

**A SOCIOLOGICAL STUDY ON THE CARE TAKERS OF
PALLIATIVE CARE WITH REFERENCE TO GENERAL
HOSPITAL, ERNAKULAM**



BY

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MARCH 2014

Department of Sociology

St. Teresa's College

Ernakulam

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PROJECT REPORT

Submitted to the Mahatma Gandhi University, Kottayam

in fulfillment of the requirements

for the award of Degree of Bachelor of Sociology

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DECLARATION

I, hereby, declare that the dissertation titled **“A Sociological Study on the Care Takers of Palliative Care with reference to General Hospital, Ernakulam”** submitted by me for the award of the Degree of Bachelor of Arts in Sociology and is a record of work carried out by me under the guidance of Miss. Lebia Gladis N.P, Department of sociology, St. Teresa’s college Ernakulam. I further testify that this work was not partially or fully submitted by anybody else.

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CERTIFICATE

Certified that the dissertation titled "A Sociological Study on the Care Takers of Palliative Care with reference to General Hospital, Ernakulam done by Rakhi.T.R as a part of reformed curriculum for completing the Degree of Bachelor of Arts in Sociology from Mahatma Gandhi University, Kottayam, during 2011- 2014 at the Department of Sociology, St. Teresa's College, Ernakulam was carried out under my guidance and supervision.


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RAKHI .T .R

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INTRODUCTION

CHAPTER I

INTRODUCTION

The World Health Organization (WHO) has defined palliative care as: 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (World Health Organization, 2002). However, a difficult problem emerges in the context of dementia since it is often not seen as a life-threatening illness. Palliative care can be regarded as a spectrum. At one end, the palliative care approach equates to good-quality, person-centred dementia care. At the other, the terminal stages of dementia may well require specialist palliative care (involving more detailed knowledge and skills, for example in pain relief). In between, palliative interventions (which in cancer care could involve palliative radiotherapy for bone pain) might comprise the raft of pharmacological and psychosocial approaches used to treat the behavioural and psychological signs of dementia. One conceptual and practical issue concerns whether these potential components of care in dementia can (and should) be usefully packaged together under the umbrella of 'palliative care'. A reasonable response might be that if conceptual packaging in this way leads to improvements in patient care, perhaps through advance care planning, then the enterprise would seem worthwhile.

Scope of the term

Palliative care is specialised medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain and stresses of a serious illness — whatever the prognosis. The goal is to improve quality of life for both the patient and the family as they are the central system for care. Palliative care is provided by a team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

A World Health Organisation statement describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with

life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." More generally, however, the term "palliative care" may refer to any care that alleviates symptoms, whether or not there is hope of a cure by other means; thus, palliative treatments may be used to alleviate the side effects of curative treatments, such as relieving the nausea associated with chemotherapy.

The term "palliative care" is increasingly used with regard to diseases other than cancer such as chronic, progressive pulmonary disorders, renal disease, chronic heart failure, HIV/AIDS and progressive neurological conditions. In addition, the rapidly growing field of pediatric palliative care has clearly shown the need for services geared specifically for children with serious illness.

Palliative care:

1. provides relief from pain, shortness of breath, nausea and other distressing symptoms;
2. affirms life and regards dying as a normal process;
3. intends neither to hasten nor to postpone death;
4. integrates the psychological and spiritual aspects of patient care;
5. offers a support system to help patients live as actively as possible;
6. offers a support system to help the family cope;
7. uses a team approach to address the needs of patients and their families;
8. will enhance quality of life;
9. 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.

While palliative care may seem to offer a broad range of services, the goals of palliative treatment are concrete: relief from suffering, treatment of pain and other distressing symptoms, psychological and spiritual care, a support system to help the individual live as actively as possible and a support system to sustain and rehabilitate the individual's family.

History

Palliative care began in the hospice movement and is now widely used outside of traditional hospice care. Hospices were originally places of rest for travelers in the 4th century. In the

19th century a religious order established hospices for the dying in Ireland and London. The modern hospice is a relatively recent concept that originated and gained momentum in the United Kingdom after the founding of St. Christopher's Hospice in 1967. It was founded by Dame Cicely Saunders, widely regarded as the founder of the modern hospice movement.

The hospice movement has grown dramatically in recent years. In the UK in 2005 there were just under 1,700 hospice services consisting of 220 inpatient units for adults with 3,156 beds, 33 inpatient units for children with 255 beds, 358 home care services, 104 hospice at home services, 263 day care services and 293 hospital teams. These services together helped over 250,000 patients in 2003 & 2004. Funding varies from 100% funding by the *National Health Service* to almost 100% funding by charities, but the service is always free to patients.

Hospice in the United States has grown from a volunteer-led movement to improve care for people dying alone, isolated or in hospitals, to a significant part of the health care system. In 2005 more than 1.2 million persons and their families received hospice care. Hospice is the only Medicare benefit that includes pharmaceuticals, medical equipment, twenty-four hour/seven day a week access to care and support for loved ones following a death. Most hospice care is delivered at home. Hospice care is also available to people in home-like hospice residences, nursing homes, assisted living facilities, veterans' facilities, hospitals and prisons.

The first United States hospital-based palliative care programs began in the late 1980s at a handful of institutions such as the Cleveland Clinic and Medical College of Wisconsin. Since then there has been a dramatic increase in hospital-based palliative care programs, now numbering more than 1,400. 80% of US hospitals with more than 300 beds have a program.

A 2009 study regarding the availability of palliative care in 120 US cancer center hospitals reported the following: Only 23% of the centers have beds that are dedicated to palliative care; 37% offer inpatient hospice; 75% have a median time of referral to palliative care to the time of death of 30 to 120 days; research programs, palliative care fellowships, and mandatory rotations for oncology fellows were uncommon.

The results of a 2010 study in *The New England Journal of Medicine* showed that lung cancer patients receiving early palliative care experienced less depression, increased quality of life and survived 2.7 months longer than those receiving standard oncologic care.

Hospital palliative care programs today care for non-terminal patients as well as hospice patients. The Patient Protection and Affordable Care Act currently being debated by house and senate would seek to expand palliative care in the U.S.

The first pan-European centre devoted to improving patient palliative care and end-of-life care was established in Trondheim, Norway in 2009. The centre is based at NTNU's Faculty of Medicine and at St. Olav's Hospital/Trondheim University Hospital and coordinates efforts between groups and individual researchers across Europe, specifically Scotland, England, Italy, Denmark, Germany and Switzerland, along with the USA, Canada and Australia.

Improves Quality of Life

Palliative care treats people suffering from serious and chronic illnesses such as cancer, cardiac disease such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's, Parkinson's, Amyotrophic Lateral Sclerosis (ALS) and many more.

Palliative care focuses on symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression. It also helps you gain the strength to carry on with daily life. It improves your ability to tolerate medical treatments. And it helps you have more control over your care by improving communication so that you can better understand your choices for treatment.

A Partnership of Patient, Specialists and Family

Palliative care is a team approach to care. The core team includes doctor, nurse and social work palliative care specialists. Massage therapists, pharmacists, nutritionists, chaplains and others may also be part of the team.

The team spends as much time as necessary with you and your family. They become a partner with you, your family and your other doctors. They support you and your family every step of the way, not only by controlling your symptoms, but also by helping you to understand your treatment options and goals. Working together with your primary doctor, the palliative care team provides:

1. Close communication
2. Expert management of pain and other symptoms
3. Help navigating the healthcare system
4. Guidance with difficult and complex treatment choices

Palliative Care Services - Holistic support to patients and their families

Cancer is preventable in some cases and curable in many others, if detected early. Unfortunately in our country patients often go to the doctor when the disease has advanced. Tata Memorial Centre, the nation's premier cancer care institution established its Palliative Care Services unit to look after the needs of these patients and to reiterate that the end of active treatment is not the end of life.

The Palliative Care Services Unit was established in the Tata Memorial Centre in 1996 and over 15,000 patients have been Cared for since its inception. Its Home Care Services was launched in 1998 to extend the Care to patients at their homes in Mumbai. In 2002 pediatric Palliative Care was added to the services of the unit. Young children with a recurrence of cancer are treated to keep them pain free and active.

The Unit comprises of dedicated doctors, nurses, psychologist, social workers and volunteers. As the size of the team has increased since the early days of the unit, so have the outreach and support services. The team provides free medical, nursing and psychosocial Care for patients in their own homes as well as emotional support and guidance to members of the patients' families to help them cope with the crisis. The team stays in touch with the family even after the death of the patient, providing bereavement support.

Palliative Care Services include:

1. Assessment and management of pain and other symptoms
2. Nursing, medication and wound management
3. Provision of prosthesis, wheel chairs, water beds and other aids
4. Psychosocial support for patients and their families
5. Financial aid for Care of patients
6. Home Care in Mumbai
7. Educational Support for children of Palliative patients where possible
8. Training in Palliative Care for Doctors, Nurses and Volunteers from Western India

Research and academics, IRB approved projects:

1. Need Analysis of Service Users in Pediatric Palliative care This project explores the specific needs of the patients registered in the pediatric palliative care service and is still ongoing
2. Management of fungating wounds using honey. The study examines the role of honey as an alternative to conventional dressings in fungating wounds in terms of acceptability to patients, cost and efficacy.
3. Distress in caregivers in terminally ill cancer patients – a feasibility study”
4. Coping with bereavement- experience of Indian Families
5. Resilience and coping adopted by families of children suffering from cancer in Palliative care -This is a qualitative study wherein caregivers are interviewed to assess their coping with the death of a beloved. The study is ongoing.
6. Perspectives of resident pediatric doctors to breaking bad news to families of dying children in the general pediatric setting. This ongoing study looks at the perspectives of junior doctors to death communication in the non-oncology setting.

World hospice and palliative care day

The second Saturday of October is celebrated world-over as World Hospice and Palliative Care Day. It is an occasion to create public awareness about Palliative Care. The Unit organizes different programmes every year which spread awareness and entertain.

Palliative Care integrates the physical, psychosocial and spiritual Care of patients suffering from advanced cancer. It assures the best possible quality of life for these patients, providing relief from pain and other distressing symptoms. Palliative Care affirms life and strives to make the last days of the patient as comfortable as possible. The team looks after the physical, emotional, practical and spiritual needs of the patients, assuring that they live and die with dignity.

National plans on palliative care

As palliative care and its provision is defined in the Belgian legislation and several Royal Decrees act as healthcare organisation guidelines for the different palliative care services, there is no separate National palliative care policy. The National Cancer Plan (March 2008) however states that the

expansion of palliative care shall be actively supported. Palliative care has gained increased recognition within the policy arena in the United Kingdom. The so-called 1995 Calman-Hine Report was crucial in influencing plans for service development in cancer. Since the year 2000, several important national and regional initiatives have been launched to promote access to end-of-life care and to improve quality of care, including the NHS Cancer Plan of September 2000; an action plan to include palliative care in 34 regional cancer networks; the 'NICE clinical guidance on supportive and palliative care for adults with cancer (2004)' The End of Life Care initiative (launched 2003) incorporating the Gold Standards Framework (GSF), the Liverpool Care Pathway (LCP) for the dying patient, and the Preferred Place of Care tool (PPC); The End of Life Care Programme comprising a comprehensive framework aimed at improving high quality care across the country for adults in the last phase of life; and the initiative "Better care: Better Lives" improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions".

According to the palliative care law of 1999, structures and organisation of palliative care and pain management must be described in the French regional health organisation plans (SROS). The SROS must determine the resources (such as mobile palliative care teams, palliative care units, home hospitalisation beds, palliative care networks) necessary to achieve the set objectives. In addition, palliative care was the subject of three governmental plans in France (1999–2001, 2002–2005 and 2008–2012). Following the Law of April 2005, the Ministry of Health created a national surveillance committee on the development of palliative care and end of life supportive care in 2006. In 2008, this committee proposed a national policy for the development of palliative care, accompany the implementation and deployment of this policy, and evaluate application of legislative and regulatory texts concerning palliative care and end of life supportive care. A third Governmental plan for the development of palliative care (2008–2012) was launched in 2008 for the further development of intra- and extramural palliative care, to pursue the development of training and research in palliative care and to improve the development of support and training for the paramedics.

In 2005, the German Bundestag officially declared the improvement of palliative care as a priority. The coalition treaty (CDU, CSU, and SPD) mentioned palliative care for the first time stating "that there is a particular need for improvement in the care and treatment of people in the final stages of their lives. Many people, even patients with serious illnesses, would like to be cared for at home to the very end, so the offered services should take this need into account. For this reason, the legal provisions governing the services, the contractual rights and obligations and the funding of statutory health and long-term care schemes must include rules designed to guarantee better palliative care". Health care reform was declared one of its top priorities for 2006 and in November 2005 they

stipulated, among others, the promotion of incentives for better coordination of care, to raise efficiency and to improve quality of care. As a result the entitlement to out-patient specialist palliative care was implemented in a law in the next electoral term (Statutory Health Insurance Competition Strengthening Act (SHI-CSA)).

For 1998–2003 the Dutch Minister of Health, Welfare and Sport initiated a stimulation programme. The underlying principle was that palliative care should be provided as much as possible by doctors, nurses, care workers and other care providers who work in regular non-private facilities. In this way access and availability to palliative care should be improved. The stimulation programme encompassed encouragement of research and innovative projects, promotion and guidance of palliative care and stimulation of the integration of hospice facilities. In 2007 the secretary of the Ministry of public health, welfare and sports did a proposal for a new national program 2007–2010 'Palliative care Plan' (Plan van Aanpak Palliatieve Zorg') with three main topics: the organisation and finance of palliative care, the improvement of quality and transparency of palliative care and education and palliative care competencies (extra training).

There is no separate national palliative care plan as such in Poland. For the years 2005–2010 palliative care was included into the National Cancer Program, which allows the development of palliative care in-patient and out-patient services included into oncology units by financing support. Each oncology centre (usually situated in each capital of the province) should have a palliative care inpatient and outpatient unit or at least a hospital support team when formation of a separate palliative care unit is impossible. Although there is no national policy, the person responsible for the organisation of palliative care is the National Consultant of palliative medicine with regional consultants in each province. The National Consultant of palliative medicine (a physician with a specialty in palliative medicine) focuses on developing palliative care in each administrative district with access to at least an out-patient unit and home care. The Spanish regulations about palliative care have followed most principles and recommendations made by international organisations. This resulted in the National Palliative Care plan which was enacted in 2001 and conceived to care for all patients in need of palliative care within the public sector. According to the vision of the plan, palliative care is to be nationwide available, on a free basis, and with no distinctions of territory, economic resources or accessed information. The National Palliative Care Plan also regulates the use of opioids for symptom control in the incurably ill and pays attention to non-cancer patients. A regional palliative care plan exists, or is under development; in several autonomous communities (15 of the 17 autonomous communities have some type of regional palliative care plan). On March 17th 2007 the Palliative Care Strategy of the National Health System, conceived as a tool for

implementing the national plan and to support Autonomous Communities in the implementation of their regional programmes, was approved by the Inter-territorial council. The National Strategy seeks to reduce differences between regions in order to make palliative care thoroughly available within the national health system across the country.

Palliative care is a holistic care which fulfills the requirements of chronically ill patients. Those who need continued supportive care spend their lives not in the hospital, but in the community among their family and neighbors. Hence, the community has a major role in the care of these individuals. Yuen et al., in their study "Palliative care at home: general practitioners working with palliative care teams" stated that home care was the preferred option for most people with a terminal illness, and providing home care relies on good community-based services, a general practice workforce competent in palliative care practice, and willing to accommodate patients' need. Devi, et al., in a study, "Setting up home-based palliative care in countries with limited resources: a model from Sarawak, Malaysia," described the set up of a home-care program in Sarawak (the Malaysian part of the Borneo Island), where half the population lives in villages that are difficult to access. The program had been sustainable and cost efficient, serving 936 patients in 2006. The results showed that pain medication could be provided even in remote areas with effective organization and empowerment of nurses, who were the most important determinants for the set up of this program. Zerzan et al., in their study, "Access to Palliative Care and Hospice in Nursing Homes", stated that hospice improves end-of-life care for dying nursing home residents by improving pain control, reducing hospitalization, and reducing use of tube feeding, but it is rarely used. Hospice use varies by region, and rates of use are associated with nursing home administrators' attitudes toward hospice and contractual obligations.

Data show that 80% of all palliative care services in the country are delivered in Kerala, reaching 30% of the needy patients, whereas these services reach only to 2% in India. Kerala's attempts at caring for terminally ill patients have been regarded as a model for the rest of the world. Kerala Government is the only State Government in Asia which has introduced a palliative care policy in the State for the first time. The Neighborhood Network in Palliative Care (NNPC) is a volunteer-driven movement that has gained momentum in Kerala, especially in Malabar Region, where the volunteers are the arms of the community, supporting the patient in collaboration with governmental and nongovernmental agencies in Kerala.

Palliative care in Cochin City

A huge demand for pain and palliative care service remains unmet as is revealed under the ongoing programme of Pain and Palliative Care Service by the District Panchayats. The programme has technical support of the National Rural Health Mission and the District Health. The programme is on in 37 out of the 84 Panchayats and the numbers of patients registered is about 6,000. Of these, about 3,000 patients need at least a weekly follow-up programme and about 800 are patients with urine catheters. Of those registered under the programme about 30 per cent are paraplegics and another 30 per cent are elderly people who are dependent on another person for meeting their daily needs. There are about 20-30 per cent people who are terminally ill cancer patients; others include mentally and physically challenged persons.

According to the district coordinator for the programme under the NRHM, the cancer patients are registered by the relatives only when they are out of all other treatment modules. While the panchayats have been providing Rs. 2.5 lakh upwards for the palliative care programme as part of the government initiative that started in 2008, so far the service providers have been able to meet only the basic care for the patients. For patients who need to see a doctor, the team also makes a reference to the nearest PHC or the secondary care taluk hospital as the need be. A team comprising a trained nurse or an auxiliary nurse along with either a health inspector or junior health inspector or junior public health nurse attached to the Primary Health Centre and a community volunteer that could be from Kudumbashree or ASHA (Accredited Social Health Activist) or the ward member or member of any NGO working in the field goes to the patient to enquire about their general health. The bystanders are given basic training to meet their daily needs as well.

Palliative care is also done by a dedicated team from the General Hospital in a mobile unit that provides need-based home care to 380 patients. Besides being a tertiary care centre for such patients, the hospital is also a training centre for doctors, nurses and volunteers engaged in palliative care. There is also a consortium of private hospitals under the organisation Pallium India that is providing palliative care to patients.

Need and Significance of the study

Man as a social being has certain duties towards society especially towards the depressed classes. The work in a Palliative Care is noteworthy as it tries to wipe the tears of many. The care, affection, dedication and self sacrifice that they show throws a ray of hope in the lives of patients who shares the hospital beds due to severe and dreadful diseases. For instances,

the care takers of Palliative Care in Ernakulam General Hospital can be taken into account. The most tormented wards like cancer wards mostly need the service of Palliative Care. The patients hailing from different family backgrounds who haven't tasted love, affection and care will get medicine and consolation along with all these. The patients are most probably heartbroken and emotionally weak and they need moral support. They ensure medical aid as well as tips for the stability of mental health. On the whole the service provided by Palliative Care is a boon and their social commitment is praise worthy. So the study has focused on the personal profile, the influential factors for the care takers to take up this task, the difficulties and problems faced by the care takers, the management strategies and the level of satisfaction in this field. So the study is considered as very relevant and significant thus the study has undertaken.



**REVIEW OF
LITERATURE**

CHAPTER II

Review of Literature

Sonja J Mcilfattrick & Tara Marphy in their article “palliative care research on the island of Ireland over the last decade”; a systematic review and thematic analysis of peer reviewed publication in 2013. The study provided baseline evidence of the nature and type of palliative care research undertaken within Ireland over the last decade. Some areas of significant strength were noted such as a clear focus to address the needs of specific groups and populations, focusing on palliative care beyond cancer. Furthermore, there was also evidence of research focusing on symptom management and palliative care service developments. Despite this, however, the current review identified several research gaps specific to palliative care including public health and policy research. While a number of papers reported on methodological and ethics issues, these were not included as they were literature reviews or reflective pieces. There was also a lack of multidisciplinary and outcomes-focused research in this area which may reflect both the relative currency of palliative care research in comparison to other countries such as the UK, US and Canada.

The research undertaken was clearly limited by issues relating to methodological rigour with a lack of measurement of outcomes, overemphasis on needs based research and limitations associated with sampling. Similar issues have been identified at a European and global level. Such an analysis is useful when seeking to identify areas for future research and research priorities. There is a clear need for future strategic direction and collaboration for palliative care research both nationally and internationally. Collaboration between palliative care researchers in the island of Ireland remains in its infancy. There is a need to maximise existing resources, leverage expertise and capability, and build critical mass in order to produce excellent, internationally-competitive research.

Julian C. Hughes, David (2007) in their article “Palliative care in dementia: issues and evidence” try to explain that there is an increasing interest in palliative care in dementia and much good work goes on (largely unnoticed) in the field. However, there are questions about how best to provide good-quality palliative care for people with dementia in a manner that becomes embedded as good practice. There is a need, therefore, for

continuing debate and research. None of the issues is straightforward. Moreover, this field amply demonstrates the extent to which clinical decisions are often ethical decisions. The ethical imperative must be to maintain or improve the quality of life, even at its end. This aspiration helps to drive the palliative care movement. It should also be a potent motivating force in psychiatric practice wherever the care of dying patients is common place.

According to **Martin Loucka** in his article he discussed about **“how to measure the international development of palliative care.”** Aim of the article was to provide critical comparative analyses of methodological approaches used to assess the development and status of palliative care services and infrastructure of and internal level. Results in this study reviewed report were found to differ in adopted methodologies and provided uneven amount of methodological information. The limitation were identified lack of theory use of experts as source of information grey literature difficulties in ranking and the problematic nature of data on services provision.

“Comparison of legislation, regulations and national health strategies for palliative care in seven European countries: a descriptive study” by Karen Van Beek, Kathrin Woitha, Nisar Ahmed, Johan Menten, Birgit Jaspers, Yvonne Engels, Sam H Ahmedzai, Kris Vissers and Jeroen Hasselaar Although all included European countries have policies on palliative care, countries largely differ in the presence of legislation and regulations on palliative care as well as the included topics. European healthcare policy recommendations should support palliative care access across Europe.

In all countries palliative care regulations and policies existed (either in laws, royal decrees, or national policies). An explicit right to palliative care was mentioned in the Belgium, French and German law. In addition, access to palliative care was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. Also, all countries had a national policy on palliative care, although sometimes mainly related to national cancer plans. Differences existed in policy regarding palliative care leave, advance directives, national funding, palliative care training, research, and the role of volunteers.

S. Robin Cohen the study was carried out in eight palliative care services in four Canadian cities. A revised version of The McGill Quality of Life Questionnaire (MQOL) is compared to a single-item scale measuring overall quality of life (SIS), and the self-administered version of the Spitzer Quality of Life Index (SA-QLI), to obtain evidence of validity. MQOL total score predicts SIS better than does SA-QLI, although much of the variance remains to be explained. The results of principal components analysis of data using this revised version of MQOL are similar to those from previous MQOL studies with different patient populations. The MQOL subscales, constructed on the basis of principal components analysis, demonstrate acceptable internal consistency reliability. The MQOL measures reflecting physical well-being and existential well-being are important for predicting SIS.

According to **Jennifer S. Temel, Vicki A. Jackson** in their article “**Integrated palliative care in newly diagnosed advanced non-small –cell lung cancer patients**” try to assess the feasibility of early palliative care in the ambulatory setting in patients with newly diagnosed advanced non-small-cell lung cancer (NSCLC). Patients were eligible if they had a performance status of 0 to 1 and were within 8 weeks of diagnosis of advanced NSCLC. Participants received integrated care from oncology and palliative care throughout the course of their disease. Participants were scheduled to meet with the palliative care team (PCT) and complete quality-of-life (QOL) and mood questionnaires monthly for 6 months. The study was deemed feasible if 64% of patients completed least 50% of their scheduled visits and QOL assessments. Integrated palliative and oncology care is feasible in ambulatory patients with advanced NSCLC.

Peter Kirk in his study “**What do Patients receiving palliative care for cancer and their families wants to be told**” explains Information delivery for patients needs to be individualised with particular attention to process at all stages of illness. Patients and families use secondary sources of information to complement and verify information given by health care’s. objective to obtain feedback from patients receiving palliative care and their relatives from various ethnic backgrounds about their experiences of the disclosure process and their Prognosis—Participants described their need for information about prognosis, its accuracy, and the importance of being able to refine their understanding about prognosis as the disease progressed. Many reported that it enhanced communication with family. The timing of disclosure about prognosis was important. Although most patients and families requested this information as soon as or shortly after diagnosis was confirmed, many reported that they were distressed at how it was given. Some stated the information had been given too soon or

when they hadn't asked for it. Participants sometimes verbalised ambiguity: they wanted to be told but they did not want to know. Often the exact words used by doctors were vividly remembered. Participants were distressed when information about prognosis was perceived as vague or inaccurate, was presented along with conflicting or inconsistent information, or was given by someone not perceived to be an expert or directly in charge of the patient. Evasiveness was often perceived as unhelpful.

Eduardo Bruera, in his article studied about "estimate of survival of patients admitted to a Palliative Care Unit": A prospective study (ration by two independent physicians after a complete medical exam performed during the first day of admission. An independent research nurse also assessed each patient during the first day of admission. The assessment included activity, pain, nausea, depression, anxiety, anorexia, dry mouth, dyspnea, dysphagia, weight loss, and cognitive status. After the assessment was completed, patients were followed until In a prospective open study, 61 consecutive patients with advanced cancer admitted to a Palliative Care Unit underwent survival estimate or death. In 47 evaluable patients, logistic regression showed a significant correlation between survival and dysphagia, cognitive failure, and weight loss. Accordingly, an "indicator of poor prognosis" was considered to exist in any patient who demonstrated weight loss of 10 kg or more plus cognitive failure (Mini-Mental State Questionnaire < 24) plus dysphagia to solids or liquids. This indicator had a similar level of sensitivity, specificity, and overall accuracy, and a higher level of significance as compared with the assessment by physician #1 and physician #2, respectively. Our data suggest that three simple determinations, which may be performed by a nurse, can predict survival more or less than 4 wk as well as the assessments of two skilled physicians. These results need to be confirmed in other trials with large numbers of patients. Perhaps confirmation of these results and identification of other prognostic factors will result in staging systems for survival estimation of terminally ill cancer patients.

I R Mcwhinney in the article "Evaluation of a palliative care service: problems and pitfalls" try to evaluate a palliative care home support team based on an inpatient unit. In designing evaluations of palliative care services, investigators should be prepared to deal with the following issues: attrition due to early death, opposition to randomisation by patients and referral sources, ethical problems raised by randomisation of dying patients, the appropriate timing of comparison points, and difficulties of collecting data from sick or exhausted

advanced cancer. To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer.

Compared with participants receiving usual oncology care, those receiving a nurse-led, palliative care-focused intervention addressing physical, psychosocial, and care coordination provided concurrently with oncology care had higher scores for quality of life and mood, but did not have improvements in symptom intensity scores or reduced days in the hospital or ICU or emergency department visits.

Janice R Ablett "Resilience and well-being in palliative care staff: a qualitative study of hospice nurses' experience of work" try to explain that although working with cancer patients is considered stressful, palliative care staff experience similar levels of psychological distress and lower levels of burnout than staff working in other specialties. There are few empirical studies in palliative care to explain this. Since working in a stressful job does not inevitably lead to psychological distress, the antecedent factors that promote resilience and maintain a sense of well-being are worthy of study. This qualitative study used interpretative phenomenological analysis (IPA) to describe hospice nurses' experiences of work. During the analysis, themes emerged relating to the underlying interpersonal factors that influenced the nurses' decisions to begin and continue working in palliative care, and their attitudes towards life and work. The emergent themes were compared with the theoretical personality constructs of hardiness and sense of coherence, and this comparison highlighted many similarities. The nurses showed high levels of commitment, and imputed a sense of meaning and purpose to their work. An area of divergence was their response to change, and this is discussed in relation to hardiness and sense of coherence. The implications for staff well-being, and for staff training and support, which, in turn, may impact on the quality of patient care, are discussed.

J. Addington in the journal "Research sensitivities to palliative care patients" deals with the methodological challenges of researching the health care experiences of palliative care patients and their families. Difficulties in defining a 'palliative care patient' are highlighted, and the question of whether there are specific ethical issues when researching palliative care explored. Methodological issues are discussed, including the negotiation of access via health

professionals, the choice of appropriate data collection methods and tools, the consequences of high attrition rates and the use of retrospective surveys of bereaved relatives. Key areas for research are identified. These include patients' and families' experiences of research participation, the impact of being approached on those who decline, how the characteristics of those who participate differ from those who do not and the likely impact of this on findings. Research is also needed into patient and family motivations for participation, and whether and how these change as the disease progresses. To ensure that the voices of palliative care patients and their families are heard by both service providers and policy-makers, research in this area needs to address the methodological challenges raised in this paper, as well as continuing to explore users' views.

Mary I s Vachon in the study on "Staff stress in hospice/palliative care" describes a review of the research in the area of staff stress in hospice/palliative care since the start of the modern hospice movement shows that, while high stress was identified as a problem in the early days of the movement, later studies have shown that stress and burnout in palliative care are by no means universal. Staff stress and burnout in hospice/palliative care has been demonstrated to be less than in professionals in many other settings. However, other studies have noted suicidal ideation, increased alcohol and drug usage, anxiety, depression, and difficulty in dealing with issues of death and dying. It is hypothesized that part of the reason that stress may be lower than expected in some settings was the early recognition of the potential stress inherent in this field and the development of appropriate organizational and personal coping strategies to deal with the identified stressors. Staffs in hospice/palliative care have been found to have increased stress when mechanisms such as social support, involvement in work and decision-making, and a realistic work-load are not available.

The stress that exists in palliative care is due in large measure to organizational and societal issues, although personal variables were also found to have an influence. Suggestions are given for the direction of future research in the field.

Marjolein Gysels, in the article "Journal of Pain and Symptom Management " aimed to explore patients' and cares' preferences and expectations regarding their contribution to research in palliative care through the use of qualitative interviews. Data were collected in the context of two studies exploring the experiences of care of palliative about their motivation to participate in research. The data were analyzed by labeling patients' reflections on their motivations for participating in these studies and identifying themes. Analysis of the recruitment process revealed differential patterns in decline and acceptance of interviews by

patients with different conditions and across settings. Among care patients and carers. Both studies recorded the recruitment process, number of patients or carers accepting and declining, and the circumstances of interviews. Participants were asked cancer patients, 21/51 declined; the proportion with other conditions that declined was small, and was 0/10 for patients with motor neuron disease. Motivation to participate in the studies was related to (1) altruism, (2) gratitude and concerns about care, (3) the need to have somebody to talk to, and (4) the need for information or access to services. Palliative care patients and carers were capable of deciding whether to participate in interviews and negotiating how they wanted this to happen. This strengthens the argument for patients' autonomy in deciding whether to participate in research. Patients and carers have different motivations for participation, reflecting the heterogeneity of the palliative care population. This suggests a need for ethics committees to reconsider their views and widen their perspectives on the involvement of palliative care patients and carers in research.

M S Jordhøy in the article **“Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized controlled trial”** (2001) Randomized controlled trials (RCTs) in palliative cancer care often experience methodological problems. In this paper we discuss issues of major concern, including recruitment, patient attrition and compliance, arising from an RCT that compared comprehensive palliative care to conventional care. The main criteria for trial entry were incurable malignant disease and a survival expectancy of between 2 and 9 months. Patients' health-related quality of life (HRQL), self-assessed by multi-item questionnaires, was a defined endpoint. The planned number of patients was successfully recruited, although the patients were referred late in the course of their disease so that follow-up tended to be short. Compliance in completing HRQL questionnaires was good up to 1 month before the patient's death; but in the final weeks it was found to drop substantially. Based on our experience, recommendations are given for those planning similar research. Procedures for improving patient recruitment are suggested, stressing the need for local data management, repeated information to referral sources, extensive screening for potentially eligible patients and simple referral routines. Precise inclusion criteria, including prognostic factors other than physicians' estimates of life expectancy, should be used to ensure a sufficient follow-up period. For HRQL assessment, multi-item questionnaires can achieve excellent compliance up to 1 month before patients' death, but in order to evaluate the very final weeks of life we recommend the use of simpler methods.

Stein Kaasa (1999) in his study **“Quality of life in palliative care: principles and practice”** explains that in healthcare, most researchers and clinicians agree that quality of life (QOL) is related to symptoms, functioning, psychological and social wellbeing, and probably

to a lesser extent to meaning and fulfillment. This multidimensional health-oriented concept has been named health-related quality of life (HRQOL). However, during end-of-life care spirituality and existential issues become more prominent, as well as family members' perception of quality of care. Outcome measures in palliative care require constructs that reflect the specific goals of palliative care, such as improving QOL before death, symptom control, family support and satisfaction, as well as patients' perceptions of 'purpose' and 'meaning of life'. It is generally recommended that internationally developed and validated patient-rated multidimensional questionnaires should be used when assessing HRQOL in research. However, 'multidimensionality', with often more than 10 possible outcomes, is a threat both to statistical analysis and clinical interpretation of data. Preferentially, a more limited number of outcomes based upon the research question(s) should be defined prior to data collection in the study protocol. The researcher needs to carefully evaluate the content of the questionnaire, in addition to other properties, such as the validity and reliability, before the final decision is made with regards to which instrument to use in a given study.

Julie Hearn (2001) in this study "**Do specialist palliative care teams improve outcomes for cancer patients**" try to focuses that the study was to determine whether teams providing specialist palliative care improve the health outcomes of patients with advanced cancer and their families or carers when compared to conventional services. The study involved a systematic literature review of published research. The source of the data included studies identified from a systematic search of computerized databases, hand-searching specialist palliative care journals, and studying bibliographies and reference lists. The inclusion criteria for articles were that the study considered the use of specialist palliative care teams caring for patients with advanced cancer. Articles were assessed and data extracted and synthesized, with studies graded according to design. A variety of outcomes were considered by the authors. These addressed aspects of symptom control, patient and family or carer satisfaction, health care utilization and cost, place of death, psychosocial indices and quality of life. Overall, 18 relevant studies were identified, including five randomized controlled trials. Improved outcomes were seen in the amount of time spent at home by patients, satisfaction by patients and their carers, symptom control, a reduction in the number of inpatient hospital days, a reduction in overall cost, and the patients' likelihood of dying where they wished to for those receiving specialist care from a multi-professional palliative.

R Harding (2013) in his study on "**What is the best way to help caregivers in cancer and palliative care**" reveals that Informal cares in cancer and palliative care are known to have

high needs and psychological morbidity, yet a literature review identified few targeted interventions. This systematic review of interventions for carers of patients using home cancer and palliative care services searched Medline, CancerLit, PsycInfo and Cinahl databases. The terms used were carer(s), caregiver(s), palliative and cancer. Papers that reported interventions for adults actively providing informal care for non-institutionalized cancer and palliative care patients were reviewed. Twenty-two interventions were identified, comprising home nursing care (four), respite services (three), social networks and activity enhancement (two), problem solving and education (three) and group work (10). Of these, nine were delivered solely to carers. Only six of the carers' interventions had been evaluated, two of these had used a randomized control trial (RCT; grades IB), three employed a single group methodology (two prospective grades IIC and one retrospective grade IIC) and one was evaluated using facilitator feedback. There was a lack of outcome evaluation designs, small sample sizes and a reliance on intervention descriptions and formative evaluations. Methodological challenges may mean alternatives to 'pure' RCTs should be considered. The current evidence contributes more to understanding feasibility and acceptability than to effectiveness. Practitioners and evaluators must prioritize the further development of intervention studies.

“The Kerala Experience in Palliative Care: An Ethical Exploration from the Public Health Perspective” by world health organization Palliative care which deals mainly with incurable illnesses, most often in the end stages of life, is a virtual minefield of ethical issues. According to the World Health Organization (WHO), "Palliative care is 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, psychosocial and spiritual." The goal of palliative care can be summarised as providing relief from needless suffering due to pain and other distressing symptoms, giving psychological, emotional and spiritual care and the creation of a support system that helps the individual whose disease is not responsive to curative treatment to live as actively as possible and helping the patient and family to cope with the illness. The aim of any palliative care programme is to maximise the quality of life of patients and their families. It affirms life and regards dying as a normal process, and hence does not attempt either to hasten or postpone death. Palliative care is often misunderstood as care during terminal illness, but in its true

sense, it relieves suffering and improves quality of life for both patients and families throughout an illness experience, not just at the end of life.

“Impact of Pain and Palliative Care Services on Patients” by S Santha has been undertaken to analyze the impact of palliative care services on patients by considering 51 variables. The study revealed that the major benefit of palliative care to the patients is the reduction of pain to a considerable extent, which was unbearable for them earlier. Second, the hope of patients could be maintained or strengthened through palliative care treatment. It is understood that the services of the doctors and nurses are to be improved further by making available their services to all the palliative care patients in a uniform manner.

“Spiritual concerns in Hindu cancer patients undergoing palliative care: A qualitative study” by Srinagesh Simha, Simon Noble, Santosh define Spiritual concerns are being identified as important components of palliative care. The aim of this study was to explore the nature of spiritual concerns in cancer. The seven most common spiritual concerns reported were benefit of *pooja*, faith in God, concern about the future, concept of rebirth, acceptance of one's situation, belief in *karma*, and the question "Why me?" No participant expressed four of the concerns studied: Loneliness, need of seeking forgiveness from others, not being remembered later, and religious struggle. This study confirms that there are spiritual concerns reported by patients receiving palliative care. The qualitative descriptions give a good idea about these experiences, and how patients deal with them. The study indicates the need for adequate attention to spiritual aspects during palliative care.

METHODOLOGY

CHAPTER III

METHODOLOGY

Methodology is a method that can be used to solve the research problems. Methodology has an important role in research. It helps in conducting research scientifically. It explains why using a particular method and why not using another so that research results are capable of being evaluated either by the research or by other. It explains why a research has been undertaken techniques, which of the various research methods available in more relevant.

Statement of the problem

Palliative care is the one of the main branch in the medical field. People realized the need to take care the sick especially the infirm. And there are people who dedicate their life for their unknown sick brethren. Therefore the present study envisages to know and evaluate the sociological profile of the care takers of the palliative care in Ernakulam general hospital. Through this study the researcher intend to high light the activities and the challenges of the care takers of the palliative care unit, concern with various aspects of socio-economical conditions. The study also focuses on the influential factors for the care taker to take up this task and the problems that face during the work. This study is considered as very important and relevant. Hence the study titled A Sociological Study On The Care Takers Of Palliative Care With Reference To General Hospital, Ernakulam has undertaken.

Objectives of the Study

General objective : To understand and analyse the role of care takers in the palliative care unit, General Hospital, Ernakulam

Specific Objectives:

1. To find out the socio- economic profile of the care takers
2. To find out the influential factors for the care takers to take up this task
3. To understand the problems and difficulties faced by the care takers
4. To find out the management strategies of palliative care unit
5. To analyses the level of satisfaction of care takers in this field

Clarification of concepts:

Palliative care

According to world English dictionary; Palliative care is the treatment and relief of mental and physical pain without curing the causes, especially in patients suffering from a terminal illness .In this study palliative care means humanitarian compulsive Care for avoiding suffering of terminal state of patient which is run under general hospital.

Care taker

According to ENCARATA “The person who took after a property such as an office block, or a school, when it is empty and supervise it’s maintain and cleaning.

In the study care taker who is responsible to look after and care another person who is sick.

Variables

Variables taken for analyzing the data were age, sex, marital status and income. These are identified as the independent variable.

Research design

The research design used is descriptive research design. It is a fact finding investigation which aims to find out the socio- economic profile of the care takers of palliative care unit. It designs to generate new insight in to activities.

Pilot study

After selecting the topic and carefully going through our objectives an initial study was made by visiting the general hospital Ernakulum and met the doctor who is in charge of palliative care unit and met some of the care takes in that hospital. Hence the researchers found that that the study is feasible.

Universe

The care takers at palliative care in general hospital in Ernakulum is universe of the study

Sample and Method of Sampling

From the list of care takers, 50 respondents were taken at random using lottery method of simple random sampling.

Tool of data collection

On the basis of pilot study, a detailed questionnaire was the tool used by the researchers to collect data from the respondents.

Pre test

A pretest was done to test to tool to make necessary correction.

Data Collection

The study focused on the care takers in the palliative care unit in General Hospital, Ernakulam. Since every second Saturday of the month the caretakers gather in the care unit the researcher could spend that day to collect the data. The respondents were very cooperative and interacting with them was an enriching experience.

Data Analysis

The collected data was edited, coded, tabulated and the interpreted. The findings are given based on this analysis.



ANALYSIS & INTERPRETATION

CHAPTER IV
ANALYSIS AND INTERPRETATION

Table No: 4.1

Distribution based on Sex

Particulars	No. Of Respondents	Percentage
Male	20	40
Female	30	60
TOTAL	50	100

The table shows that 60% of the respondents were female and 40% were male. It is understood that women by their nature they concern about others especially the suffering people.

Table No: 4.2

Distribution based on Religion

Particulars	No. Of Respondents	Percentage
Hindu	20	40
Christian	22	44
Muslim	8	16
TOTAL	50	100

It was found that 44% of the respondents were Christians 40% were Hindus and 10% were Muslims.

Table No: 4.3

Distribution based on Marital status

Particulars	No. Of Respondents	Percentage
Married	40	80
Unmarried	9	18
Divorced	0	0
Widowed	1	2
TOTAL	50	100

With regard to marital status 80% of the respondents were married and 18% were unmarried and 2% were widowed. It shows their generosity to help the needy ones rather than concentrate only on their family circle.

Table No: 4. 4

Distribution based on Education

Particulars	No. Of Respondents	Percentage
Below SSLC	6	12
SSLC	11	22
Pre Degree	15	30
Degree	14	28
Post Graduate	4	8
Any Other		
TOTAL	50	100

The table indicates that while 30% of the respondents were completed their Pre-Degree, 28% of the respondents were studied up to degree, 22% of the respondents were SSLC, 12% were below SSLC, 8% of the respondents were Post Graduate.

Table No: 4.5

Distribution based on Locality

Particulars	No. Of Respondents	Percentage
Urban	30	60
Rural	20	40
TOTAL	50	100

This table reveals that while 60% of the respondents were from urban area whereas 40% of respondents from rural area.

Table No: 4. 6

Distribution based on Family

Particulars	No. Of Respondents	Percentage
Nuclear	34	68
Joint	15	30
Extended	1	2
TOTAL	50	100

It was found that 68% of the respondents belonged to Nuclear family, 30% of the respondents belonged to Joint family and 2% of respondents were coming from Extended family.

Table No: 4. 7

No. of days the respondents go for service in week

Particulars	No. Of Respondents	Percentage
1	7	14
2	14	28
3	9	18
4	7	14
5	4	8
6	7	14
7	2	4
TOTAL	50	100

This table shows that 28% of the respondents were working 2 days per week, 18% of the respondents were doing their service 3 days in a week, 14% of the respondents work 1, 4 and 5 days respectively, 8% of the respondents doing their work 5 days and 4% of the respondents rendering their service every day in a week.

Table No: 4. 8

Respondents in Group/ alone for the service

Particulars	No. Of Respondents	Percentage
Alone	0	0
Group	50	100
TOTAL	50	100

All the respondents were working as a group, because their service is not a simple task so they need assistants to take care their patients.

Table No: 4. 9

The time of Visit

Particulars	No. Of Respondents	Percentage
Morning	37	74
Afternoon	12	24
Evening	1	2
TOTAL	50	100

It was found that 74% of the respondents visiting their patients in morning, 24% were in the afternoon and 2% were in the evening. Care takers were convenient to do the task in the morning time because they can also move to do another work.

Table No: 4.10

Doctors' accompaniment

Particulars	No. Of Respondents	Percentage
Yes	30	60
No	20	40
TOTAL	50	100

It shows that 60% of the respondents were accompanied by the doctor; whereas 40% were going without doctor.

Table No: 4.11

Reason to take up this task

Particulars	No. Of Respondents	Percentage
Interest	26	52
Love and Concern	24	48
Any Other	0	0
TOTAL	50	100

The table indicates that while 52% of the respondents taken this job due to their interest and 48 % of respondents were taken this task out of their love and concern towards this task. Majority of the Care Takers took this task by their personal interest.

Table No: 4.12

Person who motivated to take up this service

Particulars	No. Of Respondents	Percentage
Father	8	16
Mother	14	28
Teacher	2	4
Friends	5	10
Others	21	42
TOTAL	50	100

This table shows that 42% of the respondents were motivated by others to take up this task, 28% of respondents got inspiration from their mothers, 16% got inspiration from their fathers, 10% from their friends and 4% from their teachers. This fact shows that others who are not so close to us can also inspire us to do charitable service.

Table No: 4. 13

Respondents who face difficulties in the field

Particulars	No. Of Respondents	Percentage
Yes	30	60
No	20	40
TOTAL	50	100

It was found that 60% of the respondents agreed that they face difficulties in this field and 40% were not. This clearly shows that care taking is not an easy task.

Table No: 4. 14

Respondents who gets support from the patient's family

Particulars	No. Of Respondents	Percentage
Yes	48	96
No	2	4
TOTAL	50	100

The study reveals that while 96% of the respondents were got support from their family at the same time 4% were not supported by their family to do this task, because people of modern society are broad minded and they encourage their family members to help others.

Table No: 4.15

Patient's co-operation

Particulars	No. Of Respondents	Percentage
Yes	49	98
No	1	2
TOTAL	50	100

The table shows that 98% of respondents experienced co-operation from the patients and 2% did not.

Table No: 4. 16

Respondents who felt need to have more volunteers for this service

Particulars	No. Of Respondents	Percentage
Yes	50	100
No	0	0
TOTAL	50	100

All the respondents said that they need more volunteers in this field, the study shows that this task is important as well as not easy. Management of the patient can be done with more care if there are more people to help out.

Table No: 4.17

Difficulty in finding patients homes

Particulars	No. Of Respondents	Percentage
Yes	21	42
No	29	58
TOTAL	50	100

The table reveals that while 58% of the respondents were facing difficulty to find out the patient's home but 42% do not have any difficulties.

Table No: 4. 18

Respondents provided with conveyance

Particulars	No. Of Respondents	Percentage
Yes	40	80
No	10	20
TOTAL	50	100

Table shows that 80% of the respondents were satisfy with their conveyance but 20% were not. Conveyances were provided only for the Care Takers who went to distant places for taking care of patients.

Table No: 4. 19

Difficulty with the family members of the patients

Particulars	No. Of Respondents	Percentage
Yes	25	50
No	25	50
TOTAL	50	100

It was found that 50% of the respondents were facing difficulties from the family members of the patients at the same time 50% do not find any difficulties.

Table No: 4. 20

Difficulties faced from the family members of patients

Particulars	No. Of Respondents	Percentage
Not Interested	22	44
Non Co-Operative	9	18
Unwanted Comments	18	26
Any Other	1	2
TOTAL	50	100

While 44% of the respondents said that family members of the patients were not interested, 26% had warm attitude, 18% were non co-operative and 2% made unwanted comments, because the family may not have any hope on the patient and that they are not interested.

Table No: 4. 21

Strain faced in this Service

Particulars	No Of Respondents	Percentage
Yes	24	48
No	26	52
TOTAL	50	100

The table shows that 52% of the respondents do have strain and 48% do not, because the Non Co-operation from the family members of the patient can be the reason for the strain.

Table No: 4. 22

Problems faced from respondents family for taking this job

Particulars	No. Of Respondents	Percentage
Yes	5	10
No	45	90
TOTAL	50	100

It was found that 90 % of the respondents were not facing problem from their family and 5% of respondents were facing problem from their own family.

Table No: 4. 23

Problem faced mostly by the respondents

Particulars	No. Of Respondents	Percentage
Patients	21	42
Family of the Patients	22	44
Own Family	7	14
Palliative Care Unit		
TOTAL	50	100

The study reveal that while 44% of respondents face problem mostly from patient's family, 42% from their patients and 14% from their own family, because the family of the patients do not realize the effort of the Care Takers.

Table No: 4.24

Financial support from this work

Particulars	No. Of Respondents	Percentage
Yes	7	14
No	43	86
TOTAL	50	100

It was found that 86% of respondents said that they do not get financial support and 14% do get.

Table No: 4.25

Government support in this work

Particulars	No. Of Respondents	Percentage
Yes	15	30
No	35	70
TOTAL	50	100

It shows that 70% of the respondents said they do not get any support from Government and 30% do get financial support.

Table No: 4. 26

Help from other organizations

Particulars	No. Of Respondents	Percentage
Yes	15	30
No	35	70
TOTAL	50	100

The table shows that while 70% of respondents do not get help from other organizations and 30% were supported by other organizations, because some Care takers belongs to certain organizations and various clubs so they get financial support from them and others are doing this task as a social service.

Table No: 4.27

Abuse faced from patient's family

Particulars	No. Of Respondents	Percentage
Yes	24	48
No	26	52
TOTAL	50	100

It was found that 56% of respondents were not experiencing abuse from patient's family at the same time 44% of respondents were facing abuse. The findings show that since the Care takers are going with the medical group, they have less chance of any abuse from patient's family.

Table No: 4.28

Precaution taken to avoid disease from patients

Particulars	No. Of Respondents	Percentage
Yes	20	40
No	30	60
TOTAL	50	100

The study indicates that while 60% of the respondents were not taken any precaution and 40% were taking precaution while they do their service, because they are treating the patients who have no contagious diseases.

Table No: 4. 29

Problem in handling the patient

Particulars	No. Of Respondents	Percentage
Yes	5	10
No	45	90
TOTAL	50	100

It was found that 90% of the respondents were not finding any problem to handle the patients whereas 10% were facing problems. The patients were always co - operating with them.

Table No: 4.30

Medical facilities

Particulars	No. Of Respondents	Percentage
Yes	47	94
No	3	6
TOTAL	50	100

The table indicates that while 94% of respondents said that they get medical facilities at the same time 6% were not, because they are going to care the patients who are in severe condition.

Table No: 4.31

Awareness given to the family members about the care of the patients

Particulars	No. Of Respondents	Percentage
Yes	47	94
No	3	6
TOTAL	50	100

94% of care takers were giving awareness to the family members since the Care takers also felt the need to provide a careful assistance of the family members to their patients.

Table No: 4.32

Training received by respondents before entering into this work

Particulars	No. Of Respondents	Percentage
Yes	47	94
No	3	6
TOTAL	50	100

It shows that 94% of the respondents said that they got training before entering into this field. They are well aware about the training and the importance of training in performing their task.

Table No: 4.33

Training help in managing the patients

Particulars	No. Of Respondents	Percentage
Yes	49	98
No	1	2
TOTAL	50	100

The study shows that while 98% of the respondents said that the training is helpful to them in managing the patients and 2% were not. The training enables them to do their work with more attention and care and makes their task easier.

Table No: 4. 34

Satisfaction with this work

Particulars	No. Of Respondents	Percentage
Yes	50	100
No	0	0
TOTAL	50	100

It was found that all the respondents were satisfied with their job, because they have better environment and they know well about the value of the service provided to the patients.

Table No: 4. 35

Satisfaction with the administrators of the Palliative Care

Particulars	No. Of Respondents	Percentage
Yes	50	100
No	0	0
TOTAL	50	100

It was found that all the respondents were satisfied with the administrators of the Palliative Care. The Palliative Care Unit has very efficient administrators and they are doing good team work.

Table No: 4. 36

Satisfaction with the time schedule

Particulars	No. Of Respondents	Percentage
Yes	50	100
No	0	0
TOTAL	50	100

This table shows that 100% of the respondents were satisfied with the time schedule, because they choose their convenient time to provide their service.



FINDINGS AND CONCLUSION

CHAPTER V

FINDINGS AND CONCLUSION

Palliative care which deals mainly with incurable illnesses, most often in the end stages of life, is a virtual minefield of ethical issues. According to the World Health Organization (WHO), "Palliative care is 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, psychosocial and spiritual." The goal of palliative care can be summarised as providing relief from needless suffering due to pain and other distressing symptoms, giving psychological, emotional and spiritual care and the creation of a support system that helps the individual whose disease is not responsive to curative treatment to live as actively as possible and helping the patient and family to cope with the illness. The aim of any palliative care programme is to maximise the quality of life of patients and their families. It affirms life and regards dying as a normal process, and hence does not attempt either to hasten or postpone death. Palliative care is often misunderstood as care during terminal illness, but in its true sense, it relieves suffering and improves quality of life for both patients and families throughout an illness experience, not just at the end of life.

Socio-Economic profile

In this study 60% of the respondents were female and 40% were male. From this our team understands that women by their nature they concern about others especially the suffering people. It was found that 44% of the respondents were Hindus 40% were Christians and 10% were Muslims. With regard to marital status 80% of the respondents were married and 18% were unmarried and 2% were in the state of widowed. It shows that their generosity to help the needy ones rather than concentrate only on their family circle. While 30% of the respondents were completed their Pre-Degree, 28% of the respondents were studied up to degree, 22% of the respondents were SSLC, 12% were below SSLC, 8% of the respondents were Post Graduate. While 60% of the respondents were from urban area and 40% of respondents were from rural area. It was found that 68% of the respondents belonged to Nuclear family, 30% of the respondents belonged to Joint family and 2% of respondents were coming from Extended family.

Influential Factors

28% of the respondents were working 2 days per week, 18% of the respondents were doing their service 3 days in a week, 14% of the respondents work 1, 4 and 5 days respectively, 8% of the respondents doing their work 5 days and 4% of the respondents rendering their service every day in a week. All the respondents were working as a group. Because their service is not a simple task so they need assistants to take care their patients. It was found that 74% of the respondents visiting their patients in morning, 24% were in afternoon and 2% were in evening. Care takers convenient to do the task in the morning time because they can also move to do another work. It shows that 60% of the respondents were accompanied by the doctor, whereas 40% were going without doctor. While 52% of the respondents were taken this job due to their interest and 48 % of respondents were taken this task out of their love and concern towards this task. Majority of the Care Takers took this task by their personal interest. It was found 42% of the respondents were motivated by others to take up this task, 28% of respondents got inspiration from their mothers, 16% got inspiration from their fathers, 10% from their friends and 4% from their teachers. This fact shows that others who are not so close to us can also inspire us to do charitable service.

Problems and difficulties

It was found that 60% of the respondents agreed that they face difficulties in this field and 40% were doing not have. This clearly shows that care taking is not an easy task . The study reveals that while 96% of the respondents were got support from their family at the same time 4% were not supported by their family to do this task, because people of modern society are broad minded and they encourage their family members to help others. It shows that 98% of respondents experienced co-operation from the patients and 2% did not. All the respondents said that they need more volunteers in this field, the study shows that this task is important as well as not easy. Management of the patient can be done with more care if there are more people to help out. While 58% of the respondents were facing difficulties to find out the patient's home but 42% do not face any difficulties. 80% of the respondents were satisfied with their conveyance but 20% were not. Conveyance provided only for the Care Takers who went to distant places for caring patients.

It was found that 50% of the respondents were facing difficulties from the family members of the patients at the same time 50% do not find any difficulties. While 44% of the respondents said that family members of the patients were not interested, 26% were took warm attitude, 18% were non co-operative and 2% made unwanted comments, because the family may not have any hope on the patient and that they are not interested. It shows that 52% of respondents do have strain and 48% do not have, because the Non Co-operation from the family members of the patient can be the reason for the strain. It was found that 45% of the respondents were doing not face problem from their family and 5% of respondents were facing problem from their own family.

The study reveal that while 44% of respondents face problem mostly from patient's family, 42% from their patients and 14% from their own family, because the family of the patients do not realize the effort of the Care Takers It was found that 86% of respondents said that they do not get financial support and 14% do get. It shows that 70% of the respondents said they do not get any support from government and 30% do get. While 70% of respondents do not get help from other organizations and 30% were supported by other organizations. Because some Care Takers are belongs to organizations like various clubs so they getting financial support and others are doing this task as a social service. It was found that 56% of respondents were not experiencing abuse from patient's family at the same time 44% of respondents facing such abuse.

The finding shows that the Care Takers are going with the medical group they have less chance of any abuse from patient's family.

Management Strategies

While 60% of the respondents were not taken any precaution and 40% were taking precaution while they do their service, because they are treating the patients who have no contagious diseases. It was found that 90% of the respondents were not finding any problem to handle the patients whereas 10% were facing problems. The patients were always co - operating with them. While 94% of respondents said that they get medical facilities at the same time 6% were not, because they are going to care the patients who are in severe condition. 94% of care takers were giving awareness to the family members since the Care takers also felt the need to provide a careful assistance of the family members to their patients. It shows that 94% of the respondents said that they got training before entering into this field. They are well aware about the training and the importance of training in performing their task.

The study shows that while 98% of the respondents said that the training is helpful to them in managing the patients and 2% were not. The training enables them to do their work with more attention and care and makes their task easier.

Satisfaction

It was found that all the respondents were satisfied with their job, because they have better environment and they know well about the value of the service provided to the patients.

It was found that all the respondents were satisfied with the administrators of the Palliative Care. The Palliative Care Unit has very efficient administrators and they are doing good team work.

100% of the respondents were satisfied with the time schedule, because they choose their convenient time to provide their service.

Suggestions

The Palliative Care is an essential need for the present society. As the study tried to look into the various aspects like the influential factors, problems and difficulties, the management strategies and the satisfaction of care takers, the researcher could come to certain findings and conclusions. There was also number of suggestions made by the care takers. They are:

1. The need for more training to do the service more effectively
2. More hosp[ital facilities and medical facilities to help the care takers for the service
3. Government policies should be introduced and implemented to support the care takers
4. More awareness about the service should be spread in the society through various seminars and awareness programmes
5. To ensure the families support the hospital authority can provide certain medical privileges and concessions to the family members of care takers in the hospital.

To conclude that study has made an attempt to understand and analyse the role of care takers in Palliative care unit. The analysis and findings could give us more understanding and enlightenment about the services rendered by the care takers in the palliative care units.

From this study we can expose their effort into the outer world persons who do not know anything about this field, which would increase a social commitment and love concern of the people towards the persons who are in need and to the whole humanity at large.



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APPENDIX

**A Sociological study on the care takers of Palliative Care with reference to the
General Hospital, Ernakulam**

Questionnaire

1. Name:
2. Sex: Male Female
3. Age:
4. Religion: Hindu Christian Muslim
5. Marital Status: Married Unmarried Divorced Widowed
6. Education: SSLC Pre Degree Degree Post Graduate Any Other
7. Monthly Income:
8. Locality: Urban Rural
9. Family: Joint Nuclear Extended
10. How many days do you go for service in a week?
1 2 3 4 5 6 7
11. Do you go alone or in group?
12. When you visit your patients?
Morning Afternoon Evening
13. How many patients you meet each day:
14. Which are the departments running under this Palliative Care?
15. Year of experience:
16. Is there any doctors accompanying you from hospital?
Yes No
17. What made you to take up this task?
Interest Love and Concern Any Other

18. Who motivated you to do take up this service?

Father Mother Teachers Friends Others

19. Why do you select this hospital for your service? -----

20. Do you face any difficulties in the field?

Yes No

21. Do you get your family support for this service?

Yes No

22. Do your patients co-operate with you?

Yes No

23. Do you feel the need to have more volunteers for this job?

Yes No

24. Do you have any difficulty in finding their homes?

Yes No

25. Are you provided with any conveyance?

Yes No

26. Do you face any difficulty with the family members of the patients?

Yes No

27. If yes what are they?

Not Interested Non Co-operative Unwanted Comments Any Other

28. Do you have any strain in this job?

Yes No

29. Do you get your family support to this service?

Yes No

30. Do you face problems from your family because of taking this job?

Yes No

If yes what are they?-----

31. From where do you face the problem mostly?

Patients Family of the patients Own family Palliative Care Unit

32. Do you get any financial support from this job?

Yes No

If yes what are they? -----

If no how do you manage? -----

33. Do you have any Government support in this field?

Yes No

34. Do you get any help from other organizations?

Yes No

35. Do you face any abuse from patient's family?

Yes No

36. Do you taken any precaution to avoid diseases from patients?

Yes No

If yes what are they? -----

37. Do you face any problem in handling the patient?

Yes No

If yes is it patients with Psychological problem or Physical? -----

38. Are you provided with enough medical facilities?

Yes No

39. Do you give any awareness to the family members about the care of the patients?

Yes No

40. Do you get any training before you enter into the field?

Yes No

If yes which are they? -----

41. Are you satisfied with this job?

Yes No

42. If yes how far?

Highly satisfied Satisfied Moderate Unsatisfied Highly unsatisfied

43. Are you satisfied with the administrators of the Palliative Care?

Yes No

44. Are you satisfied with the time schedule?

Yes No

45. Do you have any suggestions to improve this task?
