months 3. 12-18 months 4. 18-24 months 5. 24 Moths and more
SD19	Are you satisfied with the present services of the doctor of pain and palliative care unit?	1. Highly satisfied 2. Satisfied 3. Not satisfied 4. No

		opinion
SD20	Are you satisfied with the present services of the nurse of pain and palliative care unit?	1. Highly satisfied 2. Satisfied 3. Not satisfied 4. No opinion
SD21	Are you satisfied with the present services of the volunteers of pain and palliative care unit?	1. Highly satisfied 2. Satisfied 3. Not satisfied 4. No opinion
SD22	Do you think that it is more effective that receiving home based care than hospital based care	1. Yes 2. No

Missoula-VITAS Quality of Life Index

SYMPTOM		
QL1	My symptoms are adequately controlled.	1. Agree Strongly

		2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL2	I feel sick all the time	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL3	I accept my symptoms as a fact of life.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL4	I am satisfied with current control of my symptom	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL5	Physical discomfort overshadows any opportunity for enjoyment	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly

	FUNCTION	
QL6	I am dependent on others for personal care	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL7	I am no longer able to do many of the things I like to do	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL8	I am satisfied with my ability to take care of my basic needs	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL9	I accept the fact that I can not do many of the things that I used to do.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL10	My contentment with life depends upon being active and being	1. Agree Strongly 2. Agree

	independent in my personal care.	3. Neutral 4. Disagree 5. Disagree Strongly
	INTERPERSONAL	
QL11	I have recently been able to say important things to the people close to me.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL12	I feel closer to others in my life now than I did before my illness	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL13	In general, these days I am satisfied with relationships with family and friends.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL14	At present, I spend as much time as I want to with family and friends.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5.

		Disagree Strongly
QL15	It is important to me to have close personal relationships	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
	WELL-BEING	
QL16	My affairs are not in order; I am worried that many things are unresolved	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL17	If I were to die suddenly today, I would feel prepared to leave this life.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL18	I am more satisfied with myself as a person now than I was before my illness.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL19	The longer I am ill, the more I worry about things "getting out	1. Agree Strongly 2. Agree

	of control".	3. Neutral 4. Disagree 5. Disagree Strongly
QL20	It is important to me to be at peace with myself.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly 6.
	TRANSCENDENT	
QL21	feel more disconnected from all things now than I did before my illness.	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL22	I have a better sense of meaning in my life now than I have had in the past	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL23	I am comfortable with the thought of my own	1. Agree Strongly

	death	2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL24	Life has lost all value for me; every day is a burden	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5. Disagree Strongly
QL25	It is important to me to feel that my life has meaning	1. Agree Strongly 2. Agree 3. Neutral 4. Disagree 5.Disagree Strongly