# WELFARISM OF PALLIATIVE CARE IN KERALA

(Plagiarism has been verified)

Thesis submitted to the
University of Calicut in partial fulfilment of
the requirements for the award of the Degree of

**DOCTOR OF PHILOSOPHY IN SOCIOLOGY**

by

**MALIKA U VARMA**

Under the Supervision of
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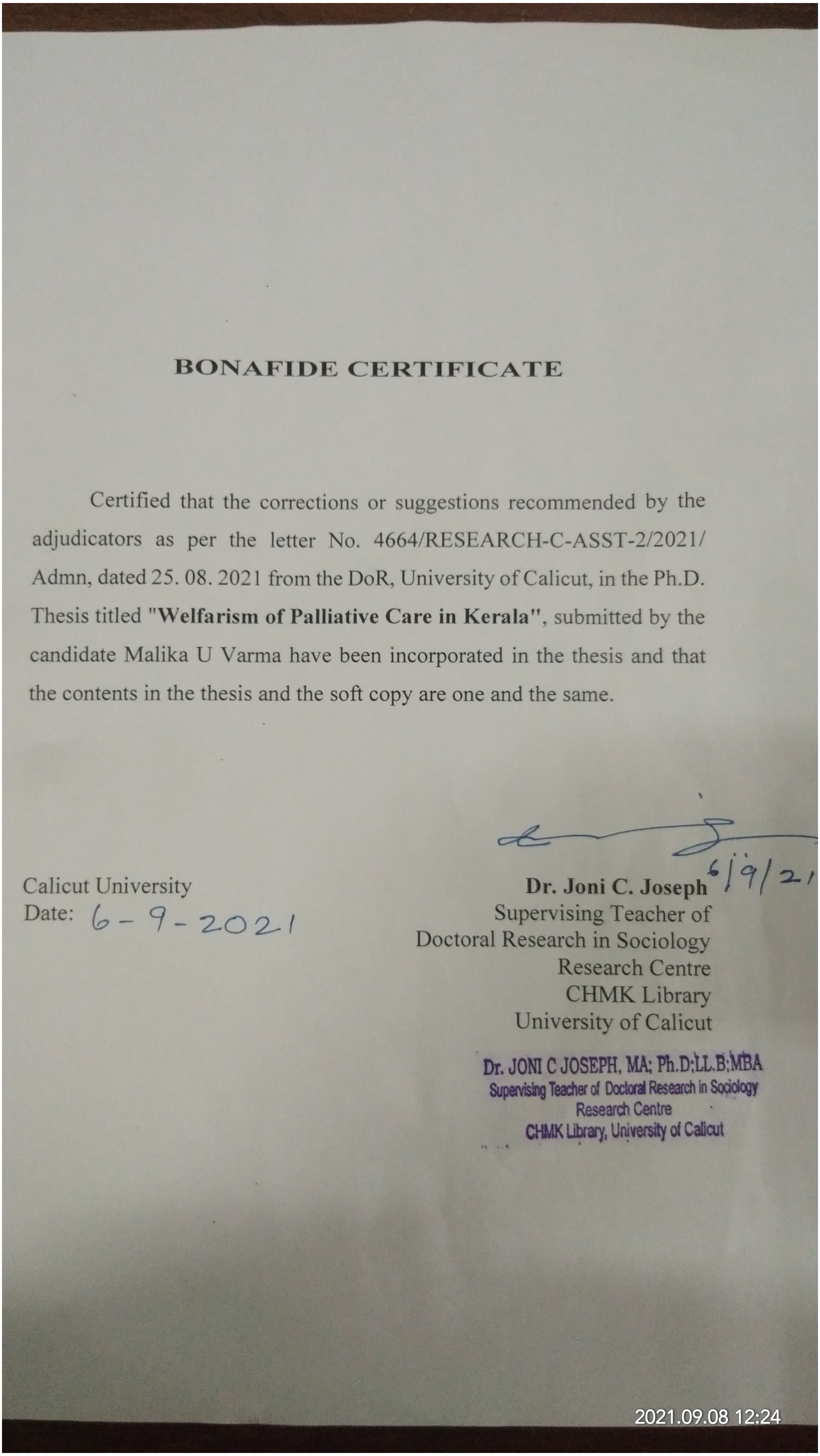

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# DECLARATION

I hereby declare that this thesis on **Welfarism of Palliative Care in Kerala** is a bonafide record of research work done by me and that no part of it has been published anywhere or had become the basis for any submission earlier for the award of any degree, diploma, or similar titles of recognition in any other university.

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# PREFACE

Instead of mere bio-medical aspects, there is a growing awareness that health, disease and disability have socio-cultural dimensions. Cultural factors decide the expectations of normal social life when social conditions seem responsible for producing sickness, complaints and physical impairments. In particular, the WHO definition associates health with well-being, and conceptualises health as a human right. Wellbeing, rather than a neutral state, refers to a positive state, framing wellbeing as a positive aspiration. Health is from this point of view, a way to live well, stressing the connection between health and participation in society.

According to the social model of disability, people are disabled by systemic barriers rather than through impairments. Environmental and cultural barriers to the social inclusion of people with disabilities are taken into consideration. The lack of entry to buildings for the disabled, the absence of elevators, ramps or accessible toilets, which impose functional restrictions on operations, are environmental challenges. Cultural issues include stereotypes of people with disabilities and attitudes toward them, such as patronising attitudes or perceptions that they may not be able to perform certain tasks, which can lead to discrimination and injustice. This can lead to environmental challenges by affecting the implementation of modifications or facilities to minimise the effects of disability, such as the assumption that a person in a wheelchair will not attend certain activities will prevent changes at certain venues.

Palliative care is a relatively modern medical specialty field that came into being in the last half century and came into prominence in the 21st century. The primary objective of medicine is to cure patients, but all diseases are unfortunately not curable, particularly those that have reached a chronic stage.

For others, this 'incurable' period can last for weeks, months or even years. If treatment options cease to operate for a patient because of either the form or stage of the disease or the patient's age, then the focus must be on keeping his or her life as trouble-free as possible. This 'painlessness' needed by a patient is not only physical painlessness, but also emotional well-being that ensures that the person is not completely robbed of the sense of dignity of life. Only after the middle of the 20th century did this fact dawn on individuals and even today, there is no full agreement on what constitutes a 'good death' or 'right death' or 'fulfilling evening of life' when the consensus was much less earlier.

To that point, we can also argue that the Palliative Care discipline does not originate as a strictly medical field, but has evolved from the collective ideas of philanthropists, social scientists, and experts in healthcare. After the middle of the 20th century, time was also ripe for the conception of the novel idea since the 1960s and 1970s were the time of the breakdown of common families as a consequence of which the sick and elderly were robbed of the treatment and protection they were assured of under large extended families. By then the medical profession had already begun to move in that direction, giving priority to end-of-life treatment that would help the dying maintain their dignity, appreciate life in every small way possible, and relieve the stress and distress of caregivers who were typically family members of the patient.

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# CHAPTER 1

# INTRODUCTION

Pain and Palliative Care Services have their roots in early Hospice Care Movement. Hospice care focuses on bringing comfort, self-respect, and tranquility to people at the fag-end of their lives. Hospice claims that the end of life is not a medical experience, it is a human experience that benefits from hospice's professional medical and holistic support. The modern hospice definition involves palliative care offered in facilities such as hospitals or nursing homes for the incurably ill, but also care provided to those who would rather spend their last stage of life in their own homes. It started to appear in the 17th century, and Dame Cicely Saunders pioneered many of the basic concepts under which modern hospice services function in the 1950s. Hospice care also encompasses assistance for patients' families to help them manage with what is happening and offer care and support to keep the patient at home.

Both in Britain and the United States, the concerns about end-of-life care had started emerging in the 1950s. In the USA, the focus was more on ineffective treatments regardless of patients' suffering and inevitable death while in Britain it was more on neglect of dying people. Whereas earlier, idiosyncratic stories related to death were common, the interest now shifted to more systematic and practical scrutiny and research about death. Movements for the legalization of euthanasia had started before the idea of palliative care came into limelight. While the number of supporters for euthanasia started growing, good end-of-life care started to be touted by some as a method to counter euthanasia.

This change in outlook led to a more open attitude about the condition of terminal patients and helped to foster the idea of protecting the dignity of medically helpless people. It introduced the idea that even when doctors medically give up on a patient, because he/she has exhausted all treatment options for that individual, the patient is still a living, pulsating human being with hopes and desires, who should be allowed to know the richness of life even for the remainder of his or her days. People started searching for imaginative ways in which this can be done. There was also a growing understanding about the interconnection between mental anguish and physical pain, which in turn led to a different insight into the notion of pain as was understood by the medical world till then. The way medical science developed, it was treating body and mind as two different entities. The arrival of palliative care ended this dualism to usher in an era of what Cicely Saunders described as 'total pain'.

In this background, when Saunders founded St. Christopher's Hospice in 1967, the idea was welcomed with open arms by many. It also became an inspiration for others to set up similar units. Once the idea of palliative care took root, people tried practising it in different settings – at homes, in daycare services, and in hospices. Palliative care units started functioning in hospitals as well, supplementing medical treatment with novel ideas of healing. The term 'palliative care' was finally introduced by Balfour Mount, a Canadian surgical oncologist, who is known as the father of palliative care. He established palliative care services in Royal Victoria Hospital and McGill - University, and is the founder of Montreal's biennial International Congress on Palliative Care. He is a man who has himself battled life-threatening illnesses from a very young age. Hospice has encountered opposition emerging from different causes, including professional or cultural taboos against open contact between doctors or the general public about death, frustration with unfamiliar medical procedures, and professional callousness towards the terminally ill. Nevertheless, the programme has, with national modifications in focus and application, spread worldwide.

In 1984, Magno who had been active in forming the American Academy of Hospice and Palliative Medicine and the former executive director of the US National Hospice Organization, established the International Hospice Institute, which in 1996 became the International Hospice Institute and College and later the International Association for Hospice and Palliative Care (IAHPC). As of 2008, the IAHPC, with a Board of Directors from countries as diverse as Scotland, Argentina, Hong Kong and Uganda, operates on the principle that each country should establish a model of palliative care based on its own resources and circumstances, reviewing other countries' hospice experiences but adjusting to their own needs. In 2006, the United States based National Hospice and Palliative Care Organization (NHPCO) and the United Kingdom's ‘Help the Hospices’ jointly commissioned an independent, international study of worldwide palliative care practices. Their study found that 15% of the world's nations delivered widespread palliative care services with integration into major health care organisations, while an additional 35% provided some kind of palliative care services, although they may be in specific locations or very small. There were an estimated 10,000 foreign initiatives aimed at offering palliative care as of 2009, although the word hospice is not often used to describe such facilities.

While Palliative Care provisions have improved a lot since it was started, more changes are supposed to be necessary to bring it on par with the new inventions and ethics of the medical field, and the nature of fast-evolving human societies. As such, certain aspects of palliative care need to be strengthened to make it more satisfactory. One of these is the development of a national policy by governments of all countries. While palliative care can be provided by private institutions also, when palliative care is considered an essential part of health services, there will be budgetary allocation for it, at least for the help of those suffering from very serious ailments. The other is that due to the growing number of medical conditions in the world as well as the growing number of individuals who need palliative care, rigorous training is needed for those who provide palliative care services.

## Palliative Care in Kerala

Pain and Palliative Care Society (PPCS), Calicut formed in 1993 is one of the pioneer organizations in palliative care in the Developing World. It is the first charitable society in palliative care in India. Since its inception, PPCS has acted as a facilitator for a large number of community based initiatives in palliative care in Kerala (Retrieved from https://www.thebetterindia.com). It was founded by some of the doctors of Calicut Medical College, under the guidance and leadership of doctors M.R. Rajagopal and Suresh Kumar. It started with a capital of Rs.1500 and a primary focus on palliative care for cancer patients. It grew and flourished quite fast and in 1995, it was recognized by the World Health Organization.

As the organization grew, they trained thousands of volunteers who later spread out to start palliative care units in their own local communities. They have also given guidance and support to palliative care units in neighboring countries like Thailand, Bangladesh, and Sri Lanka. Dr. Suresh Kumar himself had been to other parts of India like Puduchery and Arunachal

Pradesh to help train volunteers and set up palliative care units there. In January 2020, about 30000 people attended a fund-raising event organized in Kozhikode. It was a carnival that featured art, literature, music and food, with palliative care patients themselves having made many handicraft items and savory dishes that were sold at the function (Manoj, 2020).

There has been a lot of debate about and study of its organisation and function and the reasons for its achievements since the establishment of the NNPC (Neighbourhood Network in Palliative Care). Relying too much on the all-encompassing word 'NNPC' is a mistake that is sometimes made. It is incorrectly used to refer to a homogeneous, centralised entity dedicated, according to its own established principles, to the development of identical satellite centres. The units covered by the umbrella term of the NNPC vary greatly depending on their organisation, the priority of services, the availability of services, and the types of persons making up the unit. Some centres are run almost entirely by a single entity, such as a religious association. A second category of established group is created by individuals from various organisations. To become formed, to recognise leaders and to work as a team, these groups need more time. Then, the final form of centre is made up of people not affiliated with any organisation. They also work in the area of health or social work independently. This group's initiation process is also challenging because they are only joined by the geographical region and require more time to grow as a group.

According to Zaman et al, (2017), the “NNPC is an attempt to facilitate a sustainable, community-led service capable of providing palliative care to all those in need, with limited resource”. This model is based on the idea that untreatable medical conditions are social problems albeit containing some medical components and definitely not a solely medical problem. The basis of this theory is the Declaration of Alma Ata of 1978 which emphasizes the obligation of “all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world”. It was co-sponsored by WHO and emerged as a major milestone in the public health field of the 20th century. The Millennium Development goals of the United Nations in the year 2000 brought the focus back on the essence of this declaration. “The NNPC is an example of the revival of *Alma Ata* ideas and has in turn been acknowledged by WHO as a demonstration project” (Ibid, 2017). According to the authors, it is a highly progressive measure, though it elicits a crucial question about the way in which welfarist ideas are incorporated into a neo-liberal state.

As part of the expansion of the services, new initiatives are started like ‘Tracks we leave’ to organize mass public support by accepting small donations for bedridden patients. The Footprint Rehabilitation Project, initiated by the Institute of Palliative Medicine, Kozhikode, is a project that aims to incorporate chronically sick, bedridden and chronic psychiatric patients back into the community by teaching them new crafts / skills. A project that focuses on the ‘elderly’ - ‘Kiran -Living with Dignity’ is an India-based project that proposes to integrate the care of aged together with palliative care. This five-year project began on November 1st, 2007. ‘Caring 4 Childhood Cancer & Chronic Illness’ is a new project that supports children with cancer and other chronic illness (Retrieved from https://www.instituteofpalliativemedicine.org). The only state with an NRHM palliative care programme is Kerala. The project, which began in 2008, has been working towards implementing the Government of Kerala's Palliative Care Policy.

Kerala’s palliative care units are functioning well because there are lots of volunteers in these units besides health care professionals. The volunteers work not only at the institutes but also participate in home visits and even participate in emergency night visits which are coordinated by the city’s administration. The local community plays a strong part in these involvements because many people join the initiative as they see it as a venture of their community, whether bonded on religious grounds or on ideological grounds.

Dr. Suresh Kumar, the doyen of palliative care in Kerala even welcomed the entry of political parties into the sacrosanct arena of palliative care. In answer to a question about political parties entering the hallowed grounds of civil society, Dr. Kumar said that political workers were also part of civil society and that he was glad to see some of them trying to claim the social space they were entitled to (Kumar, 2012). According to him, the entry of such major players into the world of palliative care in the state is a “success of the sensitization and advocacy campaign for palliative care in the state” because the “message being delivered all along has been that ‘palliative care is everybody’s business’”.

According to Santhosh (2016), this “initiative could persuade the State to replicate this model and incorporate it in the health delivery system of the government”. Such a scenario will make “Kerala the first in India with an official palliative care policy and statewide support system in place” (Ibid, 2016). According to the author, Kerala’s community-based palliative care units are local manifestations of neoliberalism in an only-one-of-its-kind socio-political setting. Kerala’s unique socio-historic context has expedited this participation of civil society organizations in welfare programs in association with the State.

## Welfarism

The Social Welfare policies can be referred to as an action plan demonstrating the means and strategies used for the delivery of social welfare programmes. Social welfare programmes provide measures designed to address the needs of individuals and groups that are unable to access or are refused the resources and services offered by the government due to certain handicaps; social, economic, physical etc. (Pillai, 1983). Social Welfare Programme, in other words, refers to the sector that provides services for people who need special care. Welfare activities are typically targeted at participants who need to earn benefits. Members of many backgrounds can typically be subjected to these welfare facilities. It may be social, family or personal circumstances on several occasions that cause the individual to expose himself or herself to the mercy of welfare services. Hence in order to measure the intensity of welfare requirements emerging from conditions occurring among the individuals of different capability and social units, beneficiaries of the welfare services have to be considered from various angles.

On certain instances, when the health issues and associated complications within the families of various participants are taken into account, some underlying physical conditions and their behaviours on individuals lead to serious problems. Though there has been great expansion of health care services, primary health centres, dispensaries, hospitals and community health centres and also the secondary and tertiary health care level, the functioning of Health care System is not up to desired expectations (Goel, 2001). Nowadays, there has been a rising consciousness that the social scientists have an increasing role to play in respect to the preparation of curative, preventive, promoting and rehabilitative health policies and programmes, along with medical experts to solve the complete health care problems of a rapidly increasing population. Palliative Care Service is a result of such a consciousness among the medical and social scientists in the western societies.

Welfarism is a very old idea, perhaps frequently debated by economists. Their concern is to minimise economic inequality and bring about equality among members of the society. Welfarism is a form of consequentialism. Welfarism, like all types of consequentialism, is based on the belief that behaviour, strategies, and/or laws should be judged on the basis of their implications. Welfarism is the perception that the morally important consequences are effects on human (or animal) welfare. There are many different understandings of human welfare, but the term "welfarism" is usually related to the economic conception of welfare (Sen, 1979). Sociologists deal with this concept in a wider scope. The progressive functions of action of an agency in a social condition is regarded as welfarism of the agency under consideration.

## Welfarism of Palliative Care in Kerala

The description of WHO specifically connects health with well-being, and conceptualises health as a human right. Wellbeing refers to a positive state rather than a neutral state. The 1986 Ottawa Charter reformed this concept, defining health as ‘a resource for daily life, not the purpose of living’. From this viewpoint, health is a way to live well, emphasizing the link between health and involvement in society. There is an increasing realization that health, illness and disability have socio-cultural dimensions rather than mere bio-medical aspects. When social circumstances seem responsible creating illness, grievance and physical impairments, cultural aspects determine the standards of normal social life.

The 'sick position' was described by Parsons (1951) as the rights and obligations of people who are ill. Rights include exemption from usual duties, such as employment, household or care duties, and not being blamed for their illness; duties include an obligation to choose to recover and to seek medical help to do so. These rights and obligations are believed to be temporary and universal and to work together for the good of the patient and in the interests of the broader community.

However, in the case of a person with chronic or long-term disease, the sick role model should not be extended since it focuses on recovery from the disease as a duty to society for that individual person. The model neglected to explain how the chronically ill person approaches his or her condition and social life.

A sociological approach tries to go beyond the factors related with a biomedical considerate of chronic illness which normally focuses on the system of functional limitations and activity restriction. Sociological approaches emphasize the need to evaluate the impact of what Anderson and Bury (1988) call '*the mundane features of daily life dictated by contemporary culture and material conditions in the experience of chronic illness and disability*'.

People are impaired through structural obstacles rather than by impairments, according to the social model of disability (Oliver, 2013). It takes into account environmental and cultural obstacles to the social integration of persons with disabilities. Environmental challenges include the absence of entry to buildings for the disabled, the absence of elevators, ramps or accessible toilets, which place practical limitations on operations. Cultural challenges include views of individuals with impairments and attitudes towards them, such as patronising attitudes or beliefs that they may not be able to perform those activities, which can lead to oppression and prejudice. By influencing the introduction of modifications or facilities to reduce the effects of disability, this may lead to environmental obstacles, such as the presumption that a person in a wheelchair will not attend certain events can discourage adjustments at certain venues.

The wider socioeconomic context in which we operate is also an important determinant of disability as defined by the social model (Lang, 2001). Thus people with ill health or disability who are unable to fully partake in their societies may be differentiated or even excluded. This realization among some medical professionals paved the way for Palliative Care Service offering solace by treating this marginalized community.

Palliative care is a relatively new area of medical specialty that came into being in the last half century, and in the 21st century, came into prominence. The primary goal of medicine is to cure patients, but all diseases, especially those that have reached a chronic stage, are sadly not curable. This ‘incurable’ stage may prolong for weeks, months, or even years for some. If treatment options cease to function for a patient because of either the type or stage of the disease or the age of the patient, then the emphasis must turn to making life trouble-free as possible for him or her. This ‘painlessness’ that a patient requires is not just a physical painlessness, but an emotional wellbeing as well which ensures that the individual is not fully divested of the sense of dignity of life. This reality dawned on people only after the middle of the 20th century because, even now, there is no complete agreement on what constitutes a ‘good death’ or ‘right death’ or ‘fulfilling evening of life’ while earlier the consensus was far less.

To that extent, we can even say that the discipline of Palliative Care does not have its origin as a purely medical field but has arisen out of the combined ideas of philanthropists, social scientists, and healthcare professionals. Time was also ripe for the conception of the novel idea after the middle of the 20th century because the 1960s and 1970s were the time of the breakup of joint families as a result of which the sick and elderly were deprived of the care and security they were assured under large extended families. Medical field had also started evolving in that direction by then, giving importance to end-of-life care that would help the sick to maintain their dignity, enjoy life in whatever small ways possible, and ease the burden and anxiety of the caregivers who were usually the patient’s family members.

The World Health Organization(WHO) describes palliative care as “an approach that enhances the quality of life of patients and their families facing the problem of life-threatening disease through the prevention and relief of distress through early detection and faultless assessment and treatment of pain and other physical, psycho-social and spiritual issues” (Retrieved from https://www.who.int/news-room/fact-sheets/detail/palliative-care).

Palliative care is underpinned by the following principles:

- Emphasis on quality of life , including good control of symptoms
- A whole person's approach, taking into account the history and current condition of the individual.
- Care that focuses on both the individual with the disease and those who matter to the person
- A reverence for patient autonomy and choice.

- An emphasis on accessible and sensitive communication (Retrieved from https://www.facs.org/about-acs/statements/50-palliative-care).

Palliative care becomes essential when a patient has tired of his treatment options. In other words, people want it when alternatives for cure cease being beneficial, or the miseries from these treatments start surpassing their benefits, or when patients have become incapacitated enough to have reached the final stage of life. That said, Palliative Care is planned not just for patients facing death. Palliative care can also be used for chronically ill patients who have a hope of receiving a cure and returning to life to decrease the severity of their pain, discomfort, and emotional uncertainty.

It is an all-inclusive approach focused on convenience that also takes into account what the patient needs to do with his or her life. It is an interdisciplinary care that aims to get rid of suffering and improve quality of life both for patients with progressive illness and for their families. It is offered instantaneously with all other appropriate medical treatment and thus is not for dying patients exclusively (Ragan et al., 2008). By treating the client as a result of his / her physical, social, psychic and spiritual life, Palliative Care upholds a holistic approach. In these distinct realms, therefore, a solution to the sufferings of a person must be searched for.

Pain management not only needs caring for the sick person's body; the pain management function is social reinforcement and calming down of the irritated mind. Spiritual consolation may also become handy in this situation. Modern palliative care, in fact, forms, as Saunders states, a cover in between the person and pain (Saunders, 1996). Hence the person feels comfort and satisfaction in his/her otherwise desperate and suffering life.

Rapid development in the health care system in the State produced a hike in number of aged population. Old age itself creates numerous problems in the bodily, mental and social conditions of an individual. They may require support from their immediate society to resolve all these problems. Thus increasing elderly population may demand an organized system of care rather than mere medical care. Similarly the advanced technologies emerged in the field of medicine caused increased life expectancy accompanied by chronic diseases and disabilities among the citizens. Such chronically ill and disabled may include economically poor, homeless, psychologically distressed and socially excluded.

Nuclear structure of family in the information era may be almost incapable to provide care for the disabled or chronically ill member. Thus not only the chronically ill/disabled and elderly need support but also their families demand an active total care envisioned by Palliative Care. As welfarism is considered as the progressive functions of an agency in a social condition, welfarism of palliative care refers to the effect of the non-medical services on managing pain and mental agony of the beneficiaries, the contributions of the palliative care initiative in easing the responsibilities of the care giver/family of the beneficiaries, the support given to the poor who are unable to approach the paid health care system and the type of social solidarity brought about by the palliative care movement in the community.

Medical professionals generally have to confront the dilemma of balancing the technological and curative abilities of medicine with its humanistic sides like euthanasia, or the creating of a bucket list to live life to the fullest with the time one has left. This is because medical world regards death as something to be fought against and at least postponed even if it cannot be avoided. In this situation, the sociological aspect of palliative care encourages the medical world to be gentler in its confrontation of death. Thus sociologists play an important role in the successful working of a palliative care team because they can contribute significantly in areas like understanding the exact position of a sick individual within the health matrix, the social structure and idea of death, and the health provision that a terminally ill patient requires. The contributions by sociologists will help health-care professionals significantly in discharging their duties towards the patients.

Studies in Palliative Care are scarce in Kerala and in our country as a whole. Kerala is a good example of how the civil society and the State can work together in a very healthy partnership in alleviating the misery of its people in a neoliberal era because Kerala's palliative care is basically a community-led movement that gets State patronage. This healthy combination has made palliative care movement quite successful in Kerala. Community-based organizations, which include religious groups as well, play a pivotal role in Kerala's palliative care by recruiting volunteers and helping with collecting other necessary resources. On this line, this study attempts to bring palliative care under the sociological scanner because palliative care has arisen as a response to the demand for greater dignity and emotional fulfilment at the terminal stage of human life. The study tries to analyse the physical, psychological, social and economic problems of the chronically ill or disabled, the perceptions of the patients on the sufferings of their family care givers and the satisfaction of the beneficiaries with the extent of support and care provided by the Palliative Care agency.

## Structure of the Thesis

This thesis is codified in 10 chapters. The first chapter introduces the topic of research. Chapter 2 deals with the review of existing literature related to the topic. Chapter 3 explains the methodology followed to carry out the study. Chapter 4 portraits the setting of research that is the State of Kerala; its features especially the health and medical services available in the State and the Palliative Care Programme in the three specific districts Thiruvananthapuram (Southern zone), Thrissur (Central zone) and Kozhikode (Northern zone). Quantitative analysis chapters are following the 4th chapter. To identify the welfarism of palliative care agency, it seems to be appropriate to analyse the various problems faced by the beneficiaries. On this presumption, the first three chapters of analyses (Chapter 5- Bodily and Mental Conditions of Palliative Care Receivers, Chapter 6- Socio-economic conditions of the Beneficiaries and Chapter 7- Perceptions on the Stress of Care Givers) discuss the problems of the beneficiaries. The analysis chapters, chapters 5, 6 and 7 primarily deal with the problems, physical (relating to the body), economic, socio-cultural and psychological, experienced by the clientele community of Palliative Care. Chapter 8 analyses the support expected of from the Palliative Care Service by the beneficiaries and those delivered by the services and matters related to them. Chapter 9 contains three case analyses which reveals the supports given by the Palliative Care agency. Chapter 10 is the concluding chapter which consolidates the findings of the analysis chapters. The chapter also discusses sustainability of the premises proposed in the study in the light of the results received from the analysis chapters.

# CHAPTER 2

# REVIEW OF LITERATURE

The British historian, philosopher, and Nobel Laureate Bertrand Russell (1956) in his essay named ‘How to Grow Old’ states that “I should wish to die while still at work, knowing that others will carry on what I can no longer do and content in the thought that what was possible has been done”. Death is a natural process. In fact, it is probably the only event in life that people can be absolutely sure of. Still, despite being the most inevitable event, it is seen as something tragic. Sometimes death comes suddenly, without any forewarning so that people are freed of the pain and problem of confronting it.

What Russell envisages is one of the most ideal forms of life’s end but it may not come to everyone that way. Death may come slowly in some cases, announcing its arrival through a lingering illness, with all the accompanying agony, and the painful confusion about how to manipulate that dark creek connecting life and death. It is at this juncture that palliative care becomes a necessity for the suffering individual and his confused and bewildered family. Though palliative care has been practiced informally for centuries, now it is getting more and more integrated into the mainstream healthcare system and in some countries getting distinguished into primary palliative care and secondary palliative care (Quill & Abernethy, 2013).

However, this does not mean that palliative care is a field of speciality that prepares people for death. On the contrary, it is a discipline that gives emphasis to the quality of life (Kelley & Meier, 2014). It works towards relieving the patient of his pain so that he can make use of his life till his last breath. This making use of one’s life will include enjoying the good things of life, using one's skills to the maximum, and even helping others in whatever little ways the patient may be able to. Palliative care workers ensure to the maximum extent possible that the patient do not feel unwanted.

In cases where the patient is too physically incapacitated to enjoy life, Palliative Care focus will be on pain-relieving primarily, and in discussing with doctors and guiding families on how to take medically important decisions. Conventional medical practices tend to provide curative treatment, which may even be quite aggressive, during the initial stages of the disease and then divert to comfort care in the terminal stages when nothing seems to work. As different from this, Palliative Care insists on relieving suffering at all stages of the disease (Rome et al., 2011).

Palliative Care takes a holistic view of life. It means that Palliative Care givers do not just focus on the terminal disease but on the past and present circumstances of the patient, his/her psychological situation before the onset of the disease, his/her position in the society, his/her family connections, the emotional and financial impact the disease had on him/her and his/her family, and his/her general approach to life. For example, a person who had led a fulfilling life will be able to confront death with more equanimity than someone who is forced to leave behind many things unfinished. All these aspects will be taken into consideration while deciding the palliative approach to the patient. Some experts in the field consider Palliative Care as a preventative service as the discipline is focused on treating as well as preventing the tribulations of the patients as well as their families (Bickel &Ozanne, 2017).

Palliative Care is also cost-effective compared to being treated in hospitals either continuously or episodically to provide relief from a particular problem till the patient becomes asymptomatic (Smith et al., 2014). Palliative Care is nowadays offered at the patient’s home or in the old age home where he or she is residing and focuses on avoiding unnecessary treatment that will in no way improve the patient’s quality of life or provide any form of solace or succour to the family amidst whom he or she is living.

## Origin and Development of Palliative Care

Palliative Care culture has evolved from the discipline of hospice, which is a shelter for taking care of terminally ill patients. The credit for starting palliative care goes to Dame Cicely Saunders, a doctor, who opened the first hospice in London, called St. Christopher Hospice. She introduced the idea of combining medical knowledge with love and care to provide maximum possible relief to suffering patients. Though many people had helped her in her endeavour, the first financial help came from a dying patient whom she had cared for, who left her £500, which was a significant sum in 1948, when she received it. She introduced the concept of total pain, which, for her, included the “physical, emotional, social, and spiritual dimensions of distress” (Richmond, 2005).

This inclusion of different facets of distress is the nuance that differentiates a present-day Palliative Care unit from a hospice. Palliative care workers do not see medical help as the only solution for a patient’s problems. They give a lot of importance to providing emotional support to an individual and his family because of the knowledge that this solace could give a new meaning to the patient’s life. This will alter the outlook and understanding of the patient even in a situation where his days are numbered. Hospice care generally starts when there are no medical solutions left and “hospice professionals focus on caring for patients with a clearly limited life expectancy and who have made an informed decision to discontinue curative care" (Meier et al., 2011).

Palliative Care, on the other hand, can be given even to those for whom doctors have an assured cure. Palliative Care will start along with diagnosis, and is provided to make sure that the patient wades through the whole process of traumatic treatment with minimum physical and mental agony. Painful and difficult diseases, even if they are not terminal illnesses, "may alter a person's ability to fulfill roles critical to self-identity, such as caring spouse, or devoted parent. Through their longitudinal relationship, PCPs can help individuals explore these issues and find ways to adapt and prioritize in the face of a serious illness" (Buss et al., 2017).

In the early stages of introduction of palliative care, it was focused mainly on the needs of cancer patients. Even now, quite a lot of studies on palliative care focus on cancer patients. Some doctors fear that "as long as a patient is eligible for anti-cancer treatment, active communication of PC may undermine the patient's trust and diminish hope" (Gärtner et al, 2019). The authors point out that palliative care can be used quite early in the course of an illness, along with other therapies meant for prolonging life because many patients experience difficult problems or symptoms even in the early phases of such illnesses. Such basic palliative care, which can be introduced at any stage of the disease, is referred to as 'general' or 'primary' palliative care. Integration of specialist palliative care (SPC) to the treatment trajectory has to be above and beyond this utilization of general palliative care.

There is some difference of opinion on the need of and the help rendered by specialist palliative care mainly because there is no full consensus on what differentiates a specialist in the field from a non-specialist. According to a study conducted using the Delphi method, “specialist palliative care clinicians have advanced knowledge of identifying dying, skills to assess and manage complex symptoms to improve quality of life, have advanced communication skills and perform distinct clinical practices” (Forbat et al, 2020). On the other hand, non-specialist palliative care “involves discussions around futile or burdensome treatments, and care for people who are dying” (Ibid, 2020). It is suggested that those with disease-specific specialities should be more involved in discussions on treatment and care of terminal patients, in collaboration with specialists in palliative care whenever required.

Specialist palliative care (speciality palliative care) services are delivered by those who have a higher level of palliative care training than those who provide primary palliative care. According to Gaertner et al, (2015) one advantage of “SPC services is that they can *focus on alleviating and preventing suffering* without being primarily responsible for the disease-modifying therapies” and if “such *conjoint and interdisciplinary cooperation* of the primarily responsible disciplines (e.g., cardiology, oncology, or neurology) with SPC services is well coordinated, the joining of the expertise, vigilance, and workforce of both disciplines may improve efficacy and safety of care”. According to the authors, there is evidence that getting special palliative care could have some economic benefits as well.

A resolution adopted by WHO in 2014 “calls to ensure that palliative care is an integral component of all relevant global disease control and health system plans” irrespective of whether they are communicable or non-communicable diseases. “It is noteworthy that ensuring the availability of palliative care services is an obligation of health care systems under international human rights law” (Al-Mahrezi, 2016). Every year nearly 40 million people require palliative care and most of them (78%) are in low-income or middle-income countries. In the case of children this percentage is as high as 98%. This is mainly because treatment options are comparatively less in low-and-middle income countries. Even in high-income countries the need for palliative care is steadily increasing because of increased life expectancy. When people live longer, they are more prone to cancer or chronic disease than in the past. Depending upon the requirements of the patient, palliative care can be availed in "different settings: as a stand-alone service in a center or hospice, hospital-based, community-based, and home care" (Ibid, 2016).

### Solidarity Brought About by Palliative Care Movement

Solidarity is a mutual understanding and responsibility, a bonding that generally happens because of shared interests. "In sociology, solidarity has acquired a clear definition, namely, the degree of social cohesion in a group or society whereby individuals, because of various motivations, are willing to serve and promote the collective interest of the group or of society" (Meulen, 2016). Emile Durkhiem (1893), the French Sociologist, introduced the concept of 'mechanical solidarity' that helps the maintenance of social order in primitive societies. Mechanical solidarity is spontaneous in a society because the beliefs and value systems cherished by the people of that society will be more or less similar and so can be easily enforced by either social control or regulations of those in power.

Modernisation of societies led to the formation of what is known as 'organic solidarity'. Public health care systems can be seen as a manifestation of organic solidarity though they incorporate in them elements of mechanical solidarity as well. "In the domain of health and social care, solidarity is first and foremost understood as a moral value and social attitude regarding those in need of support" (Meulen& Wright, 2010). However, the "solidarity which is fundamental to family care has a personal, concrete meaning that is different than the organic solidarity which tries to organise collective interest in an abstract way" (ibid, 2010).

The way Palliative Care works, there is bound to be a three-way connection generated among the participants of the discipline because, besides the strong bond between the patient and the caregivers, there will also be a compelling sense of responsibility shared by the family members of the patient and those who provide the palliative care. All these together generate a healing solidarity. "Historically, the concept of solidarity in the context of healthcare policy has referred to how "communities of mutual recognition" translate this sense of interdependence into publicly funded healthcare policies" (Pettus, 2016).

Pain and suffering are inseparable parts of all serious illnesses. However, every healthcare professional does not see pain and suffering as different entities. Suffering is believed to result from pain and is viewed as a psychological dimension of pain. This leads to some physicians remaining focused on curing the pain because they feel that by extension, suffering will also get removed. However, this does not mean that all are impervious to the spiritual and existential dimensions of suffering. Though their professional response may be more to the idea of pain, "most physicians incorporate elements of both sets of beliefs in their professional lives, although they often do not appreciate the resultant incompatibility" (Coulehan, 2009). Doctors become effective healers when they embrace the idea of "compassionate solidarity, which preserves a form of objectivity while promoting the formation of empathic relationships with patients" as different from the "doctrine of objectivity and detachment in medicine" (ibid, 2009).

Whatever the definition of solidarity in Sociology, in the field of Bioethics, it is suggested to have a "theoretical status independent of its sociological interpretation: the fact that individuals are willing to support the greater good does not mean that they should be doing so as a moral imperative" (Meulen, 2016). It is contended that in medical ethics, solidarity is a principle that works against patient autonomy, especially in the question of euthanasia or assisted dying, and what is considered to be proper medical practices in general. In conventional societies where euthanasia did not even exist as a concept, treatment of the terminally ill was done based on the principles of solidarity because decisions about treatment and terminal stage practices were taken by family members in consultation with the physician and in accordance with social practices.

To reduce the distress of very sick patients, palliative care providers sometimes give what is known as palliative sedation. This is done when very ill patients are not relieved of their pain even by administration of very high doses of medication. There is some argument and confusion whether palliative sedation and euthanasia is one and the same. According to Bhyan (2020) "There is broad clinical, ethical, and legal consensus that palliative sedation is appropriate at the end of life to treat intractable and intolerable symptoms such as extreme pain, dyspnea, nausea, and vomiting as long as the intent is to treat patient symptoms and not to hasten death". The difference between palliative sedation and euthanasia is the intent. The former aims to relieve extreme distress while the latter aims at ending life. In the case of palliative seduction, the principle of double effect, which makes the distinction between an intended effect and an unintended effect of an intervention, is acceptable. According to this, “intentionally causing death is not acceptable, but prescribing high doses of opioids and/or sedatives to relieve pain is, even if the resulting death is foreseen” (Ibid, 2020).

However, the ethical controversies regarding palliative sedation and euthanasia refuse to die down. When different types of sedations are used as part of palliative care for pain relief, there is always the risk of people interpreting the intention in their own way. This confusion is further strengthened by the expansive way in which the very concept of intention is used. There is a school of thinking that palliative sedation is taking palliative care back to the pre-palliative care times when emphasis was more on therapy than care. According to this point of view, the significance of intention has to be linked to “other ethical parameters to demarcate the practice of palliative sedation: terminality, refractory symptoms, proportionality, and separation from other end-of-life decisions. These additional parameters, although not without ethical and practical problems, together formulate a framework to ethically distinguish a more narrowly defined practice of palliative sedation from practices that are tantamount to euthanasia” (Have & Welie, 2014).

Patient autonomy or the patient’s right to make decisions regarding his or her treatment options and care, even when those choices are in conflict or at variance with the doctor’s recommendations is an important aspect of health care. According to (Vernooij-Dassen et al., 2005) patient autonomy problems “feature among the top 5 problems in palliative care and were mentioned even more frequently than pain problems”. According to them, patients’ sense of dependency and loss of control over themselves can be significantly reduced by identifying and addressing autonomy problems and that the “attainment of the central goal of palliative care might thereby be facilitated”. At the same time, they point out that respecting patient autonomy is not the same as doing what the patient demands. The crux of the issue is the need to provide help and support in a rather subtle, inconspicuous way, so that the patient would not feel that he is totally helpless and at the mercy of others.

According to Zalonis and Slota (2014), major aspects of palliative care are “the facilitation of patient autonomy, access to information, and choice”. The authors propose “palliative care as one means of responding to the challenge of a widespread lack of autonomy in decision making” and for simultaneously ensuring improved quality of life, increased survival, and prospects for the exercise of patient autonomy. Though they say that palliative care can “promote autonomous decision making at any point in the disease trajectory” they also point out that the earlier palliative care is incorporated into the treatment regimen, the better the chances would be for the patient to exercise autonomy and the better the eventual outcome would be. According to them, allowing a confused, end-stage patient to engage in decision-making would be tantamount to a breach of informed consent. On the contrary, early exercise of patient autonomy can avoid “dissonance between patients and proxy decision makers in end-stage disease”.

In France, when more people started insisting on patient autonomy and right-to-die, the authorities, in a regulatory text, insisted that palliative care teams should tend to the physical, spiritual, social and psychological needs of terminal patients. Later, in a report entitled ‘Reflections on the End of Life from a Perspective of Solidarity’, it was suggested that while patient autonomy had to be respected, it was important to introduce palliative care from the time of diagnosis of a serious illness and even deep sedation can be offered to people who are in too much distress.

The French word *accompagnement* used in discussing terminal life practices was used conventionally in the sense of solidarity, but has later evolved to express solidarity and autonomy. “This term, so long associated with Palliative Care, expresses the duty of society towards dying patients and their loved ones, a duty which implies a confrontation with death, a fight against the feeling of abandonment and loneliness, and finally, equal access to Palliative Care” (Gaille& Horn, 2016).

Though doctors do their best to mitigate the suffering of patients, they cannot always do that. In such a situation, there is some difference of opinion as to what is the ideal course. Many feel that avoiding torment and distress should be made the primary goal of medical therapies and palliative care. That is why they advocate physician-assisted suicide (PAS) or euthanasia. However, many people consider this a utilitarian approach which refuses to take into consideration the inherent value of human life. According to Erdek (2015), the developments in the field of palliative care and pain medicine suggest new solutions to this constant dilemma. He says that a contrast comparison can be drawn between the two approaches “using both theological and medical sources to show that the enlightened use of both interventional and non-interventional pain medicine approaches in an integrated palliative care setting are a theologically grounded and medically feasible alternative to euthanasia or PAS”.

Social solidarity is absolutely necessary in providing effective palliative care support, especially in rural areas. So far as people do not understand palliative care as part of health care, it will be difficult for health care professionals to introduce and implement it together with other health-related services. Families of patients have to understand that the emotional support palliative care workers provide is as important as the medical care that hospitals offer. “The strong value of community and mutuality that characterized life in our study communities has been noted as a strength that supports high quality, integrated health care through social solidarity, close knit relationships, and community commitment” (Pesut et al., 2011).

Social solidarity in the context of palliative care is sometimes difficult to define because there is no universally acceptable yardstick by which the success of palliative care can be measured. Even the clearly-delineated goals of palliative care, which are meeting the requirements and ensuring the quality of life of the patient, are sometimes disputed. There is a school of thought which says that since “quality of life has no shared or coherent understanding” it cannot be used as a yardstick and that patient requirements are difficult to be evaluated when they are understood within the background of harm because it is difficult to agree upon what constitutes harm when death is the only choice. To overcome these challenges, there should ideally be a framework to evaluate palliative care, consisting of premises like “embedded within community; palliative care is timely, comprehensive, and continuous; access to palliative care education and experts; effective teamwork and communication; family partnerships; policies and services that support rural capacity and values; and systematic approach for measuring and improving outcomes of care” (Pesut et al., 2013).

“Palliative care understands that people are more than their disease and that interventions must be contextualized to meaningfully address the values, concerns and priorities of each individual served” says Otis-Green (2019), while analysing the importance of social work in the field of palliative care. According to her, social workers can help the palliative team in screening the symptoms and providing interventions to minimize the physical distress of the patient. He/she can also help in managing functional impairment and remove many misconceptions related to pain management strategies. Social workers also play a crucial role in palliative care when the patient is nearing the end of life. They can help in building legacies, when it is possible, and can also educate patients and their families by “offering anticipatory guidance and exploring an individual’s values and preferences to aid in advance care planning and bereavement” (Ibid, 2019).

## Welfarism in Palliative Care

The word welfarism has different meanings, depending upon where and how it is used. In philosophical ethics, welfarism is very similar to consequentialism, where it means that only the consequences of an act have to be considered for morally evaluating that act. Nobel Laureate Amartya Sen supports the moral importance of consequences but also insists on according due importance to aspects other than consequences. Sen does not support the idea of evaluating consequences only on the basis of the utility of an act. He “rejects welfarism and suggests replacing utility by the notion of freedom, i.e., the opportunity people have to live the kind of life they have reason to value. At the same time, he also rejects income or resources or anything else that has an instrumental role in achieving freedom as the basis of social evaluation” (Osmani, 2009).

Technical welfarism is slightly different where “more complex states of affairs which include also non-consequential features like the intentions or motives” are considered important (Rechenauer, 2003). Further, human welfare, even in the way it is used in Sociology has different nuances of meanings, even though it is more commonly understood as economic or material welfare. For a layman, the word human welfare is synonymous with having or providing material comforts. According to Harold Wilensky, a welfare state is a “government-protected minimum standards of income, nutrition, health, housing, and education, assured to every citizen as a political right, not as charity” (Alfreðsson & Eide, 1999).

In a welfare state, the government is supposed to provide all its citizens at least a basic level of material welfare. Social welfare is an endeavour as well as a system consisting of support programs that protect people during different situations of their lives. These programs are designed to deal with the requirements that are identified in the society from time to time and deemed to be necessary to improve the quality of life of its members.

Requirements that warrant social welfare programs may vary from country to country but in the present-day society palliative care has become almost a universal need. “Palliative care is a public health concern, because the problems faced by patients and their families represent a substantial burden of illness and cost to society, which is likely to increase markedly in the future as the world’s population continues to age” (Dzingina et al., 2015).

World Health Organization defines 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, psychosocial and spiritual” (Retrieved from https://www.who.int/news-room/fact-sheets/detail/palliative-care).

Because of the various barriers to getting proper palliative care, it is suggested that palliative care should ideally be rebranded, focusing “on the benefits of early integration of palliative care into chronic disease management, emphasizing quality care for people living with serious chronic illness,” and using public funds in as practical and cost-effective a manner as possible. “This rebranding needs to include administrators and politicians” (Hawley, 2017).

McParland and Johnston (2019) point out that it is important to have proper palliative care and end-of-life care even in prisons because prisoners generally suffer poorer health than the general population. However, in prison there are many physical barriers like locked rooms, isolated wards, and restricted movement of volunteers, that create difficulties in providing palliative care. Besides this, there are ideological barriers also, which may even include negative public opinion about such help. Despite these problems, the authors advocate that it is very important to help prisoners maintain their relationships during the final stages of their life. These relationships include both the relationships they had outside the prison and the ones they have forged within, during the incarceration. Another thing that they point out is the importance of inmate volunteers in the palliative care within prison. Finally, palliative service delivery within prison has to be very carefully planned because the “regime and physical environment of a prison conflicts with best practices in palliative and end of life care”.

In India, to spread palliative care all across the country and incorporate it into social welfare programs, some proposals have been made by the Ministry of Health and Welfare. These include encouraging attitudinal shifts among healthcare workers by including principles of palliative care into the course curricula of social work, medicine, nursing, and pharmacy; promoting "behaviour change in the community through increasing public awareness and improved skills and knowledge regarding pain relief and palliative care leading to community owned initiatives supporting health care system"; making proper palliative care available through health centres of the country; and developing "national standards for palliative care services" and continuously evolving the "design and implementation of the National program to ensure progress towards the vision of the program"(https://docplayer.net).Further, to implement the program, the target population has to be clearly defined and "priority of interventions across the spectrum" has to be decided.

## Palliative Care in Kerala

The South Asian Region, where one-fourth of the world's population lives, gets 1.33 million cancer patients every year, with many of them in the terminal stages. Besides, there are many people suffering from other illnesses like cardiovascular problems, renal failure, heart ailments, and respiratory problems. All these people require specialized care, but the palliative care services available in the region are not sufficient to meet the demand of the area (Philip et al., 2018).

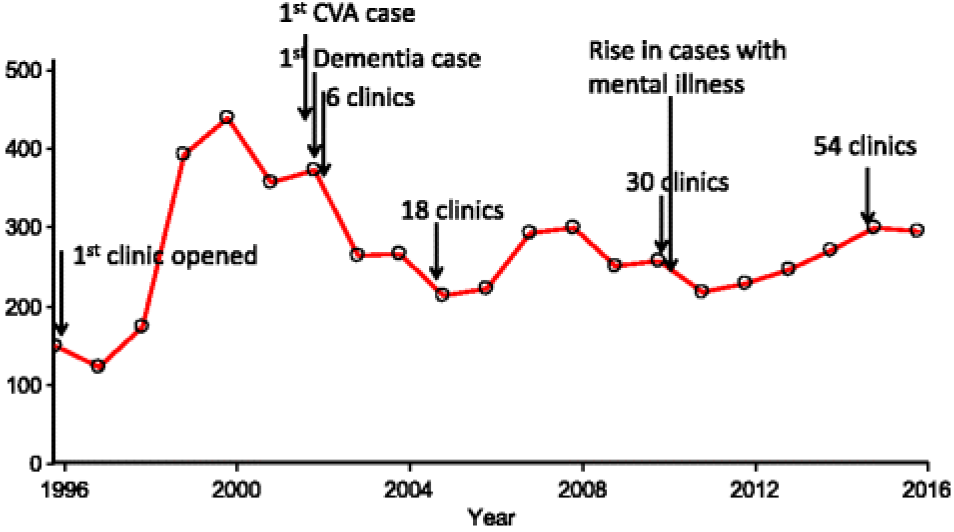
In India, which is part of South Asia, the trend appears to be slightly different from the general trend of the area. Despite India's high population density, regional diversity, differing attitude among health care workers about the use of painkillers on terminal patients, conventional beliefs about treating terminal patients, and difficulty in getting palliative care volunteers, the "last two decades have seen palpable changes in the mindset of health care providers and policy makers with respect to need of palliative care in India" (Khosla et al., 2012).

In India, palliative care is a relatively young discipline. Palliative care social work is less so. But the idea has been gaining momentum in the 21st century and nowadays many professional social workers are working to provide palliative care in various settings. By proper training, they learn to interact with people from different cultures and socioeconomic backgrounds. "In India, social work knowledge and skill development in the PC and end of life care is uneven and not integrated sufficiently with theoretical concepts and research" (Ragesh et al., 2017). According to the authors, to cater to the needs of palliative care, it is crucial to develop competent human resources in the field of palliative care social work. For this, social work curriculum should incorporate palliative care and end-of-life care values and practices from graduation level itself. They advocate that till such time that codes of practice for PC are fully established in India, PC social workers can follow the Standards for Palliative and End of Life Care set by the National Association of Social Workers (NASW).

Kerala, which is a small state in the southernmost part of India, the trend is still more different because it is a place that has made remarkable progress in the field. According to the information found in the 'Proposal of Strategies for Palliative Care in India', "In India, currently there are approximately 908 palliative care services delivering palliative care through either through home care, outpatient basis and in patient service. More than 841 of these centres are in Kerala" (Retrieved from https://docplayer.net/12068996-Strategies-for-palliative-care-in-india.html). This means that the state has more than 90% the country's palliative care centres though it houses only about 3% of the country's population. This development is the combined result of a substantial number of home-care services, enthusiasm of the involved volunteers, and the support given by the family members of the patient. It has to be remembered that in Kerala, as in the countries of Asia in general, one's family is an individual's most important social security and the family dwelling will be one's chosen ambience for living. So, without the family's moral support, it will not be possible to connect the patient and palliative care workers.

"Kerala pioneered community-based palliative care through a socially innovative approach called the Neighbourhood Network in Palliative Care in an attempt to develop a free of charge, sustainable, community led, service capable of offering comprehensive long-term care and palliative care" (Philip et al., 2018). The first place for the programme to be introduced was the district of Kozhikode in Northern Kerala. It was initially started for cancer patients but was later widened to include patients with many types of illnesses that required long-term care.

**Number of New Patients Enrolled in Manjeri Palliative Care Unit from 1996 to 2016 in Kerala, India**



*Source:Proposal of Strategies for Palliative Care in India (Expert Group Report), Directorate General of Health Services: Ministry of Health & Family Welfare, November 2012.*

Neighbourhood Network in Palliative Care (NNPC), which was started as a group of community-owned projects, became successful wherever they were started in Kerala. In Malappuram, where it was first started, it recorded a 70% increase in 2 years. It was equally successful in the other districts of the state where it was started, namely Kozhikode, Waynad, and Trichur. Later it was started in Kannur and Palghat districts also. In places where NNPCs are functional, palliative care and long term care were seen to be much more prevalent than the rest of Kerala, and in fact “much higher than anywhere in the developing world where the estimated coverage is 0 to less than 5%” (Kumar & Numpeli, 2005). NNPCs are now spreading to the neighbouring state of Tamil Nadu and faraway state of Assam as well.

Pain And Palliative Care Society (PPCS) is an NGO started in the year 1997. It has branches in Calicut and Trissur. Institute of Palliative Medicine (IPM) is the training, research and outreach arm of Pain and Palliative Care Society, located in the Medical College campus, Calicut. It is the first World Health Organisation Collaborating Centre (WHOCC) for community participation in palliative care and long-term care in developing countries. IPM is planning to found palliative care units in other parts of India as well as abroad (Retrieved from https://www.instituteofpalliativemedicine.org/).

IPM gives importance to community-based palliative care where the involvement of the local community is important in assessing, planning, implementing, managing, mobilizing resources, and delivering services. ‘Tracks We Leave’ and ‘Because I Care’ (BIC) are arms of IPM that help in their activities. The former is set up for resource mobilization while the latter is for spreading awareness among students about palliative care (https://www.instituteofpalliativemedicine.org).

In a study on the palliative care movement in Kerala, Santhosh (2016) discusses the particular "socio-historic context that facilitated increased involvement of civil society organizations in the welfare programs in conjunction with the state in Kerala". In Kerala, many religious organizations and civil society groups play crucial roles in providing resources necessary for palliative care. The author asserts that it is the combination of state patronage and civil society involvement that has made palliative care movement so effective in Kerala. However, according to him, such a situation makes it difficult to understand the way in which a neoliberal welfare state works. He underscores the need to analyse better the local level materializations of neoliberalism in diverse socio-political backgrounds, in order to understand the situation.

In 2008 the Government of Kerala introduced a Pain and Palliative Care Policy, through which the "government declared palliative care as an integral component of primary health care" (Chacko, 2017). This policy is unique in many ways because,

- It is the first policy in the field of palliative care introduced by any government in Asia.
- The policy focuses on community-based care given at homes under the guidance of local self-governments.
- It underscores the need for integrating "palliative care with primary health care and disease specific treatment programmes for effective coverage" (Paleri 2008).

## Palliative Care as a Necessity in Kerala

Palliative care is a necessity all over the world because only about 10% of the human population are likely to die suddenly (Lewis et al., 2016). The rest are condemned for a lingering death, whatever the age be when death comes visiting. This general principle applies to Kerala also.

Palliative care workers are necessary for providing emotional succour not just to the patient but to his or her traumatized family as well. This job often gets complicated with the different levels of collusion that exists in the medical field. Sometimes the patient's family colludes with the doctor to keep the patient in the dark about the seriousness of the disease or the medical professionals and the patient may collude to keep the family in the dark about the gravity of the situation. This is generally done with good intention to spare the individuals in question agony and anguish but can often complicate the process of palliative care because "one significant trigger to collusion lies in the transition from curative to palliative treatment" while the other is "when the topic of death and dying enters into the channels of communication" (Chaturvedi et al., 2009).

Such collusion is common in both eastern and western cultures and is influenced by many factors like the patient's gender, age, earning capacity, role in the family, the family's ability to reconcile with the situation, psychological vulnerabilities of the patient and family members, and financial situation of the family. The optimism that the colluding partners hope to generate by their blatant lies or partial disclosure may "appear helpful in the initial phases of the illness trajectory, but are found to be painful when it becomes clear that this optimism was based on illusions (i.e., false and unrealistic hope as opposed to realistic hope)" (Chaturvedi et al., 2009). Skilled palliative care providers may be able to work through these conundrums and find a solution that will be least painful to the colluding participants.

Just as in the rest of India, in the traditional Kerala society also, joint families were more the norm than exception, and three-generation households and four-generation households were not a rarity. However, all over the world, urbanization, industrialization, increasing education, change in the status of women in society, and stress on individuality have led to significant changes in family structure, turning “tradition-based extended structures to nuclear households” (Priya, 2017).

Kerala has also not been immune to this change. Within the ramparts of the joint family system, everyone remained protected, be they old, childless, unmarried or physically challenged. But this scenario is changing because of the arrival of nuclear families, geographical dislocation, increasing divorce rate, inter-generational conflict etc. Even for nuclear family members who have assured support in the form of a spouse or son, getting care from them may not be possible because that spouse or son may be the breadwinner of the family who cannot give up a promising career to nurse someone at home. Then there are single men and women and childless couple. India has 7.4 crore single women – nearly 12% of its female population – and Kerala’s single women are “pegged at nearly 13.6 lakh” (Varghese, 2018).

According to 2011 census, there are 17,378,649 females to 16,027,412 males (https://www.census2011.co.in) and this ratio is bound to leave many women single. Among the married women of Kerala, 10.5% are seen to be childless (Aiswarya & Moli, 2012). Added to this is the significant number of bachelors in the state. All these will contribute to eventually producing many people without any form of family support in old age and necessitate palliative care.

Another reason could be the inability of the caregivers on the family side to cope with things like pain management or other medical aspects of the problem. For example, drugs are not the only remedy for easing pain. There are many other treatment options like radiation therapy, relaxation techniques like guided imagery, massage, acupuncture, pet therapy, and physical therapy (Retrieved from https://www.webmd.com/palliative-care/managing-pain-beyond-drugs). The family may be hesitant to experiment these on the patient but may do it a little confidently under the guidance of a trained palliative care worker.

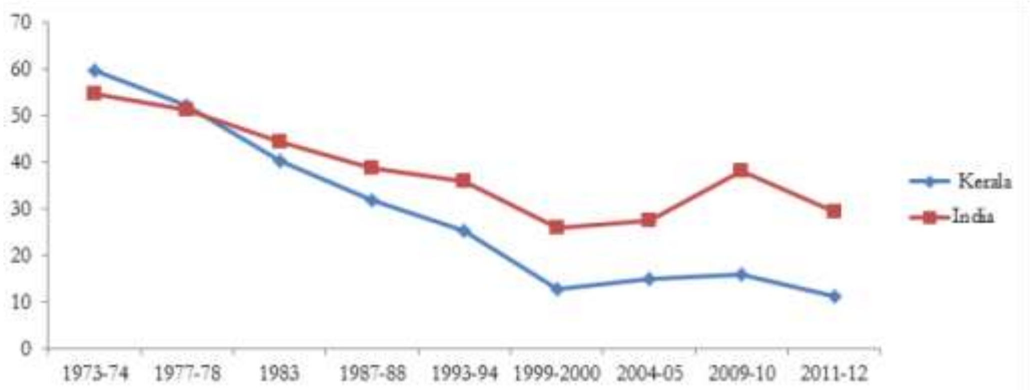
According to a study organized in the District of Malappuram in Kerala, about 40% of those in the end-stages of life would have been helped by the incorporation of palliative care into their regimen. “In Kerala, with a population of 32 million and a crude death rate of 6.3 (Reference: Census 2001) around 80,000 dying patients and their families would be benefited each year. If people who are chronically ill for a long duration also added with the statistics, the total number will be much more exceeded.”(Retrieved from https://palliumindia.org).

## Socio-economic and Physical Conditions of the Clientele Community

Studies have revealed that patients belonging to the privileged strata of society, i.e. those who are affluent or in more remunerative jobs or better-educated or well-connected, are more likely to die in their homes while with those belonging to the underprivileged sections of the society, the chances of dying in a hospital or an institution are more (Gill et al., 2013). This pattern is seen to be more or less the same in countries with health care policies and those without (Lewis et al., 2011). “For care received in the last year of life, proximal social determinants such as ability to pay for care, housing conditions suitable for supporting care at home, understanding and awareness of illness, and availability of services are likely to be important" (Davies et al., 2019).

Though income is a major yardstick by which an individual's socioeconomic status can be measured, it is definitely not the only possible one. As Nobel Laureate Amartya Sen (2016) said, "Poverty is not just a lack of money; it is not having the capability to realise one's full potential as a human being" (Retrieved from https://www.oecd.org/about/secretary-general/addressing-the-hidden-dimensions-of-poverty-paris-may-2019). In Kerala, land reforms that freed tenants from the exploitation by landlords, spreading of education, government's public distribution system that provides free and subsidized commodities to people, the network of primary health centres across the state, women's awakening through collectives like *Kudumbashree* that encourage entrepreneurship with the help of microcredit, various pension schemes, and NRI remittances have contributed significantly to reduction of poverty.

**Poverty rate in Kerala and India from 1973-74 to 2011-12**



*Source: Planning Commission, GOI, 2014. *(Rangarajan Committee) Report of The Expert Group to Review the Methodology for Measurement of Poverty, Government of India, Planning Commission, June, 2014*

This reduced poverty and increased awareness have made the people of Kerala quite receptive to the idea of palliative care. The people in need of palliative care in Kerala have been assessed to be one out of three hundred in the state and this is projected to be one lakh people needing such care across the state (Koshy, 2009). The state government is taking an active interest in introducing palliative care programs under the leadership of local self-governments (LSGs). “In Kerala, majority of the panchayats (LSGs) are now conducting home-based palliative care as part of primary health care incorporating the LSGs and community based organizations (CBOs) with the primary health centres (PHCs)” (Thayyil and Cherumanalil, 2012).

The popular Kerala film star Mammootty is the patron of Pain and Palliative Care Society of Kerala and the fact must have bolstered the popularity of the discipline among the people for whose need the services were introduced. The public were highly supportive of the idea as seen from the favourable response of the press, which opted to see palliative care as a “humane and altruistic provision of medical care, in contrast to what was seen as the commercialization of modern medicine in India. As part of this policy of openness, visitors and international experts were encouraged to come and share their specific area of expertise, which added legitimization to the efforts” of palliative care workers (Bolini et al., 2004).

Palliative care workers sometimes face difficulty in taking their services to remote villages mainly because there is limited awareness among the locals about the usefulness of this service. Distance to these villages also makes it difficult for palliative care providers to commute daily to the patient’s home. Making palliative care services community-based is one way of solving the former problem while the latter problem is best solved by training local people.

Otherwise increased funding may become necessary for workers to get a separate vehicle for commuting. “Dedicated groups from rural area itself need encouragement and proper training, so that difficult symptoms can be managed locally” (Manna, 2016).

## Palliative Care Eases the Responsibilities of Family Caregivers

Palliative care is not a support system just for the patient but for the patient’s family as well. The help that families get from palliative care workers for taking medical decisions, for nursing the patient, and for preparing themselves for the change in their lives will take a big burden off their shoulders.

Meier et al., (2011) narrates the story of a 27-year-old leukemia patient who suffered from intense bone pain, panic attacks, and breathing difficulty and was denied opioids for pain relief because they were worried about her getting addicted to it. The alternative that the hospital prescribed did not reduce her pain and she cried out in pain most of the time. Finally the hospital itself sought the help of a team of palliative care workers to handle the woman whom they referred to as a ‘drug-seeking patient’. At their recommendation, the regimen of her pain relief treatment was changed and she improved significantly. She was later cured and returned to a normal life.

Throughout her bone marrow transplant, the palliative care team worked with her doctors. The team had to give thorough and systematic counselling to her and her parents about “the harms of untreated pain and the safe use of opioids but also about the existential, spiritual, economic, and emotional consequences” of  her illness. This story explains how palliative care workers give importance to not just helping the patient but the family as well and even interacting with her medical team to minimize complications and the burden of all and ensure cure (Meier et al., 2011).

Palliative care need not always be linked to the prognosis of the disease because with the help of new treatment methods, patients may now continue living many years with chronic illnesses. In such cases palliative care workers may focus less on disease-specific treatment and more on improving the quality of life, boosting the morale of family caregivers, ensuring harmonious interaction with the patient and family members, and in encouraging the patient to be productive. Palliative caregivers, some of whom will be qualified doctors, will be able to advice the patient on treatment options after understanding his focus in life and his family's needs. The patient will thereby be able to reduce over-dependence on hospitals, take decisions on what type of treatment he should opt for, and reduce non-beneficial use of medicine or intensive care (Wright et al., 2008).

A core aspect of palliative care is counselling of the patient and this in turn will become highly beneficial for the family members involved in taking care of him/her. In this counselling the counsellor and the patient "each draws on the expertise and knowledge of the other in order to assist the patient with any physical, psycho-social or spiritual issues he/she would like to explore" (Nieuwmeyer & Hosking, 2006). In such a counselling, the counsellor's expertise is the result of his training, "self-awareness and awareness of his culture and value system. The expertise of the patient lies in his knowledge of his own body, his past life experience and acquired skills and wisdom, and his/her knowledge of his/her culture, history and belief systems".

The counsellor always ensures that such conversations sustain hope, even when no cure for hope exists. The counsellor, who will have medical knowledge, can share that knowledge with the patient and thus help him/her take suitable decisions regarding his/her life, “thus restoring to him/her some elements of control in a life where he/she may feel he/she has lost control and independence”(Nieuwmeyer& Hosking, 2006). The discussions may involve the importance of handling relationships, especially preparing the family to gather resources for coping with the impending absence of the patient if the time remaining for him/her is very limited. Such conversations will strengthen the entire family and give them the fortitude to face death with equanimity.

### Non-medical Services and Distress Management

Palliative care is a special form of care where medical care is supplemented with many forms of non-medical care like personal care, social support, psychological care, and spiritual support. Medical care mainly involves diagnosing the disease, prescribing a treatment regimen, and helping the patient follow that treatment regimen by providing specialized helps like surgery, post-operative care, intravenous infusion of drugs etc. Depending upon the country, non-medical staff are also given different levels of freedom to prescribe drugs. Studies reveal that though the number of prescriptions issued by non-medical prescribers may not be very high, they have the right to prescribe a fairly good range of drugs so that the “mainstay of their prescribing activity is pain management which is of crucial importance particularly in end-of-life care” (Ziegler et al., 2017).

Patients to whom palliative care is offered may need help in basic things like moving around, bathing, eating, and maintaining personal hygiene. There is no medical training necessary to provide such help and anyone with reasonable physical health can give such assistance. However, from the point of view of palliative care, even those providing such basic help should ideally have the ability to understand the feelings of the person who receives the care, to bond with him or her cognitively as well as emotionally, and to distinguish between his/her own perspective and that of the patient (Riess, 2017). Though "empathic medical care is associated with many benefits including improved patient experiences, adherence to treatment recommendations, better clinical outcomes, fewer medical errors and malpractice claims, and higher physician retention", in-depth medical training has a tendency to reduce empathy as a result of continuous exposure to serious health issues whereas those with less medical training may be able to have more compassion to others (ibid, 2017).

"Cognitive empathy may be defined as the ability to imagine oneself in the place of the other; emotional empathy is one's emotional participation in the other's situation" (Kliszcz, 1998). Good non-medical care providers will use cognitive empathy to deal effectively with the patient even if there is not sufficient emotional empathy because of religious, ethnic, racial, or ideological differences. The empathy that a palliative care worker can have for a patient will have a profoundly soothing effect on the patient and will also significantly reduce the burden of the patient's involved family.

Non-medical care workers could be better-equipped to understand the cultural sensitivities of a patient, or his/her family's preferences, unlike a medical professional whose focus will be primarily on controlling the disease. A patient's response to pain may vary from culture to culture or that individual's personal experiences. Since pain is subjective, another individual's ability to understand a patient's level of pain will depend on that patient's ability to communicate the intensity of it. To minimize this problem, the patient should be informed of all pain-relieving options – both pharmacologic and non-pharmacologic. The patient should be told that "while opioids will ease suffering and pain, they may also cause a certain amount of clouding of the mind which some cultures feel it is important to avoid" (Givler et al., 2019). Palliative care workers who understand the cultural nuances of the patient will be able to deal with these things better, even if they are not fully medically-trained.

In many parts of the world, specific food items are taboo for certain groups of people. Some people shun certain foods on religious grounds while others shun things on ethical grounds (e.g. sticking to vegetarian food because they feel that killing animals is wrong). Vegans take vegetarianism to an extreme and drastically reduce variety in their menu. Then there are seasonal culinary preferences, fasting schedules, and special diets that families follow. Complications occur when physicians do not understand these subtleties. "Values so ingrained in physicians as to be unquestioned may be alien to patients from different backgrounds" (Crawley et al., 2002).Palliative care workers, especially when they are local, could be contributing to the same cultural sensitivities and so will not disturb these practices unless they are highly detrimental to the health of the patient. They try to find mutually acceptable golden means between the cultural complexities.

Ethical dilemmas are common in medical profession because they conflict with each other "when applied to issues such as abortion, contraception, euthanasia, professional misconduct, confidentiality truth telling, professional relationship with relatives, religion, traditional medicine and business concerns" (Iyalomhe, 2009). Non-medical palliative care workers have to help the patient and the family to resolve these problems with the help of their own experience in the field, existing laws, traditions, rules of morality, and the patient's religious conviction.

## Palliative Care for Different Diseases

Palliative care may be required by people of all ages and for all types of diseases. In India in the year 2010, the main diseases that needed palliative care were non-communicable diseases that caused 53% of deaths that year. Among these, cancer was the reason for 6% of deaths, cardiovascular diseases for 24%, respiratory diseases for 11%, injuries for 10%), and diabetes for 2% (Sarkar, 2016). And the global requirement for palliative care is believed to increase because of the growing number of ageing populations and people with non-communicable diseases (Retrieved from https://www.who.int/ageing/publications/global_health.pdf).

Cancer is considered to be one of the main diseases for which round-the-clock palliative care is highly recommended. Metastatic non–small-cell lung cancer is a very incapacitating disease and one of the foremost among cancers that cause death. According to the prognosis of this disease, patients are not likely to live for more than one year after diagnosis. Those who received integrated palliative care early into the treatment regimen of this cancer, along with regular oncologic care, had better quality of life, less depressive symptoms, "had improved mood, more frequent documentation of resuscitation preferences, and less aggressive end-of-life care" than those who received only standard oncologic care (Temel et al., 2010).

In a study done on Palliative Care in Heart Failure (PAL-HF), it was revealed that proper palliative care resulted in considerable improvement in quality of life of the patients and "across the domains of depression, anxiety, and spiritual well-being" though there was no difference in mortality rate or hospitalization rate as a result" (Adler & Wettersten, 2017). In the case of patients with chronic kidney problems, "withdrawal from dialysis is associated with an increased mortality is ESRD patients. No standardized criteria exist to guide how to approach patients with this option" (Rak et al., 2017). At such junctures, interdisciplinary palliative teams can effectively coordinate discussions between the medical team, the patient, and the patient's family about end-of-life care. They will be able "to make decisions that satisfy the patient's and the medical team's desires for end-of-life care" (ibid, 2017).

Dementia is an irreversible, life-limiting condition which involves, besides memory loss, personality changes, language deficiency, lack of emotional control, and disorientation. Such patients may have difficulty in managing their daily activities and maintaining personal hygiene so that their caregivers are put to lot of difficulties. In the case of dementia, "palliative care plans for hospitalised patients with end stage dementia seem to reduce inappropriate interventions (for example, feeding tubes, phlebotomy and systemic antibiotics)" (Harris, 2007). According to him, there is no strong evidence that antibiotics and artificial feeding will significantly benefit those with advanced dementia so that palliative care in such cases focuses on "relieving pain and other distressing symptoms".

Reducing undesired invasive producers is an important aspect of the palliative care of Palliative Excellence in Alzheimer Care Efforts (PEACE) Program (The University of Chicago) also. They too strive to avoid unnecessary hospitalization and to ensure that patients die in their desired location. They advocate limiting the treatment of Alzheimer patients to symptom management and try to make the family members understand that lack of aggressive care is not sub-optimal care. PEACE members interview their patients and the family members involved in their care once at the beginning and then every six months. The data collected from these interviews "contribute to evaluating PEACE as a pilot project" and are also used to understand the needs of the patients and thereby improve the care (Shega et al, 2003).

Heins et. al., (2018) establishes through one of their studies that there is difference between the palliative care requirements of people suffering from different diseases like cancer, heart failure, chronic obstructive pulmonary disease (COPD) etc. For cancer patients, especially those in advanced stages, patient autonomy was seen to be more crucial than patients in other groups. All patients considered it important to get some support and relief when in pain though relief for other symptoms were less important for all. Overall, it was found that "most patients with advanced cancer receive the care that they consider important".

Patients with communicable diseases like HIV/AIDS "still present many palliative care challenges and opportunities" because in many cases these patients may suffer from chronic pain and impaired physical functions, may have other medical comorbidities independent of HIV infection, and could suffer from complexities resulting from antiretroviral medications taken in the earlier stage, though this treatment is not used now (Merlin, 2013).

In many cases, palliative care consultations are requested for terminally ill patients with communicable diseases like AIDS, thereby integrating palliative care and intensive care. In a study conducted by Souza et al., (2016) to compare "the therapeutic interventions and end-of-life care before and after evaluation by the palliative care team", it was found that after "the evaluation of the patients by the palliative care team, there was a significant reduction in the use of blood products, antibiotics, prophylaxis for opportunistic infections, and HAART for the terminally ill patients". The study also recommends the setting up “of clinical bioethics committees, which can propose and endorse medical decisions for institutionalized patients unable to make decisions”. Palliative care workers have to ensure that HIV/AIDS patients are not stigmatized and that palliative care is not denied to them due to social or political reasons.

Palliative care requirements of old people could be different from those suffering from serious illnesses, for whom the course of the disease may be more or less predictable. Old people mostly die of slowly progressing or lingering chronic illnesses which may require repeated hospitalization and may result in partial or full recovery. Timing of death is less predictable or assessable in such cases. “This fundamental mismatch between care paradigm and clinical reality has resulted in an approach to palliative care in the elderly characterized by reacting to acute exacerbation of chronic illness” (Jerant et al., 2004). To solve this problem, the authors are suggesting what they call the TLC model of palliative care which acknowledges the longer time that old people may remain face-to-face with death and “accounts for the wide variation in the point in time at which patients, families, and physicians perceive that death is approaching” (ibid, 2004).

**TLC Model of Palliative Care for Elderly Patients**

| Letter | Model Element | Elaboration |
|---|---|---|
| T | Timely | Proactive rather than reactive approach to avoid prolonged unnecessary suffering |
|  | Team oriented | Nurses, social workers, trained laypersons, and others involved |
| L | Longitudinal | Balance of palliative and curative measures evolves with time |
| C | Collaborative | Patients, family members, and providers share decisions |
|  | Comprehensive | All empirically supported domains of palliative care are addressed |

## Making Palliative Care Accessible to All

Palliative care is considered one of the human rights in the present-day scenario but still it is not uniformly available to all. “Of the 40 million people globally in need of palliative care, just 14% receive it, largely in high income countries” (Anderson & Grant, 2017). In many low-resource settings, the public as well as policymakers have no awareness of it, and do not have a clear-cut idea as to what palliative care entails and what its benefits are. Attitudes to the idea of death, belief that palliative care is only for the terminally ill, and the “misconception that improving access to opioid analgesia could lead to increased substance abuse” are the other barriers to increasing the availability of palliative care. (ibid, 2017).

To ensure that palliative care is available and accessible to the majority of the needy, a major thrust should be on a primary health care approach. World Health Organisation observes that “The fundamental responsibility of health profession to ease the suffering of patients cannot be fulfilled unless palliative care has priority status with in public health and disease control programme; it is not an optional extra. In countries with limited resources, it is not logical to provide extremely expensive therapies that may benefit only a few patients, while the majority of patients presenting with advance disease and urgently in need of symptom control must suffer without relief” (https://www.who.int/cancer/publications/nccp2002/en/).

There are marginalized populations for whom access to regular healthcare itself is not guaranteed. For them, access to palliative care is more difficult, often because of the indifference of the society and patients’ ignorance of the existence of palliative care facility. To solve this problem, it has to be identified “when palliative care is necessary, who receives palliative care and where, and what is necessary to complement palliative care. Inclusive and accessible palliative care can become possible through building on the existing strengths in palliative care, as well as addressing existing barriers" (Stienstra & Chochinov, 2012). For such inclusion, it has to be ensured that there are hospices or palliative care centres in places which are physically accessible to such groups. There should also be proper coordination of palliative care with other healthcare services, and barriers to access should be clearly analysed and removed. According to the authors, novel, creative ideas should be forthcoming to ensure inclusion.

According to Gibson (2001), "Pilot projects can be a useful way to jump-start palliative care for the poor and disenfranchised". She feels that such projects can give effective training to all about various diseases, human mortality, and familiarize people with the various cultural perspectives on the ability to bear pain and confront death, lessons about illness, death and dying from different cultural perspectives. Such lessons can be a "key factor in ensuring community involvement and ownership and, hence, sustainability". It is difficult to take palliative care to all without involving the whole community.

This novel approach to the welfarism perspective of the Palliative Care agency has to get the attention of academic community. Therefore this study investigates the welfare activities of Palliative Care agencies to support the needy. It is natural to have various bodily, mental, socio-cultural and economic problems associated with a person's chronic disability either due to disease or old age. Analysing those problems of the beneficiaries is thought to be appropriate to identify the various supports provided by the agency. Hence this study is attempted with the objectives specified in the methodology chapter.

# CHAPTER 3

# METHODOLOGY

## 3.1 Statement of the Problem:

Prolonged serious diseases and old age health problems which cause severe pain and sufferings and have no effective cure but take away the life of the diseased, prompted philanthropists, medicine men and social scientists to think about palliative care. Breaking down of the larger family or family system itself which once attended to the chronically diseased or bed ridden elderly persons also prompted the society to device a caring system which would help to maintain the dignity of the suffering individual and ease the burden and anxiety of the caring group, usually the family.

Kerala is one of the premier States which introduces a Palliative Care wing attached to the State Health Department. The study is expected to portray the structure and functions of the Palliative Care delivery system in the State and how it is assisting the clientele, particularly the marginalized sections of the population. This would entail the assessment of the assistance aspired for by marginalized sections in such precarious situations and the extent of the aspirations fulfilled. On elevated theorizing on the findings of the study, it may identify the ‘societal community’ effect (Parsons, 1951) of these kinds of agencies. Kerala is a forerunner in this field which started the programme in 1993 in Kozhikode (Calicut) and it has become a matured programme today. Hence a study here will be productive for assessing and evaluating the welfarism of Palliative Care agencies everywhere in terms of a model extracted in the light of this research.

Both quantitative and qualitative methods are used as part of scientific method in the research. Creswell (2013) opines that mixed research methods involve combining both statistical trends and stories to study human and social problems. The prime idea is that it gives a better understanding of the issue when an inquirer incorporates both quantitative and qualitative approaches than using either one of the approaches. Studies in Palliative Care are scarce not only in Kerala but also in our country as a whole. Hence this study is proposed with the following major objectives.

**The major objectives of the study are:**

1 To portray the functioning of Palliative care in Kerala.

2 To analyze the socio-economic and physical conditions of the clientele community of the programme.

3 To assess the contributions of the palliative care initiative in easing the responsibilities of the caretaker/family of the beneficiaries.

4 To analyze the effect of the non-medical services on managing pain and mental agony of the beneficiaries.

5 To study the support given to those who are unable to approach the paid health care system.

6 To study the type of social solidarity brought about by the palliative care movement in the community.

## 3.2 Major Hypotheses

The primary hypothesis of the study is that the Palliative care by its method of functioning contributes to maintaining the dignity of the individual and welfare of the community and by thus increases the integration of the society.

**The subsidiary hypotheses are:**

Palliative Care Service helps the beneficiaries in managing their bodily discomforts which in turn helps maintain the physical fitness of the clientele community.

1. Palliative Care reduces the mental agony of the beneficiaries and by thus contributes to the maintenance of a healthy psychic condition of the community.
2. Palliative Care agency supports the clientele community in alleviating the non-medical problems and their holistic approach keeps the community in good stead economically, socially and psychologically.
3. Palliative Care Agency, by offering, in addition to health care services, those which are necessary to tide over the crisis situation of the individual and his/her care givers contribute to the welfare needs of the clientele community.
4. The services of the Palliative Care are primarily oriented to the poor sections of the society and by thus the agency is helping to improve the welfare of the subaltern section of the clientele community.
5. The new initiative in the field of health care which opens an arena for philanthropic common people to join with medical professionals and serve the needy gives the poor people a sense of security and comfort.
6. Easy accessibility to the Palliative team creates confidence in the beneficiaries about merit of the programme and their ability to help tide over the situation.
7. The ‘familism’ shown by the Palliative Care Agency by itself is capable of reducing the mental and physical agonies of the beneficiaries.

### 3.3 Definition of Concepts

The major concepts involved in the study are explained below:

#### 3.3.1 Welfarism

Welfarism is a very old concept, probably, much discoursed among economists. Reducing the economic deficiencies and bringing about equality among members of the community is their concern (Sen, 1979). Sociologists deal with this concept in a wider scope. The positive functions of action of an agency in a social situation is considered as welfarism of the agency under consideration. On this line, this study considers the concept as indicative of the holistic welfare of the clientele community of the programme.

#### 3.3.2. Palliative Care

Palliative care is defined by the World Health Organization (WHO) as "an approach that improves the quality of life of patients and their families facing the problem associated with serious illness, through the prevention and relief of suffering by means of early detection and accurate assessment and treatment of pain and other, physical, psycho-social and spiritual problems" (WHO, 2002).

#### 3.3.3 Disability

"Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)" (WHO, 2001).

#### 3.3.4 Impairment

"Impairment is any temporary or permanent loss or abnormality of a body structure or function, whether physiological or psychological" (WHO, 2001).

### 3.3.5 Prolonged Life

‘Prolonged’ means ‘Extended’ and ‘Prolonged Life’ means ‘Extended life’. There are many treatment options in the field of medicine to prolong the life of the patients from the life threatening diseases or injuries. Here in the study, ‘Prolonged Life’ means the ‘Extended Life’ of the patients through medical treatments.

### 3.3.6 Isolated Existence

‘Isolation’ means the condition of being alone and ‘Existence’ means the ‘state of living’. Thus ‘Isolated Existence’ means the condition of living alone. Here isolation refers to the social isolation that being felt by the patients. “Social isolation is the inadequate quality and quantity of social relations with other people at the different levels where human interaction takes place (individual, group, community and the larger social environment)” (Zavaleta et.al, 2014).

### 3.3.7 Life Satisfaction

Satisfaction with one’s life implies a contentment with or acceptance of one’s life circumstances, or the fulfillment of one’s wants and needs for one’s life as a whole. In essence, life satisfaction is a subjective assessment of the quality of one’s life. Because it is inherently an evaluation, judgments of life satisfaction have a large cognitive component.

“Satisfaction with one’s life implies a contentment with or acceptance of one’s life circumstances, or the fulfillment of one’s wants and needs for one’s life as a whole. In essence, life satisfaction is a subjective assessment of the quality of one’s life” (Sousa, L and Lyubomirsky, S, 2001) .

### 3.3.8 Self-Perceived Burden

Self-perceived burden is a “multi-dimensional construct arising from the care-recipients’ feelings of dependence and the resulting frustration and worry which then lead to negative feelings of guilt at being responsible for the caregivers’ hardship” (Cousineau N et. al, 2003).

### 3.3.9 Home Care

The term home care can be considered as any care given behind someone’s front door or more broadly, relating to services allowing people to continue living in their home setting. “As regards to the type of services, home care may refer to care given only by professionals or in combination with care given by a spouse or relative” (Genet N et al, 2012).

### 3.3.10 Institution Based Care

Institutional care is given in a common living environment designed to meet the practical medical, family, social, and housing needs of people with physical, emotional, and/or developmental disabilities. In institutional environments, such as orphanages, nursing homes, rehabilitation institutions and facilities, vulnerable children and older adults, persons with intellectual disabilities, mental retardation, chronic mental disease, and physical disabilities are more likely to receive treatment. “Care and services in institutional settings often include, but are not limited to, 24-h supervision/monitoring, assistance with activities of daily living, skilled nursing care, rehabilitation, adaptive aids and equipment, psychological services, therapies, social activities, and room and board” (Galik E, 2013).

### 3.3.11 Family Stress

A disruption in the steady state of the family system is considered as family stress. Such disruption may occur from the external contexts of the family or from internal contexts or simultaneously from both. The balance of the family system is in any case, threatened by transition. (Retrieved from https://uk.sagepub.com). Here in the study, the changes happen to the family as one of its members become chronically ill or disabled cause stress in that family.

### 3.3.12 Clientele Community

Clientele community means the group of people who are getting advantages or benefits of certain social welfare policies. Families living in bad housing, children in poverty, the physically disabled, historically disadvantaged or mistreated minorities, and patients of certain diseases are all targets of social welfare initiatives. In the study, clientele community includes the patients/care receivers of the Palliative Care Services. In certain situations, the term 'beneficiaries' also is used. The terms are used considering them as synonyms.

### 3.3.13 Care Takers

Care takers in this study include those family members who are primarily attending to the patients who are incapable of maintaining their life requirements by themselves.

## 3.4 Variables and their Measurements

Quantitative research gives much significance to variables because the major objective of quantitative research is to find out the relationship between two or more variables. The independent and dependent variables included in this study are discussed below:

### 3.4.1 Independent Variables

Independent variables are those which influence or predict the changes in dependent variables.

#### 3.4.1.1 Gender

Gender is an analytical category that is socially fabricated to differentiate the biological difference between men and women. The term gender is also used to define the differences in behaviour between men and women which are labelled as ‘masculine’ and ‘feminine’ (Retrieved from http://archive.mu.ac.in). The study includes the two genders ‘Male’ and ‘Female’. Respondents from the third gender were not available.

#### 3.4.1.2 Age

Age of the respondent is defined as the number of years the respondent has completed at the time of the interview since his/ her birth. The respondents included in the study are divided based on their age (in years) as 20-40, 40-60, 60-80 and 80-100. Respondents who are above 100 years of age were not available.

#### 3.4.1.3 Religion

Religion, which is a matter of belief and practice, is a common social concept that almost every living person is seriously concerned with. Religion is widely interpreted by many as a belief in the influence of the Divine or the Supreme Being and their relationship with their surrounding world. It is known as one of mankind's oldest institutions and is found in both past and present societies. Durkheim (1912) defines religion as a united system of beliefs and practices comparative to sacred things, that is to say, things set apart and forbidden. The study considered three major religions of Kerala; Hindu, Muslim and Christian.

#### 3.4.1.4 Education

Education is referred to the act of evolving the intellect, critical thinking abilities, social and cultural understanding, and realising of one's own self. Education is considered as an active and a dynamic process which takes place constantly during one's life by way of innumerable experiences through either in a formal or in an informal manner (Retrieved from https://www.hzu.edu.in). Present study categorizes the respondents based on their educational attainment as 'Illiterate', 'Primary Education', 'Secondary education', and 'College education'.

#### 3.4.1.5 Marital Status

Marital status is individual's state of being Married, Unmarried, Widowed, Separated or Divorced. The respondents in the study are categorized based on their marital status as 'Married', 'Unmarried', 'Widow/Widower' and 'Separated/ Divorced'.

#### 3.4.1.6 Family Size

As the structure of family changes from Joint to Nuclear, family size is a matter of discussion in particular life situations. The respondents' families are considered as 'Small' (Minimum 2 and Maximum 4 members), 'Medium' (Minimum 5 and Maximum 7) and 'Large' (More than 7 members).

#### 3.4.1.7 Family Income

Monthly income of a family in rupees is considered as crucial variable in the study. However most of the families have no regular income. The study categorized the families of the respondents based on their monthly income as 'Low income Family' (Families do not have their own income but financial support from neighbours or friends), 'Middle income Family' (Families have their own irregular income from daily wage earnings) and 'High income

Family' (Families with regular income through salary, pension etc.). The present study considers those who have a monthly income below 5000 as 'Low Income Family', those who have a monthly income between 5000-10000 as 'Middle Income Family' and those who have a monthly income above 10000 as 'High Income Family'.

### 3.4.1.8 Nature of Disability

Disability means the physical or mental deficiency induced by an illness or condition with the disability suffered by the person. The disability charity model also sees people with disabilities as the issue and depends on others' sympathy to provide assistance in a charity or welfare mode. "Institutional, environmental and attitudinal discrimination is stressed in the social model as the real foundation for disability" (Retrieved from https://www.ncbi.nlm.nih.gov). The study encompasses all these models of disability.

Nature of disability among the respondents is complex to be classified into two or three different categories. For the purpose of analysis the disabilities are classified into three. They are 'Old age disabilities', 'Disabilities due to Disease' and 'Disabilities due to both Disease and old age'.

### 3.4.2 Dependent Variables

Dependent variables are those which are being influenced by the independent variables such as Age, Gender, Religion, Marital Status, Education, Family size, Family income and Nature of disability. Dependent variables in the study are:

### 3.4.2.1 Psychological Problems

Psychological disorders are conditions characterized by abnormal thoughts, feelings, and behaviors.

Psychological problems in the study means the mental stress and strain experienced by the patients and their family, created by the impairment either directly or indirectly. Chronically ill patients often have various mental disturbances due to their physical ill health, lack of social interactions, economic deterioration of the family caused by the unexpected expenditure for medicines and other requirements of treatment. They may feel isolated from their family and also from the society. They may behave as emotionally unstable, depressed and abandoned. They may be anxious about the prognosis of the disease and consequential strains for their family members. All these psychological miseries are associated with various factors like respondents' age, gender, marital status etc.

### 3.4.2.2 Social Interactions

A social interaction is an exchange between people and is an essential part of culture. People design laws, organisations and frameworks through which they strive to live by communicating with one another.

Social interaction in the study refers to the level of interactions of the patients and the family with the society. Interactions within the family and outside the family are essential for individuals to lead active social life. Chronic illness or disability due to old age make individuals withdrawn from social interactions. Consequently they feel worthless and undignified. Perhaps various factors other than ill health may also contribute to the level of social interactions by the respondents. Unmarried patients may already have social stigma and may withdraw from social interactions. Illiterate respondents may be unaware of the benefits of being interacted with others and so on.

#### 3.4.2.3 Economic Problems

The study defines economic problems as the financial constraints faced by the patients and their families due to the chronic disabilities for generating income. The extent of economic problems may be varied with different factors such as age, marital status, gender, education, family size, family income, nature of disability of each individual patient/ family.

#### 3.4.2.4 Perceptions on the Family Stress

Perceptions on the family stress refers to how the patients/ care receivers perceive the stress and strain of their family in maintaining the care receivers.

One of the most important problem expressed by the respondents is the physical, psychological, economic and social strains experienced by their informal care givers; their family members.

#### 3.4.2.5 Satisfaction with the Services of Palliative Care Agency

Palliative care offers different types of service to the needy. Satisfaction with the services means how far the beneficiaries are satisfied with the given services of the agency.

The important purpose of the study is to evaluate the services provided by the Palliative Care Agency to their beneficiaries. Satisfaction of the respondents with the diverse services offered by the Agency is analysed and found as influenced by different independent variables used in the study.

## 3.5 Population of the Study

Population of the study includes all the Palliative Care beneficiaries in the State of Kerala. According to PalliumIndia.org there are 360 Palliative care centers in different districts in the state. The district wise statistics are shown in the table given below. Each unit has a capacity to accommodate around 200 patients at a time.

**Number of Palliative Care Units Situated in Different Districts in Kerala**

| Sl.No | District | No: of Centres | Sl.No | District | No: of Centres |
|---|---|---|---|---|---|
| 1 | Thiruvananthapuram | 26 | 8 | Thrissur | 29 |
| 2 | Kollam | 11 | 9 | Palakkad | 21 |
| 3 | Alappuzha | 4 | 10 | Malappuram | 63 |
| 4 | Pathanamthitta | 14 | 11 | Kozhikode | 65 |
| 5 | Kottayam | 30 | 12 | Waynad | 24 |
| 6 | Idukki | 7 | 13 | Kannur | 20 |
| 7 | Ernakulam | 42 | 14 | Kasargode | 4 |
| **Total** | | | | | **360** |

Source: www.paliumindia.org as on 01/10/2020

### 3.6 Sample and Sample selection

Palliative care ethical committee restricts studies among the clientele community to avoid inconvenience to the beneficiaries. The researcher had to get the approval from the ethical committees of different districts to collect the data required for the study.

300 Palliative Care beneficiaries of the State constitute the sample of the study. The samples are the patients. However in the case of very few patients who are incapable of describing their conditions due to severity of their illness, care givers’ description of their conditions were depended upon. The researcher made elaborate discussion with the care givers of those patients who are very weak and incapable of describing their conditions. Amidst these discussions, the stress faced by them also was enquired into and that was added in the analyses chapters at the appropriate contexts. Kerala is considered as

constituted by three major zones, the southern, central and northern represented respectively by Thiruvananthapuram, Thrissur and Kozhikode Districts for the purpose of sampling. From each zone, 4 different Palliative Care units were randomly selected. From each unit 25 beneficiaries were selected randomly. 100 beneficiaries from each zone were included in the study (3 x 4 x 25 = 300). In the selection of sample patients, no time specification regarding how long have they been under the palliative care was not considered. The selection was made randomly from the list of patients provided by the agency.

One specific case from each zone (3 x 1 = 3) are also selected for qualitative study to reinforce the findings of quantitative analyses. The cases selected will reflect a cross section of the population of the study to find out the different types of service provided by the palliative care agency.

The characteristics of the sample are given in frequency tables in Annexure III of the report.

### 3.7 Sources of Data

The source of primary data was interview of the selected sample using a semi structured interview schedule prepared for the study. In order to collect data for the case analyses depth interviews were carried out using an interview guide. The interviews were carried out at the dwelling places of the care receivers without the interference of others.  Secondary data was collected from published materials and online sources.

### 3.8 Tools of Data Collection

Semi- structured interview schedule was the main tool used for collecting quantitative data required for the study. The tool was prepared based on a pilot study, literature review and observation of the people who are beneficiaries of the project by the researcher. Extensive consultations with the authorities of the Palliative Care agencies were carried out to shape the schedule properly. Pretest of the schedule was done in non -sample area and modified accordingly. Interview-guide was the tool used to collect qualitative data.

## 3.9 Data Collection

The researcher collected the primary data for the research. Fieldwork was done by the researcher during April 2015 and May 2016. Four centers from each zone were randomly selected. Palliative Care Centres situated at Jagathi and Muttacaud, the Palliative Care Clinic attached to General hospital and Medical College hospital Palliative Care Division were the selected centres from Thiruvananthapuram. The details of the different centres were provided by Pallium India, Thiruvananthapuram. Palliative Care centre functioning at former District hospital building, Palliative Care Clinic at Thrithallur, Clinic attached to Govt. Hospital Puthukkad and Health Care Institute Kodungallur were the four centres selected from Thrissur. The authorities of Pain and Palliative Care Society, working at the core centre provided the address and details of different centres of Palliative Care in Thrissur. From Kozhikode, Palliative Care Centres at Koilandy, Narikkuni, Mukkam and Farook College were selected. Institute of Palliative Medicine was the source of information about the different Palliative Care units working in the District. 25 beneficiaries randomly selected from each centre (total 12 centres) were interviewed at their homes. Data collection was done as a very cautious process as the researcher had to ensure the consent and convenience of beneficiaries as per the direction of Palliative Care Ethical Committee.

## 3.10 Data Processing and Analyses

To get reliable results the collected data were to be converted into valid information. The data were checked, edited, coded and a computer data base was created. The data were analysed using a computer software based on the objectives of the study. Hypotheses were tested using chi-square statistic. Frequency tables and cross tables are used to interpret the analyses. Descriptive and inferential statistics were used for data reduction and predictive purposes.

In the qualitative approach case studies were used. Depth interviews were carried out by the researcher by using interview guide as the tool to acquire maximum details about the cases selected for the study. Case studies were done to reinforce the results obtained by the quantitative analyses. On the basis of the interpretations made conclusions are arrived at.

# CHAPTER 4

# RESEARCH SETTING

The research setting here is the State of Kerala as the sample of the study is taken from there. The state of Kerala consists of 14 districts. Based on the geographic, historical and cultural similarities the state's districts are generally grouped into three parts- the Northern zone consisting of Kasaragod, Kannur, Wayanad, Kozhikode and Malappuram; the Central zone consisting of Palakkad, Thrissur, Ernakulam and Idukki; and the South zone consisting of Thiruvananthapuram, Kollam, Alappuzha and Pathanamthitta. Such a regional division ensued being part of historical Kingdoms of Kochi, Travancore and British Province of Malabar.

Kerala is a small, but heavily populated, state of India, nestling on one side between the Arabian Sea and the Western Ghats. The state's geographical features enabled it to achieve a distinctive community. It was enabled by the long coastline to have contact with foreign cultures. Its unique geographical location, with the natural boundaries of the sea and the mountains to the west and east, has allowed it to enjoy a measure of isolation from the rest of the country and to establish its own way of life, culture and institutions genuine by the major political cataclysms which quivered the rest of the country. The geographical isolation, has however not prevented Kerala from making its rich contribution to the cultural heritage of the country as part of the general mainstream of Indian culture (Menon, 1987).

Kerala is situated on the extreme southwestern tip of the subcontinent of India. The state is bordered to the north by Karnataka, to the south and east by Tamil Nadu and to the west by the Arab Sea.  It lies between Northern latitude of 8°.17'.30" N and 12°. 47'.40" N and East longitudes 74°.27'.47" E and

77°.37'.12" E. The state has an area of 38863 sq. Km of land representing 1.18 percent of India's total territory. Kerala is renowned for its lush greenery, thick forests, varied ecological ecosystems, topography and for the variety of its habitats.

As a fort defending the state, the Western Ghats stand tall. With mild temperatures and ample rain, the climate is nice. The rich diversity of flora and fauna and the abundance of bodies of water make the state 'God’s Own Country '. The state is blessed with evergreen vegetation that makes for a cool climate as well. The main crops in the state are paddy, cacao, arecanut, banana, tapioca, rubber, etc. The State spices like pepper, cardamom, ginger are common around the world.

### 4.1: Demography of Kerala

The total population of Kerala is 3,34,06,061, as per the Census of 2011. 1.45% of this population were officially recognised as Scheduled Tribes or Adivasis, who are thought to be the original inhabitants. 9.1 per cent of the total population is the Scheduled Caste population in the state (Census, 2011). Kerala is home to 2.76 percent of the nation's population, though its land area (38,863 sq.km) is just 1.2 percent of the country's total land area. Among the Indian states, it is 23rd in size and 13th by way of population.

Because of its unusual demographic characteristics, such as low population growth, low infant mortality rate and maternal mortality rate, increased life expectancy, positive sex ratio, the state is unique in the world. As per the 2011 census, Kerala is the only state in the nation with a sex ratio favourable to women, 1084 females per 1000 males. There is a density of 859 people per square kilometre in the province. Kerala has the highest proportion of literate individuals among the Indian population. As per Census 2011, the effective literacy rate is 93.91 per cent.

**Table 4.1: Demographic Characteristics of the State of Kerala**

| | |
|---|---|
| Capital | Thiruvananthapuram |
| Number of Districts | 14 |
| Geographical Area | 38863 Square Kilometres |
| Total Population | 33406061 |
| Male Population | 16027412 |
| Female Population | 17378649 |
| Rural Population | 17471135 |
| Urban Population | 15934926 |
| Population Density | 859 |
| Sex Ratio | 1084 Females per 1000 Males |
| Decadal Growth Rate | 4.91 |
| Literacy Rate | 93.91 |
| Male Literacy Rate | 96.02 |
| Female Literacy Rate | 91.98 |
| Life Expectancy | 74.9 Years |

Source: Government of Kerala & Census 2011

## 4.2: Religious Composition

The community of Kerala in general and the religious situation in particular are exceptional for several reasons. According to the 2001 census, 57 percent of Kerala's population are Hindus, 24 percent are Muslims and 19 percent are Christians. Various religions have existed harmoniously and happily as a result of religious freedom. In addition, religions such as Christianity and Islam could find a place to develop and branch out.

**Table 4.2: Religious Composition of Kerala**

| Religion | Percentage Population |
|---|---|
| Hindu | 54.73 |
| Islam | 26.56 |
| Christian | 18.38 |
| Others | 0.33 |

Source: Census 2011

## 4.3: Rural Urban Composition

Urbanization is a significant aspect of the economic and social growth process and is linked to many factors, such as migration from villages to cities, the relative cost of catering to cities for economic and social services, such as housing, water, sanitation, transport and electricity, location and dispersion of industries, etc. The principal explanation for urbanisation is the growth of the tertiary sector in the context of Kerala. It is not the product of rapid industrialization and urbanisation. Urbanisation, as measured by the share of urban population of the State, has shown a sharp increase from 25.96 per cent in 2001 to 47.72 per cent in 2011 (Kerala Economic Review, 2016).

**Table 4.3: Rural-Urban Composition of Kerala**

| Area | Male Population | Female Population | Total | Decadal Growth Rate |
|---|---|---|---|---|
| Rural | 8408054 | 9063081 | 17471135 | -25.89 |
| Urban | 7619358 | 8315568 | 15934926 | 92.76 |
| Total | 16027412 | 17378649 | 33406061 | 4.91 |

Source: Census 2011

## 4.4: Educational Scenario

Education is a strong social role predictor and is also seen as the simpler way to quantify socio-economic status as it precedes other measures such as income or social position based on employment. The impressive achievements of Kerala in the field of social development and high quality of life are primarily due to the educational progress the state has made over several years. During the past decades, Kerala's educational system has gone through many changes. Massive spread of education by Christian community formed a conducive climate for rapid social changes in all the communities (Mahadevan and Sumangala, 1987).

Kerala has excellently settled the first generation issues of illiteracy and insufficient school enrollment. Literacy is an elementary step towards education, which is a process of life learning and entrance to the world of communication and information.

**Table 4.4.1: Number of Schools in Kerala**

| Type | LP | UP | HS | HSS | VHSE | Total |
|---|---|---|---|---|---|---|
| Government | 2749 | 867 | 1266 | 852 | 261 | 5995 |
| Aided | 3919 | 1873 | 1444 | 846 | 128 | 8210 |
| Unaided | 367 | 271 | 806 | 379 | NA | 1823 |
| **Total** | **7035** | **3011** | **3516** | **2077** | **389** | **16028** |

(as on March 2020, source: Government of Kerala-/sametham.kite.kerala.gov.in)

**Table 4.4.2: List of Universities in Kerala**

| Sl. No | Name of the University | Location |
|---|---|---|
| 1 | University of Kerala | Thiruvananthapuram |
| 2 | University of Calicut | Malappuram |
| 3 | Cochin University of Science and Technology | Kochi |
| 4 | Mahatma Gandhi University | Kottayam |
| 5 | Kannur University | Kannur |
| 6 | A. P. J Abdul Kalam Technological University | Thiruvananthapuram |
| 7 | Kerala University of Health Sciences | Thrissur |
| 8 | Kerala Veterinary and Animal Sciences University | Wayanad |
| 9 | Kerala Agricultural University | Thrissur |
| 10 | Kerala University of Fisheries and Ocean Studies | Kochi |
| 11 | National University of Advanced Legal Studies | Kochi |
| 12 | Sree Sankaracharya University of Sanskrit | Kochi |
| 13 | Thunchath Ezhuthachan Malayalam University | Malappuram |
| Deemed Universities | | |
| 1 | Kerala Kalamandalam | Thrissur |
| 2 | Indian Institute of Space Science and Technology | Thiruvananthapuram |

## 4.5 Age Structure

Kerala had an elderly population of only 0.986 million (above 60) fifty years ago. Their number had risen to 3.340 million by 2001. Their population would reach 10 million by 2051, about 3.2 times the number in 2001.

Another changing pattern is that 6.3 million people belonging to the 'young old' group (60-74 years) will be in Kerala in 2026 and another 2.0 million in the 'old old' group (75 years and above). In other words, Kerala's elderly population in 2026 would be equal to Kerala's total male population in 1961 (Rajan, 1989).

**Table 4.5 Demographic Scenario of Kerala Past, Present and Future (In million)**

| Year | Below 15 | 15-29 | 30-44 | 45-59 | 60 & above |
|---|---|---|---|---|---|
| 1961 | 7.205 | 4.158 | 2.837 | 1.714 | .986 |
| 1971 | 8.595 | 5.715 | 3.481 | 2.228 | 1.328 |
| 1981 | 8.901 | 7.716 | 4.116 | 2.809 | 1.909 |
| 1991 | 8.617 | 8.793 | 5.645 | 3.374 | 2.567 |
| 2001 | 7.243 | 8.761 | 6.940 | 4.498 | 3.340 |
| 2011 | 6.862 | 8.251 | 8.149 | 6.082 | 4.120 |
| 2021 | 6.296 | 7.514 | 8.558 | 7.308 | 5.710 |
| 2031 | 5.567 | 7.260 | 7.706 | 8.081 | 7.876 |
| 2041 | 5.147 | 6.639 | 7.318 | 7.603 | 9.778 |
| 2051 | 4.671 | 6.018 | 6.817 | 6.948 | 10.781 |

Source: Zachariah, K.C (2008). “A Century of Developments in Kerala Demography”, in B.A. Prakash and V.R Prabhakaran (eds.), *Kerala's Development Issues in the New Millennium*, Serials Publications, New Delhi, pp.44-46.

The ageing population of Kerala is specific among the states of India. Even though the growing proportion of older individuals is a worldwide and also a national phenomenon, the progression is considerably faster in Kerala. One of the supreme challenges of Kerala in 21st century would be in dealing the ever increasing number of elderly population who are gradually getting older. This is known as ‘Greying of Population’

### 4.6: Political Scenario

The political organisation of different religious and caste groups in the state is also very powerful. The state is also known for its strong democratic decentralisation implementation. In the growth of the state, the three-tier Panchayatiraj system plays a pivotal role. The state has also introduced reservations of seats for women, SC and STs in different local bodies.

When compared to other states, the state of Kerala has a special political culture. Two main political fronts, the Left Democratic Front (LDF), led by the Communist Party of India (Marxist), and the United Democratic Front (UDF), led by the Indian National Congress, dominate politics in Kerala. Since the 1980s, these two fronts have alternatively dominated the regime.

**Table 4.6: List of Major National and State Political Parties in Kerala**

| | |
|---|---|
| National Parties | Indian National Congress<br>Communist Party of India<br>Communist Party of Inda (Marxist)<br>Bharatiya Janatha Party<br>National Congress Party<br>Bahujan Samaj Party |
| Major State Parties | Janata Dal( Secular)<br>Janata Dal (United)<br>Kerala Congress<br>Kerala Congress(M)<br>Indian Union Muslim League<br>Rashtriy Janata Dal<br>Revolutionary Socialist Party<br>Shiv Sena |

(Source: Election Commission of India)

## 4.7: Economy

When viewed in aggregate terms, Kerala's economic output is very low. However, with heavy government involvement in the social sectors, including health and education, its growth trend has been unique and has gained considerable attention.

The characteristics of the Kerala economy are declining agriculture, sluggish industry, an increasing service sector, high dependency on foreign remittances, raising debts and a relatively high rate of educated unemployment. However, with the New Economic Strategy, substantial investments have been made by the State in various fields, including IT. Paddy, coconut, rubber, arcanut, pepper, cardamom and tapioca are the main crops in the state. Fisheries and cattle also contribute significantly to the economy of the State.

**Table. 4.7: Contribution of Different Sectors to Kerala GDP**

| Sector | Percentage Share in GDP (2015-16-current prices) |
|---|---|
| Primary | 12.07 |
| Secondary | 24.27 |
| Tertiary | 63.66 |

## 4.8: Migration

Migration has played a major role in the economy of Kerala. In the sense of Kerala, migratory patterns were inherent and the economic and social aspects of the state were formed. Within the Gulf countries, the economic boom gave migration a big boost, hitting its height in terms of both numbers and remittances. Ironically, Kerala is experiencing a reverse labour migration. (Rajan & Zacharia, 2019).

Although every year lakhs of Keralites migrate to different countries, Kerala is home to a large number of migrant workers from other parts of the country. The state is estimated to be home to approximately 2.5 million migrant workers from other parts of the world. Relative economic growth, decent working conditions, high wage rates, a stable environment, better protection of workers ' rights, good weather conditions, etc. draw migrant labour from other states to the state.

## 4.9 Health Care and Medical Services

There is a long tradition of organised health care in Kerala. The foundation for an effective health care system had already been laid when the state was established in 1956. There was remarkable development and expansion of government health programmes thereafter. Many chapters in development are offered by the growth of health facilities in Kerala. A crucial factor in the growth of health care services has been the active participation of the state government. Kerala's primary health care system has achieved a decent level after the reorganization of the state. Various factors like the infrastructural facilities, their accessibility and awareness among the people about health care etc. made the state a model in the field.

Health care systems can prevent death from a specific disease either by preventing it from developing or by effectively treating it once it has developed. A key element in effective treatment is impeccable diagnosis. However, almost no internationally comparable data exist on the actual occurrence of various diseases, which is the appropriate measure of the success of prevention (Crimmins et. al, 2010). However prevention and treatment of diseases gradually led to the increased life expectancy of the population. Kerala’s life expectancy increase could be identified in one way as the advanced health care facilities in the state. The progress in people's health status has been attained through the statewide increase in public, private an co-operative institutions of health care and also with the increasing awareness among the people and active involvement of the National Rural Health Mission (NRHM).

**Table 4.9: Expectation of life at birth by sex and residence, India and Kerala, 2010-14**

| | Total | | | Rural | | | Urban | | |
|---|---|---|---|---|---|---|---|---|---|
| | Total | Male | Female | Total | Male | Female | Total | Male | Female |
| India | 67.9 | 66.4 | 69.6 | 66.7 | 65.1 | 68.4 | 71.5 | 70.0 | 73.2 |
| Kerala | 74.9 | 72.0 | 77.8 | 74.9 | 71.7 | 78.1 | 75.0 | 72.7 | 77.1 |

*Source:https://www.censusindia.gov.in/Vital_Statistics/SRS_Life_Table/2.Analysis_2010-14.pdf*

Increased life expectancy in the state pose certain challenges also. Proportion of chronically ill or old persons are increasing which demands additional facilities in the health care system. Kerala health care sector has some inadequacies in special health amenities and high expenditure of treatments make the access of quality care difficult for the poorer sections. Increasing number of lifestyle diseases and disabilities associated with ageing also demand certain interference to modify the system. Palliative Care initiatives are the reflections of such demands from the society to care the chronically ill or disabled population who are being marginalized from corporate health care.

The health care system of Kerala is composed of Allopathy, Ayurveda and Homeopathy. Together, these three-tier medicine schemes have 9220 government sector institutions with 51,740 beds. Of the total institutions, 69% are subject to Allopathy, 19% are subject to Ayurveda, and 12% are subject to

Homeopathy. Of the total beds, 86% are subject to Allopathy, 11% to Ayurveda and just 3% to Homeopathy. During 2011, the three systems together treated approximately 22.83 lakh inpatients and 791.06 lakh outpatients. In addition to these, there are 74 Co-Operative hospitals in Kerala with 6,767 beds and 1440 doctors and 3467 nurses and Para medical staff. These cooperative hospitals are managed by both the government and private organisations. Among these, however, some hospitals are under liquidation and some are not operating. There are 12 hospitals with 1123 beds in the ESI and 137 State Dispensaries. In hospitals, there are 241 physicians employed and 316 physicians in dispensaries. The number of other paramedical workers employed both in hospitals and pharmacies, including nurses, is around 740. Together, the three structures have 51740 beds in Govt. field. In the government sector, the bed for every ten thousand people is about 15.5. In addition, in the ESI and Co-operative sectors, there are 8,650 beds. The ratio of the combined bed population is 19 beds/10000. 1405 Allopathic medical institutions with 57071 beds, 4332 Ayurveda institutions with 5502 beds and 3226 Homoeopathic institutions with 813 beds are registered private health care facilities in Kerala.

## 4.10 Palliative Care Services

According to the information found in the ‘Proposal of Strategies for Palliative Care in India’, “In India, currently there are approximately 908 palliative care services delivering palliative care through either through home care, outpatient basis and in patient service. More than 841 of these centres are in Kerala” (https://docplayer.net).This means that the state has more than 90% the country’s palliative care centres though it houses only about 3% of the country’s population. This development is the combined result of a substantial number of home-care services, enthusiasm of the involved volunteers, and the support given by the family members of the patient. It has to be remembered that in Kerala, as in the countries of Asia in general, one’s family is an individual’s most important social security and the family dwelling will be one’s chosen ambiance for living. So, without the family’s moral support, it will not be possible to connect the patient and palliative care workers.

“Kerala pioneered community-based palliative care through a socially innovative approach called the Neighbourhood Network in Palliative Care in an attempt to develop a free of charge, sustainable, community led, service capable of offering comprehensive long-term care and palliative care” (Philip, 2018). The first place for the programme to be introduced was the district of Malappuram in Northern Kerala. It was initially started for cancer patients but was later widened to include patients with many types of illnesses that required long-term care.

### 4.11 Cultural Features

By merging Malabar, Kasargod Taluk, and the state of Travancore-Cochin, Kerala was established in 1956. Over the last centuries, influences from other parts of India and abroad have formed the culture of Kerala (Menon, 1978). Kerala's culture is an amalgam of styles of native art, language, literature, style of architecture, music, festivals, cuisine, archaeological sites, and so on. It was helped by the geographical location and peculiar physical features of Kerala to create a distinct individuality. The cultural identity of Kerala was established by contacts with other cultures in the country and with foreign cultures from ancient times. The language spoken by 96 percent of the people of Kerala is Malayalam and it is also the state's official language. While adivasis have their own dialects, and Tulu and

Kannada are spoken on the borders of Tamil Nadu in areas bordering Karnataka and Tamil, almost all the inhabitants of the state can converse in Malayalam. The state has a rich variety of styles of art, dance, and music. Some of the state's main forms of art are Kathakali, Koothu, Mohiniyattam, Thiruvathira, Theyyam, Margam Kali, Oppana, etc.

### 4.12 The Specific Localities of the Study

The samples for the study were selected from the three districts of Kerala, namely, Thiruvananthapuram, Thrissur and Kozhikode, respectively representing the Southern, Central and Northern zones of the state. A brief sketch of the three districts is given in this section.

#### 4.12.1: Thiruvananthapuram District

Thiruvananthapuram is the state's capital city, located in the southernmost part of Kerala. The district shares a boundary with Tamil Nadu's Kanyakumari district in the south and east, and Kollam district in the north. The long Arabian Sea coastline forms the district's western boundary. The district's total geographical area is 2189 sq.km and it is the 4th smallest district in the state by area. As per the 2011 census, the population of the District is 3301427 individuals. There is a population of 1508 people per square km in the district. The district's sex ratio is 1087 females per 1000 males, and the literacy rate is 93.02%. Hindus, followed by Christians (19.10 percent) and Muslims (13.72 percent), are the largest (66.46 percent) religious group in the District.

"The district is the adobe of the Hindu god" Ananthapathmanabhan, "so in ancient times it was called" Ananthapuri. The modern period starts with the founder of modern Travancore, Marthanda Varma. It was a wonderful period for intellectual and cultural centres, and during the era of Maharaja

Swathithirunal (1829-1847), it reached its zenith. Swathi Thirunal's progressive improvements, including the introduction of English education, the establishment of an observatory and a charity hospital, mark the foundation of a new epoch in the History of the District. Sri. Moolam Thirunal, the first legislative chamber in an Indian state, is most remembered for the inauguration of the Legislative Council in 1988(www.spb.kerala.gov.in). The district is famous for the Temple of Sri Padmanabha Swami and world-renowned tourist attractions like Kovalam. Being a border district, a mixture of Malayalee and Tamilian cultures is the culture of the region.

The district is home to the University of Kerala, the Indira Gandhi National Open University regional headquarters, fifteen engineering colleges, three medical colleges, three Ayurveda colleges, two homoeopathy colleges, six other medical-related colleges and two law colleges (www.spb.kerala.gov.in).Institute of Science Education and Research (ISER), Liquid Propulsion System Centre (LPSC), Vikram Sarabhai Space Centre (VSPC), Indian Institute of Space Science and Technology (IIST), Tumba Equatorial Rocket Launching Station (TERLS), Jawaharlal Nehru Tropical botanical Garden and Research Institute (JNTBGRI), Rajiv Gandhi Centre for Biotechnology (RGCB), National Institute of Interdisciplinary Science and Technology, Shree Chitra Thirunal Institute of Medical Science and Technology (SCTIMST), Regional Cancer Centre (RCC), Central Tuber Crops Research Institute (CTCRI), Centre for Earth Science Studies (CESS), Kerala Science and technology Museum, Priyadrshini Planetarium, Kerala Highway research Institute, and Kerala Fisheries Research Institute are the major science and technology institutes in Thiruvananthapuram (www.spb.kerala.gov.in).

Thiruvananthapuram is popular for medical tourism. Thiruvananthapuram is the best city in Kerala to reside in and is well known in Southern India as the most popular hub for health facilities. Founded in 1951, Trivandrum Medical College is now home to a large range of hospitals and other healthcare institutions. In order to exemplar the type of facilities and services available at AIIMS, the All India Institute of Medical Sciences, the whole facility has constantly undergone numerous changes. The major healthcare institutions situated in Thiruvananthapuram include the Medical College Hospital, Regional Cancer Center (RCC), Sree Avitttom Thirunal Hospital for Women and Children, Child Development Center, Mental Health Center, Regional Artificial Limb Fitting Centre and the Regional Cancer Care Centre.

### 4.12.2: Thrissur District

In south-west India, 10.52 ° N and 76.21 ° E, Thrissur is located and lies in the central part of Kerala, India. The surface is approximately 66.15 km2. Swaraj Round, where the famous *Vadakkumnathan* temple and *Thekin Kaadu Maidan* (teak forest) are located, is the centre of the town. It is also the location for the Thrissur Pooram, the famous colourful cultural festival.

Thrissur is popular as the cultural capital of the State. Institutes such as the *Kerala Sahitya Academy, Kerala Sangeetha Nataka Academy and Kerala Lalithakala Academy* are headquartered in Thrissur to promote the development of Kerala's Malayalam language, literature, dance, music, drama, folk arts, fine arts and artistic heritage. Also located in Thrissur District is the popular *Kerala Kalamandalam.*

The *Perumpadappu Moopil*, known as *'Kerala Chakravarthi,'* had managed the Central Kerala. The Zamorins of Calicut had managed to control a significant part of the current Thrissur district in the 14th and 15th centuries. The ancient port of India, Kodungalloor, attracted European powers to Kerala to trade in spices and other commodities. With the swearing ceremony of Raja Rama Varma in 1790, who is popularly regarded as Sakthan Thampuran (1790-1805), the history of modern Thrissur began. As the architect of Thrissur city, the mighty ruler, Sakthan Thampuran, is legendary.

There are more than 60 schools and colleges in Thrissur district. Health Care is also remarkable in the district as near 100 hospitals are situated in the district. The city has the Ashtavaidya tradition, Oushadhi, Vaidyaratnam Oushadhasala, Sitaram Ayurvedic Pharmacy Ltd and SNA Oushadhasala. All these organizations have been contributory in spreading the eminence of Kerala Ayurvedic treatment, as lot of foreigners visit the Ayurvedic treatment facilities in and around Thrissur, every year. Vaidyaratnam manages a medical college and *Chikitsalayam*, with global standards. Sitaram have an eight storied super specialty hospital with more than 100 beds in the city of Thrissur, envisioned as the first of its kind Ayurveda super specialty hospital in the country.

### 4.12.3: Kozhikode District

With the discovery of the Sea Route to India in 1498 by the Portuguese navigator Vasco da Gama, the district of Kozhikode is of great significance in world history. The arrival of Gama at Kappad eventually altered India's very past. Kozhikode, also known as Calicut, has been a major source of international trade in spices for many centuries. Also, the town of Kozhikode was the capital of a former indigenous kingdom ruled by monarchs called Zamorins. According to the historian, K.V Krishnan Iyer, the term Kozhikode means koyil (Palace) Kodu (Fortified) (spb.kerala.gov.in.). During classical antiquity and the Middle Ages, Kozhikode was dubbed the “City of Spices” for its role as the major trading point of Eastern spices (kozhikode.nic.in). The district of Kozhikode is located on India's southwestern coast. The district is bordered by the Kannur district to the north, the Wayanad district to the east, the Malappuram district to the south, and the Arabian Sea to the west. The district has an area of 2345 square kilometres of land. The total population of the district is 3086293 people, as per the 2011 census. The population density of the district is 1316 per square kilometre, with a sex ratio of 1098 females per 1000 males and a literacy rate of 95.08%. The population constitute 56.21% Hindus, 39.24% Muslims and 4.26% Christians. Muslims and Hindus are traditional groups. Christianity came to the area by the establishment of Basel Mission.

Kozhikode is a city with a long-standing past. The city, with its prosperity, has drawn travellers from time immemorial. For more than 500 years, Jews, Arabs, Phoenicians, and Chinese have been trading in spices such as black pepper and cardamom. The Arab and Chinese merchants preferred it to all other ports, because Kozhikode offered complete freedom and protection. Kozhikode was the capital of Malabar during the time of Sri *Samoothiri Maharajas* (Zamorins), who ruled the region before the British took over (kozhikode.nic.in). There is a rich cultural heritage in the district and a tradition of mutual cohesion. Many notable literary figures in Malayalam, including S.K. Muhammed Basheer, M.T. Vasudevan Nair and N.P. Pottekkat, Vaikkom Muhammad spent the majority of his literary life in Kozhikode Region. The Indian Institute of Management (IIM), the National Institute of Technology (NIT), the National Institute of Electronics and Information Technology (NIELIT) and the Institute of Mental Health and Neuro Sciences

(IMHANS) are major higher education centres in Kozhikode. There is a government medical college in the district, one of the state's biggest, and two private medical colleges. While situated in the Malappuram district, is the University of Calicut and Calicut International Airport are named after Kozhikode. The district has a long tradition of cultural pluralism and unity with religion. In Kozhikode, where a number of traditional structures and cultural forms are evident, Kuttichira is a place of historical significance. Among some Muslims, Matriliny is followed in different parts of the district.

Kozhikode has a total network of hospitals, clinics and specialist healthcare that take care of the Kozhikode people's health needs (kozhikodeonline.org). They are General Hospital, Calicut, Govt. Hospital, Koyilandy, Govt. Hospital, Nadapuram, Govt. Hospital, Vatakara, Baby Memorial Hospital Arayidathpalam, Calicut, Fatima Hospital, IQRAA Hospital Malapparamba, Calicut, Kozhikode District Co- Operative Hospital, Aster MIMS, Star Care Hospital etc.

# CHAPTER 5

# BODILY AND MENTAL CONDITIONS OF PALLIATIVE CARE RECEIVERS

A disease is an objective phenomenon characterized by improper functioning of the body as a biological organism; whereas illness is a subjective phenomenon in which individuals perceive themselves as ‘not feeling well’ and therefore tend to alter their normal behavior (Wertheimer, 1996). Thus while disease causes bodily defects, illness causes mental agony tied up with the physical dysfunctions. An illness regardless of its duration may create lot of physical, psychological, social and economic problems to oneself and his/her relatives and to the society. Physical and functional losses due to aging and diseases decrease human mobility, freedom and quality of life. In addition to age-related degenerations, a larger section of the population is expected to be affected by mobility-related impairments due to prolonged diseases (Grimmer et al., 2019).

Similarly the chronically ill or disabled individual may feel mental imbalance and lack of confidence. They may feel isolated and depressed. They perceive themselves as a burden to their family and to the society.

This chapter attempts to analyse the patients’ bodily discomforts and mental agonies associated with the impaired condition. The association between mental conditions of the respondents and the background variables like age, marital status, gender, religion, education, family size, family income and nature of disability are also examined through cross analyses. Since bodily problems of the respondents do not show association with any of the background variables, the analyses are given in frequency tables.

## 5.1 Bodily Discomforts Associated with the Ill Health

The damaging impacts of physical inactivity on health and physical functioning are well recognized. Individuals with a chronic disease are prospective to become less physically active which in turn leads to a phase of body deconditioning. The result of this downward cycle is a loss of functional capacity and subsequent further reductions in the ability to perform daily activities (Durstine et.al, 2012). Bury's (1982) frequently cited article, 'Chronic illness as biographical disruption' has been widely recognised as constituting a significant contribution to our understanding and conceptualisation of experiences of illness (Lawton, 2003).

A disease incapacitates an individual. It affects his primary activities like food intake, movement, and other routine activities. When an individual is not able to consume as much food that his system needs, it will affect the functioning of his/her other organs and energy level. Sometimes strong medicines also cause lots of negative side effects. All this will diminish the person's ability to perform and thereby his productivity. When a patient becomes too debilitated, his willpower also dries up. In such a state of pain and lethargy, most patients become disinterested in communicating with those in their social circle and often with their immediate family. Added to this is the mental anguish that patients feel because of their loss of productivity and dependency on others.

### 5.1.1 Bodily Changes Caused by the Impairment

Physical reactions of the body to old age, the disease itself, administration of drugs, and even mental anguish vary over a wide spectrum. What the patient is going through may be a headache, sleeplessness, pain in certain body parts, loss of weight, lack of appetite, difficulty to move on one's own or feed oneself, negative reactions to certain foods, indigestion, inability to express oneself properly, or memory loss.

This study enquired into the nature of changes occurred to the body of the patients. The respondents were asked about the changes that happened in their body due to the impairments. The responses were analysed as shown in Table 5.1.1

**Table 5.1.1: Bodily Changes Caused by the Impairment**

| Bodily Changes | Frequency | Percentage |
|---|---|---|
| Severe | 250 | 83.33% |
| Moderate | 50 | 16.67% |
| Total | 300 | 100% |

It is revealed that 83.33% of the respondents suffered severe changes to their bodily conditions and the rest changes of moderate nature. The results indicate that patients under palliative care are victims of severe bodily changes due to their prolonged illness. This enables us to assess what would have been the conditions of the patients if the service of the organization was absent.

Nevertheless, everybody may not feel the same way about the severity of the change, because quite a lot depends on how the change is evaluated by its bearer. For example, let us consider a bodily change that reduces an individual’s ability to use his legs. If it happens to a sportsman/woman, or a farmer who has to work in his/her fields, he would categorize that change as a severe one. On the other hand, a writer may not find such a change equally bad because he/she may still be able to sit in a wheelchair and use his/her laptop to write. In other words, patients evaluate changes on different scales.

Besides this, for people with disabilities, the change they experience need not always “stem directly from their bodies, but rather from their unwelcome reception in the world, in terms of how physical structures, institutional norms, and social attitudes exclude and/or denigrate them" (Goering, 2015). This attitude too may have a catalytic role in making a patient understand his bodily change as severe or medium.

### 5.1.2 Severity of Bodily Pain Due to the Impairment

Managing the competing demands of multiple chronic health conditions is a major challenge for many patients and their primary care givers. Chronic pain is of specific concern as a co-morbid condition considering its predominance among older persons, who also tend to have other chronic conditions and its association with amplified disability, poorer health status and diminished quality of life in general (Butchart, 2009).

Many diseases, especially terminal illnesses, cause intense physical pain and discomforts like nausea, vomiting, constipation, delirium, fatigue, depression etc. If these distresses are left untreated, they are likely to become more complicated and severe. Besides treating pain with medications, the patient should ideally be told what causes that pain. If the pain is caused by some harmless physical impairment, the patient's awareness of it will benefit him/her psychologically.

Patients in palliative care are found to be victims of severe bodily changes. Naturally, a doubt arise as to how agonising was the pain suffered by them. An enquiry into the matter was made by asking the patients, how severe has been the pain suffering from. The responses are given in Table 5.1.2

**Table 5.1.2: Severity of Bodily Pain Due to the Impairment**

| Severity of the Pain | Frequency | Percentage |
|---|---|---|
| Severe | 153 | 51.00% |
| Moderate | 147 | 49.00% |
| Total | 300 | 100.00% |

In certain reported studies, the use of Visual Analogus scale is referred to for assessing the severity of pain suffered by patients. However, in this study, the sample size was large and making them aware about such a measuring instrument was thought practically difficult. The gravity of the pain was assessed from the oral responses and body language of the patients.

It is revealed that the responses divide themselves between 'severe pain' and 'moderate pain' almost equally (51 and 49 percents respectively). Comparing the results from analyses 5.1.1 and 5.1.2, the implication is that the palliative care agencies are doing what is necessary for pain management. Probably this is what is usually expected of them since helping recovering from the diseased condition is out of the question; the patients may be in a state of terminal period or in some other conditions where from coming back is not expected. This also reveals that the agency is well executing their expected services.

Analgesic therapy mostly starts with the management of nociceptive pain (the most common type of pain resulting from an injury or damage– e.g. dental pain), combined with or followed by the management of neurogenic pain, (pain resulting from the dysfunction of central or peripheral nervous system). Adjuvant analgesics like antidepressants and anticonvulsants are also used to treat chronic pain. Palliative care workers generally individualize analgesic therapy after taking into consideration the patient's memory of pain episodes, his or her reactivity to pain, religious beliefs, the support received from families and friends, personal defense skills, and therapeutic strategies (Sholjakova et al, 2018).

### 5.1.3: Routine Activities Affected Due to the Illness

The high prevalence and duration of chronic illnesses often require long-lasting care that contributes to an increase in the disability burden. The most difficult outcome for individuals with a chronic illness and bodily incapacity is prevention of working, performing normal daily tasks, and social interactions, which necessitate assistance from a caregiver and thus increases economic burden for the individual, household, and the country (Sultana et al., 2017).

A normal person has a daily routine which include their physical activities, work schedules, mealtimes, shared time with family or friends, and even hobbies. All these aspects of daily life will come to a standstill once he/she is in the grip of a disease. They may perform some of these with the help of caregivers but such assisted activities hardly give any satisfaction to an individual who has been used to living an active life. The table below evaluates the extent to which routine activities are affected in sick people.

**Table 5.1.3: Routine Activities Affected Due to the Illness**

| Response | Frequency | Percentage |
|---|---|---|
| Very Much | 162 | 54.00% |
| Somewhat | 129 | 43.00% |
| Not Affected | 9 | 3.00% |
| Total | 300 | 100.00% |

Table 5.1.3 shows that majority (54%) of the respondents have their daily routines seriously affected because of their disabilities while a lesser percentage (43%) feel that the effect has not been very intense. Further, there is

still a small portion (3%) whose ability to manage day-to-day tasks has not been affected at all. At least part of the credit for such a situation goes to the proper palliative care they could be receiving.

Inability to manage their routine tasks, especially taking help for bathroom needs, can be emotionally very taxing for a patient. Research has shown that even terminally-ill care-receivers have a sense of wellbeing when they are able to perform these tasks themselves. As such, palliative care workers do their best to reduce the functional decline of their beneficiaries and the resultant feeling of helplessness. It is reassuring to see that among the seriously ill, there is a 3.00% whose ability to perform basic tasks have not been affected. The 43.00% whose ability is partially affected are probably able to keep it so with the help of palliative care. Palliative care workers may suggest incorporating new fixtures within the toilet or rearranging the room functionally to help the patient become more independent and maintain personal hygiene and grooming.

However, priorities change through the trajectory of the sick period and sometimes performing of routine tasks may become secondary to pain relieving. Care workers continuously assess the patient and try to bring him/her back to the stage of self-reliance in basic tasks. When a patient is able to manage his/her physical needs himself/herself, it is bound to make them mentally stronger. This may even lead to the patient worrying less about himself/herself and participating in whatever is happening in the household.

### 5.1.4: Assistance needed to Move Around in the Disabled Status

Diseases make a normal person weak, bedridden, and depressed most of the time. Certain diseases may increase the likelihood of developing certain disabilities, for example arthritis may lead to disabilities related to mobility like walking, climbing stairs, raising arms, grasping small objects etc. A stroke may lead to difficulty in moving certain parts of the body, sensory disturbance, speech impairment, and difficulties related to memory and thinking. Using a physiological outline of understanding disability, Fried et al. examined the cross sectional relationship between chronic diseases and damages and disabilities, and found that certain diseases were associated with disability of diverse types of tasks, such as arthritis with mobility tasks and stroke with complex instrumental activities of daily routine (ADL) tasks (Hung et al., 2012). Disabilities make people depending on others to move around and manage their basic necessities. The diseased persons seek support from others to move around and finish their necessities.

The study enquired into the assistance needed by the respondents in moving around in their disabled condition. Table 5.1.4 shows the analysis of the responses received.

**Table 5.1.4: Assistance Needed to Move Around in the Disabled Status**

| Nature of the Need | Frequency | Percentage |
|---|---|---|
| Always | 131 | 43.67% |
| Sometimes | 142 | 47.33% |
| Not at all | 27 | 9.00% |
| Total | 300 | 100.00% |

A patient’s inability to move may result from arthritis, muscle fatigue, extreme exhaustion, spinal problems, fracture, and many other diseases. Some of these conditions, like a fracture, are surgically remedied and patients recover fully. Such patients are trained by palliative care workers to walk through different phases. First they help him/her to sit up, then gradually stand up, then walk with the help of other people’s support, and then walk using a walker.

This same scenario may not work with old patients or weak patients who are victims of serious diseases that cause impaired muscle strength, decreased motor control etc. In such cases, palliative care workers often recommend the use of wheelchair. Wheelchair in itself can be of many types. There are self-propelled manual wheelchairs that patients operate themselves and attendant-propelled wheelchairs manipulated by helpers. There are also electric-powered wheelchairs, controlled by a joystick on the arm-rest of the chair.

According to Table No. 5.1.4, only 9.00% of the respondents do not require help for moving around. Of the remaining, 43.67% are immobile to the extent that they always need help to get around. The partial inability of the remaining 43.67% to walk may be due to different reasons. Some could be trained to use a self-propelled wheelchair. Another could become more mobile if provided with a wheelchair and a full-time assistant to push it. Training in using a walker could be the requirement of yet others while muscle-strengthening exercises could be the requirement of some. Most palliative care workers are able to understand the causes that limit the mobility of patients and they do their best to remove these obstacles.

### 5.1.5: Condition as Bedridden

Becoming bedridden is a slow process by which a person becomes increasingly confined to one location. Though instances like a serious injury or a paralytic stroke may confine a person to bed suddenly, in many cases it is a slow process that takes place with increasing age or an increasingly debilitating disease. This will reduce the patient’s interests in family matters and general affairs, and make him lethargic. Various factors influence an individual’s reaction to such a situation, like attending circumstances, availability of professional care, emotional reaction of the family, the patient’s interaction with the family, and other structural factors which can even include the arrangement of furniture in a patient's room.

Many of the factors causing bedridden condition may be different from patient to patient and many are modifiable also. In some cases it can even be prevented if warning signs are heeded and preemptive measures taken (Zegelin, 2008). Lifestyle choices can also lead to a bedridden condition. And a bedridden condition can lead to problems like bedsores, wasted muscles etc. and also aggravate many existing conditions.

Analysis was done by asking the respondents about their condition as bedridden. Table 5.1.5 shows the percentages of people in various stages of confinement to bed.

**Table 5.1.5: Condition as Bedridden**

| Condition as Bedridden | Frequency | Percentage |
|---|---|---|
| Permanently | 167 | 55.67% |
| Occasionally | 125 | 41.67% |
| Never | 8 | 2.66% |
| Total | 300 | 100.00% |

Analysis in Table 5.1.5 shows 55.67% of the respondents are permanently confined to bed because of their constant sickness. 41.67% state that they are confined to bed now and then though not always. However 2.66% is completely free of a bedridden condition.

Chronic diseases make people unable to get up from their bed and do their basic activities. The bedridden condition makes them feel more drowsy and tired. Generally bedridden persons think of them as useless and burdensome to their family and society. Becoming bedridden is quite humiliating and agonizing. People become bedridden due to general deterioration, debilitating diseases, spinal injuries etc. While that is bad enough, once a person becomes bedridden, he/she becomes vulnerable to additional health risks like getting bed sores, urinary infection, muscle hardening, pneumonia etc. As food intake is difficult in a supine position, many patients develop digestion-related complications also. Those who provide palliative care for bedridden patients should be highly skilled and must know how to prevent further deterioration of the patient.

For example, if a patient is catheterized, it is important for the care provider to frequently empty the drainage bag. The tip of the drainage valve should ideally be cleaned with an alcohol wipe, soiled diaper should be frequently changed, and the patient should be fed large quantities of fluids. To prevent development of sores, the patient should be regularly turned on the bed, kept well-cleaned, and ideally be kept outside the bed at least for a little while every day. None of these things are easy but the difference in percentages of permanently bed-ridden patients and occasionally bed-ridden patients is heavily influenced by the ability of palliative care workers in managing patient care perfectly.

### 5.1.6 Disturbed Sleep Due to Pain

Chronic pain is associated with the symptoms that may weaken a patient's quality of life, including emotional distress, tiredness, and sleep disruption. There is a high prevalence of concomitant pain and sleep disturbance. Studies substantiate the hypothesis that sleep and pain have a reciprocal relationship. Clinicians who manage patients with chronic pain often focus on interferences that relieve pain and assessing and treating sleep disturbance are not addressed (Cheatle et al, 2016).

Pain often deprives people of sufficient rest and lack of rest in turn leads to insomnia. Some people have difficulty in falling asleep due to consistent pain but once they fall asleep they manage a few hours of undisturbed sleep while others have difficulty in maintaining their sleep also. Many patients have limited exposure to proper daylight and this too reduces the quality of their sleep.

The study enquired into how far the sleep of the patients are disturbed due to pain related to the disability. Table 5.1.6 reveals how much the pain of the respondents disturb their sleep.

**Table 5.1.6: Disturbed Sleep Due to Pain**

| Disturbance to Sleep | Frequency | Percentage |
|---|---|---|
| Very much | 195 | 65% |
| Moderately | 76 | 25.33% |
| Very Little | 20 | 6.67% |
| Not at all | 7 | 2.33% |
| Total | 300 | 100.00% |

Analysis in Table 5.1.6 discloses that majority of the respondents (65%) are very much disturbed by pain with sleep while 25.33% are moderately disturbed, and 6.67% have very little problem in this regard and a negligible percentage (2.33%) are not at all disturbed by this.

Chronic insomnia may coexist with chronic physical and psychiatric conditions, and its predominance is often higher among patients with these complications than in the general population. Evidence suggests that insomnia as a feature of chronic disease inclines to be more severe and persistent than insomnia that does not occur in the situation of chronic illness. Furthermore, comorbid insomnia can have a profound adverse impact on patients' quality of life and overall functioning, and may be associated with better healthcare resource utilization. In some cases, treatment of the underlying disorder may improve sleep, whereas in other cases, treatment of the sleep symptoms may in fact improve the underlying disorder (Ancoli-Israel, 2006).

### 5.1.7 Duration as Disabled

A serious health issue can incapacitate a person permanently and disrupt all aspects of his or her normal life. A patient's energy level depletes considerably when he/she falls sick and because most patients feel anger, frustration, powerlessness, guilt feelings, and immense fear because of the situation they are in, they generally become indifferent to life. Added to this are serious problems like dementia, incontinence, loss of speech etc. that totally destroys a patient and leaves him or her completely at the mercy of caregivers and medical professionals for a prolonged duration of time. Longevity of life also may be a reason for prolonged disablement and dependency on care givers.

The statistics and surveys of the World Health Organization (WHO) release an increase in life expectation (expecting 400 millions of population over 60 years old at 2050), longer treatments for chronic diseases as cancer, diabetes, cardiovascular conditions, and prevalence of Alzheimer's disease and dementia, which causes an increase in health costs and a social problem for personal care and hospitalization. According to the forecast of the United Nations, 65 years and older will occupy 15.7% of the total population in 2030 (Retrieved from https://population.un.org).

With this presumption this study enquired into the respondent's duration as disabled. Analysis given in Table 5.1.7 reveals the duration of disability of the respondents at the time of interviewing.

**Table 5.1.7: Duration as Disabled**

| Duration | Frequency | Percentage |
|---|---|---|
| Less than 1 year | 36 | 12.00% |
| Less than 2 years | 53 | 17.67% |
| Less than 4 years | 58 | 19.33% |
| 4 years and above | 153 | 51.00% |
| Total | 300 | 100.00% |

Analysis 5.1.7 reveals that the majority of the respondents (51%) have been in a disabled condition for four years and above. While 12% of them are in impaired condition for less than a year, almost equal proportions (17.67% and 19.33% respectively) of the respondents are under the disabled condition for less than two years and less than four years.

Talcott Parsons, recognized illness as a social situation rather than as a completely biological condition. Health, as against illness, being defined as: 'The state of optimum capacity of an individual for the effective performance of the roles and tasks for which s/he has been socialised' (Parsons, 1951).

A debilitated individual encounters torment. Disease creates torment in the person's body and he/she is unfit to do any work. He/she progresses toward becoming tired very soon and gets depleted in the difficult condition. An individual who is experiencing a transient infection like fever, intestinal sickness, typhoid, a ruptured appendix etc. may experience torment amid the time of illness. He/she needs to experience the excruciating circumstance for an exceptionally prolonged stretch of time and this influences his/her character, day by day schedule, relations with relatives and companions. He/she stays troubled and discouraged for more often than not.

There is no stage in human life when a person will not need medical aid. From neonatologists to geriatricians, and from allergists to oncologists to pulmonologists, doctors cater to the needs of people of different ages and diseases of different types. Palliative Medicine, as a specialty, is besides all these. Medical Council of India (MCI) recognized “Palliative Medicine as a specialty in 2010 and the first specialist Palliative Medicine training commenced at Tata Memorial Hospital, Mumbai in 2012” (Salins, 2015). Unlike other medical specialists, palliative care doctors are trained in symptom management, providing of psycho-social support to patients and their families, and handling medical and non-medical options for disease management. They are given competency-based training in “working in a multi-disciplinary/inter-disciplinary team, working in different clinical settings, communication skills, decision making skills, procedural skills relevant to Palliative Medicine, ethics based good practice, leadership, teaching, and research” (Ibid, 2015).

Palliative medicine focuses primarily on reducing pain and ensuring the comfort of the patient. A person who is in need of palliative care may have different bodily problems like backache, headache, nausea, breathing difficulty, problems with bowel movement, itching, incoherence etc. The primary responsibility of the palliative care team is to remove or at least minimize these agonies and make the patient’s remaining life pain-free. Towards this, palliative care doctors may work together with other medical specialist treating the patient. But unlike the medical specialist, the palliative care doctor focuses strongly on removal of the patient’s bodily discomfort and less on fighting the disease.

## 5.2 Psychological Problems of the Impaired

Seriously ill patients are mostly exhausted individuals and they tend to lose confidence. They would then become constantly worried about the problems they are creating for others. Many patients become de-motivated and find no reason for living. Some lose interest in personal appearance and some lose their aesthetic sense as well. People with persistent chronic physical conditions need to alter a considerable lot of their goals, way of life and work. The wretchedness rising up out of such misery may diminish an individual's inspiration to access restorative consideration and furthermore undermine the capacity to adapt to torment (Turner and Kelly, 2000).While medication assuages the physical enduring to a degree the passionate expense of long haul treatment left ignored.

### 5.2.1 Life Satisfaction in the Midst of Disability

'Social Indicators of Well-being' (Andrews and Withey, 1976) emphasized on social connections, wellbeing, business related conditions, individual welfare, freedom, virtues and character characteristics as a wellspring of Life Satisfaction. Life fulfillment is a significant marker of emotional prosperity in interminable patients. Emotional prosperity catches the full of feeling sentiments and intellectual decisions individuals have about the nature of their lives. Life satisfaction is a type of abstract prosperity that mirrors the view of whether one is content with one's life. Life fulfillment is related with positive life results, for example, wellbeing and life span. It appears to be coherent to accept that patients who experience various continual medical issues would likewise experience lower life fulfillment.

The analysis given in Table 5.2.1.1 shows that 62 % of the respondents are somewhat satisfied in their personal life. But one third (33.00%) of them feel no satisfaction in their personal life and only a negligible portion (5.00%) opine they are very much satisfied in their life.

#### 5.2.1.1 Marital Status and Life Satisfaction in the Midst of Disability

Marriage is a life-long commitment. It helps people to grow into mature human beings and teaches them how not to live just for oneself but for other members of a family as well. A successful and healthy marriage is also a gateway to a very enriching life where people may be able to realize a higher purpose in life. Marriage is for delight, joy and genuine feelings of serenity by virtue of fulfillment through collaborations with others' trust, understanding and satisfying social commitments and improving character development.

Marriage is associated with longer life and better health in both men and women. Marriage attaches people to other individuals, to social groups (e.g., extended family), and to other social institutions, which are further sources of social benefit. Based on the above evidence it could be expected that being married would serve as a buffer against the psychological suffering associated with chronic disability (Wade et al., 2013). Analysis in Table 5.2.1.1 shows the association between marital status of the respondents and their life satisfaction in the midst of disabilities.

**Table 5.2.1.1: Marital Status and Life satisfaction in the Midst of Disability**

| Marital Status | Very much Satisfied | Somewhat Satisfied | Not at all Satisfied | Total |
|---|---|---|---|---|
| Married | 12 (6.38%) | 130 (69.15%) | 46 (24.47%) | 188 (100.00%) |
| Unmarried | 2 (5.56%) | 16 (44.44%) | 18 (50.0%) | 36 (100.00%) |
| Separated/Divorced | 0 (0.00%) | 8 (47.06%) | 9 (52.94%) | 17 (100.00%) |
| Widow/Widower | 1 (1.69%) | 32 (54.24%) | 26 (44.07%) | 59 (100.00%) |
| Total | 15 (5.00%) | 186 (62.00%) | 99 (33.00%) | 300 (100.00%) |

Chi Square Value =18.94, df=6, Table Value =12.59, P≤0.05
The association is significant

Analysis 5.2.1.1 shows that 69.15% of married respondents are happy to some degree with their life despite their problems, while half of the unmarried respondents are unable to find any satisfaction or fulfillment while having the disability. Respondents of the category Separated/Divorced, likewise, do not appear to be satisfied. Only 47.06% of them are experiencing at least a reasonable fulfillment. Compared to unmarried or separated/divorced people, there are more people in the widow/widower category who are seen to be reasonably happy even with their disability.

Available statistics point to the fact that married people generally have better emotional health and less risky behavior. The sharing and caring involved in married life have significant influences on their abilities to remain level-headed even while going through difficulties. Sometimes they are also pressurised to be not overtly emotional in the interest of other family members. The analysis above substantiates this. Another factor revealed here is that Widow/ Widower category is comparatively better in life satisfaction who suffer from chronic disability than Unmarried and Separated/ Divorced category.

Analyses of the relation of life satisfaction with other variables namely age, gender, education, religion, family income, family size and nature of disability were made but no association between the variables are revealed. So the details of the analyses are not given here.

### 5.2.2 Interest in Prolonged Life

Survivors of chronic diseases and old age disabilities experienced altered lives and had needs related to fear of recurrence and facing the spiritual aspects of having survived a life-threatening condition. Several demographic factors had significant impact on the quality of life. The growing population of such survivors has prolonged needs for nursing care that address multidimensional aspects of Quality of Life (Ferell et al, 1995).

An analysis was done to find out the interest of the respondents in their prolonged life with disability. It is found that while half of them (50%) shows interest in the prolonged life with expectation of recovering from the disabled condition, the other half is not interested to live with such a serious disability that cannot be treated and cured.

In order to understand the association between the interest in prolonged life and the background variables, analyses were carried out. It was revealed that marital status and the feeling were closely associated.

#### 5.2.2.1: Marital Status and Interest in Prolonged life

Being married typically is expected to lead to greater availability of emotional, social support, meaning and purpose in life, and social control, which are considered key processes that promote physical wellness (Umberson, 1987). Living with spouses in this way encourages people to stay sure, confident and hopeful. Individuals with perpetual illnesses who are Unmarried, Divorcee, Widow/Widower or Separated are not likely to get the type of nursing help that married people can expect from a spouse. They may also find it difficult to be open about their misgivings and emotional churnings to acquaintances or relatives with whom they were never emotionally close. All this will lead to an aversion in them towards prolonging their life.

**Table 5.2.2.1: Marital Status and Interest in Prolonged life**

| Marital Status | Not Interested | Interested | Total |
|---|---|---|---|
| Married | 73<br>(40.33%) | 115<br>(61.17%) | 188<br>(100.00%) |
| Unmarried | 27<br>(75.00%) | 9<br>(25.00%) | 36<br>(100.00%) |
| Separated/Divorced | 7<br>(41.18%) | 10<br>(58.82%) | 17<br>(100.00%) |
| Widow/Widower | 43<br>(75.14%) | 16<br>(27.12%) | 59<br>(100.00%) |
| Total | 150<br>(50%) | 150<br>(50%) | 300<br>(100.00%) |

Chi square=31.28, df= 3, Table Value=11.34, P≤0.01

The association is significant

Analysis 5.2.2.1 demonstrates that majority (61.17%) of the Married respondents don't feel that they have nothing to anticipate however they are in a perishing stage. At the same time, 75.14% of the respondents among the Widow/Widower feel that they don't have anything to accomplish for their family and society. While the lion’s share (75%) of the respondents among the Unmarried feel that they are free from all the individual and familial duties, 58.82% of the respondents in the class of Separated/Divorced don't have such a vibe.

According to more than 130 empirical researches on a number of well-being indices, married men and women are generally contented and less stressed than the unmarried. Marriage is particularly worthwhile for men. The protection/support that a marital partner provides companionship and emotional aid buffers individuals against physical and emotional pathology (Coombs, 1991). Basic to our contention, being in a close relationship and the kind of such relationship have been found to alter the seriousness of the impeding outcomes that negative life occasions and advances can have on people's psychological prosperity.

### 5.2.3 Feeling as Mentally Strong

Chronic illnesses and disabilities can have consequences on mental health. These consequences may vary in strength. Psychological distress among chronically ill might occur as a psychiatric disease in itself or it may be a psychological reaction to primary or secondary consequences of the chronic disabilities, which acts as stressor (Heijmans et al., 2001). An endless, serious ailment can leave people feeling broken, worn out, concerned and empty. Many agree that those in incessant agony must be solid so as to live with torment on a long haul scale. At the point when people live with an uncommon, hopeless ailment, they frequently feel like they are ceaselessly returning to parts of their life. Despite the fact that they are burdened with numerous new obstacles to cross, they are as often as possible helped to remember the regular battles, as well. It can start to feel like they are on a steady treadmill of stress, concern, dread, energy and cynicism.

The study enquired into the perceptions of the respondents on their mental strength during the incapacitated situation. Analysis in Table 5.2.3.1 shows that majority (74%) of the respondents feel strong mentally even in the disadvantaged condition. Only 3.33% feel as very much strong to certain level. The respondents who do feel as mentally strong constitute almost 1/4th of the sample.

### 5.2.3.1 Gender and Feeling as Mentally Strong

Sex difference influences sicknesses on a progressively organic dimension, whereas gender may affect the way wherein an individual reacts to such infections. In any case, in view of chronicled information and research predispositions, some social health care suppliers and the overall population are adapted to search for ailment pointers that are increasingly basic in just one sex. It is significant for human services suppliers and people in general to understand that side effects for a similar sickness may introduce themselves diversely dependent on gender.

**Table 5.2.3.1: Gender and Feeling as Mentally Strong**

| Gender | Very much feel mentally strong | Somewhat feel mentally strong | Do not feel mentally strong | Total |
|---|---|---|---|---|
| Male | 6<br>(4.41%) | 109<br>(80.15%) | 21<br>(15.44%) | 136<br>(100.00%) |
| Female | 4<br>(2.44%) | 113<br>(68.90%) | 47<br>(28.66%) | 164<br>(100.00%) |
| Total | 10<br>(3.33%) | 222<br>(74.00%) | 68<br>(22.67%) | 300<br>(100.00%) |

Chi square=7.87, df=2, Table Value=5.99, P≤0.05

The association is significant

Analysis in Table 5.2.3.1 shows that an overwhelming majority (80.15%) among the male respondents feel that they are somewhat strong mentally to confront the challenges created by their sickness whereas female respondents are lesser (68.90%) who feel strong to deal with their impaired condition.

A review of the ongoing writing, be that as it may, demonstrates that there is presently a general accord among social researchers that women experience more mental trouble than men and this is to a great extent because of parts of their societal jobs. Besides, over the most recent couple of years the aggregate proof shows that women do in actuality have higher rates of dismalness than men and this likely is generally an outcome of their social roles.

### 5.2.3.2 Education and Feeling as Mentally Strong

Positive mental health is a key component of overall health that intensely affects individuals' functioning in life and subjective well-being (Keyes et al, 2010). Distinct from merely the nonexistence of mental disorder, the World Health Organization characterizes mental health as the ability to recognize one's full potential, cope effectively with stress, work efficiently, and contribute to community (Retrieved from https://www.who.int).

Being constantly sick is a ceaseless procedure of adjusting the requests of the ailment and the requests of regular day to day existence. Educational attainment of the constantly sick has an impact on such procedure of adjusting among life and sickness. Education causes individuals to know about a numerous things about the happenings around them and how to carry on in such circumstances. In this study it is assumed that the educational background of the clientele community is associated with their feeling of mental condition.

**Table 5.2.3.2 : Education and Feeling as Mentally Strong**

| Education | Very much feel mentally strong | Somewhat feel mentally strong | Do not feel mentally strong | Total |
|---|---|---|---|---|
| Illiterate | 2<br>(1.55%) | 108<br>(83.72%) | 19<br>(14.73%) | 129<br>(100.00%) |
| Primary | 2<br>(1.69%) | 76<br>(64.41%) | 40<br>(33.90%) | 118<br>(100.00%) |
| Secondary | 5<br>(13.51%) | 24<br>(64.86%) | 8<br>(21.62%) | 37<br>(100.00%) |
| College | 1<br>(6.25%) | 14<br>(87.50%) | 1<br>(6.25%) | 16<br>(100.00%) |
| TOTAL | 10<br>(3.33%) | 222<br>(74.00%) | 68<br>(22.67%) | 300<br>(100.00%) |

Chi square= 30.09, df= 6, Table Value=16.81, P≤0.01

The association is significant

Analysis in Table 5.2.3.2 reveals that majority of the illiterate respondents (83.72%) and those who have college education (87.50%) feel that they are mentally strong to certain extent to face their debilitated situation. Also among the respondents who don't feel as mentally strong, both the illiterate and graduates are small in proportion when compared to those who have primary or secondary education. Majority of the school educated categories also come under the section who feel somewhat strength in their mind.

A serious disease is a very tough challenge and remaining mentally strong at such a juncture could be very difficult. Still, there are many who manage to do it. They do so by accepting reality instead of thinking about all the negativities of the disease, and making the best of the situation. The patient has to live each day as it comes, instead of thinking about all the things that may or may not happen because of the illness. Patients who are mentally alert can try to engage themselves in some productive activities like teaching children, playing online games etc. When a person is mentally strong, he/she has better chances of healing.

The illiterate may not think deeper into their impaired condition. So they are not very much worried and feel mentally strong. On the other hand the better educated think rationally/ philosophically about their impaired condition. So they are mentally keeping themselves somewhat strong like the college educated group.

Psychological care, in the case of a sick individual, is about "enabling the individual to express thoughts, feelings and concerns relating to illness, assessing individual needs and resources for coping, and ensuring that appropriate psychological support is available" (Payne & Hanes, 2002).

Though some palliative care teams may have clinical psychologists as members, many volunteers in the team, who are resourceful communicators, also do this job by finding creative solutions for patients' problems.

Analyses of the relation of feeling as mentally strong with other variables namely age, marital status, religion, family income, family size and nature of disability were made but no association between the variables are revealed. So the details of the analyses are not given here.

### 5.2.4 Feeling of Isolated Existence

Loneliness/Isolation has been defined as a unique psychological construct consisting of distressing emotions that are derived from the absence or perceived absence of estimated meaningful interpersonal relationships. Studies establish that there are links between loneliness and chronic disabled conditions especially among older adults (Petitte, 2015). Social isolation is a serious concern for people living with chronic illnesses. Social isolation come to be an important risk at older ages because several events occur at the same time: decrease in financial possessions, mobility impairment and death of contemporaries, among others (Cantarero-Prieto, 2018).

Analysis in Table 5.2.4.1 reveals that majority (64%) of the respondents sometimes feel isolated in their disabled condition and a minority (19%) never feel isolated. Another 13.33% often feel isolated.

#### 5.2.4.1 Income status and Feeling of Isolated existence

Family income is another factor which influences the psychological ups and downs of the diseased people. People who have a satisfactory family income may not confront with financial crisis during the diagnosis and treatment. But the case is different with those who have a very low family income. The struggles associated with the economic instability of their family will make them mentally frustrated and gradually depressed. They may feel isolated most of the time because of the inability to move and work as desired.

The study enquired into the influence of family income on the feelings of isolation of the respondents.

**Table 5.2.4.1: Family Income and Feeling of Isolated Existence**

| Family income (Monthly in Rs.) | Never feel isolated | Sometimes feel isolated | Often feel isolated | Always feel isolated | Total |
|---|---|---|---|---|---|
| Low (Below 5000) | 41 (17.30%) | 157 (66.24%) | 34 (14.35%) | 5 (2.11%) | 237 (100.00%) |
| Middle (5000-10000) | 10 (20.83%) | 29 (60.42%) | 4 (8.33%) | 5 (10.42%) | 48 (100.00%) |
| High (10000 and above) | 6 (40.00%) | 6 (40.00%) | 2 (13.33%) | 1 (6.67%) | 15 (100.00%) |
| Total | 57 (19%) | 192 (64%) | 40 (13.33%) | 11 (3.67%) | 300 (100.00%) |

Chi square=14.54, df= 6, Table Value=12.6, $P \leq 0.05$

The association is significant

Analysis 5.2.4.1 epitomizes that as family income increases the feeling of isolation decreases. While 40% of the respondents in high-income group never feel isolated, the corresponding figures in middle-income group is 20.83% and low-income group is 17.30%. When one of the earning members falls ill and becomes bedridden, other adult members have to search for further income generating source. This virtually reduce the support given to the impaired one. If the chronically ill person is a member of a high-income family, there may be at least a paid assistance to take care of the patient. Also high income families are capable of providing him/her the latest digital gadgets to keep himself entertained, and help him keep in touch with his acquaintances.

Among the respondents from low income and middle income families, majority (66.24% and 60.42% respectively) sometimes feel isolated. The family care givers may need additional support system to deal with the situation. Palliative care workers play a big role in providing such a support system. To make a patient not feel lonely, a care-giver should listen to him as much as administering to his needs. Many people get an aura of protection when others are ready to hear what they have to say. However, every patient may not prefer to have listeners. Some may dislike to expose themselves to others in their pathetic condition. A palliative care worker should discern the attitude of the patient and create the type of ambience he or she needs.

Analyses of the relation of feeling of isolated existence with other variables namely age, gender, marital status, education, religion, family size and nature of disability were made but no association between the variables are revealed. So the details of the analyses are not given here.

### 5.2.5 Feeling of Mental Happiness

Patients with continual sickness will come across permanent adjustments in health status. This risk is carefully associated to psychological distress, such as depression. Feeling adequately supported when having a chronic sickness can also seem unattainable, in particular when you consider that chronic illnesses are long-lasting and can appreciably have an impact on individuals' life. Thus achieving mental happiness is difficult for those who depend upon their care givers for each and every issue concerned.

An analysis was done to find out the feeling of mental happiness among the respondents in the midst of their impaired condition. It is found that 55.67% of them feel happy even in the disadvantaged condition. But a considerable portion (39.67%) among them feel not at all happy and only a minuscule portion (4.67%) feel happy in the disabled situation.

### 5.2.5.1 Family Income and Feeling of Mental Happiness

Treatment of disease is very costly. The loss of income from the vocation of the incumbent when coupled with the expenditure for treatment the financial burden of the family become unbearable. Under this condition how can the patient and the family feel relaxed and happy? However those families with better income can absorb the burden to certain extent and feel relaxed. This logic prompts to assume that the family income of the disabled and their feeling of mental happiness are associated.

The study enquired into whether the family income of the respondents and their feeling of mental happiness are associated.

**Table 5.2.5.1: Family Income and Feeling of Mental Happiness**

| Family Income (Monthly in Rs) | Feel not happy | Feel somewhat happy | Feel happy | Total |
|---|---|---|---|---|
| Low (Below 5000) | 102 (43.04%) | 127 (53.59%) | 8 (3.38%) | 237 (100.00%) |
| Middle (5000-10000) | 16 (33.33%) | 29 (60.42%) | 3 (6.25%) | 48 (100.00%) |
| High (10000 and above) | 1 (6.67%) | 11 (73.33%) | 3 (20.00%) | 15 (100.00%) |
| Total | 119 (39.67%) | 167 (55.67%) | 14 (4.67%) | 300 (100.00%) |

Chi square= 15.16, df= 4, Table Value=13.28, $P \leq 0.01$

The association is significant

Analysis in Table 5.2.5.1 shows that the feeling of mental happiness of the respondents in general is influenced by their family income. While 43.04% of the respondents from low-income families feel not happy, only 6.67% of the high-income group says they feel not happy because of their diseased condition. Respondents from middle-income families show only a slight difference from the low-income group in their opinions.

Income level and mental happiness appear to be associated. High-income respondents have the highest percentage who feel happy (20.00%), followed by middle-income respondents (6.25%), and then by low-income respondents (3.38%). Correspondingly, low-income patients have the highest percentage (43.04%) who feel not happy. The strength of middle-income group is 33.33% and high-income groups is 6.67%. This is only to be expected because financial security gives a lot of comfort to people. Lack of money limits the opportunities for better treatment, better care and better material comforts.

Though income may mean different things to different people, especially at different ages and under different economic settings, it is a more or less accepted fact that having enough money for comfortable living gives life satisfaction even to ordinary people who are not sick at all. So, what we see in patients is probably just an extension of what they feel in normal life. Even for palliative care units to work well and give comfort to patients, money is required.

Anxiety and depression are commonly seen in many patients seeking palliative care. Dying patients may have problems about bequeathing property, writing a will, settling business matters, evicting a recalcitrant tenant, finding financial resources for supporting their parents or educating their children after their death. These are material problems for which solutions can be found by getting a lawyer (for bequeathing property), getting official/local help (for evicting a tenant), or starting a fund (for children's education after his death).

Palliative care volunteers, in many cases can manage these and the patient's mental condition will obviously improve as a result.

Analyses of the relation of the feeling of happiness with other variables namely age, family size, nature of disability and religion were made but no association between the variables are revealed. So the details of the analyses are not given here.

## Summary

When a patient becomes sick enough to need palliative care, his bodily condition may not be normal and he may face lot of discomforts due to the disabled bodily activities. Adding to this discomforts could be many other factors like income depletion, break from routine activities, lack of sleep, prolonged incapacitation, movement restrictions, and others. How an individual reacts to bodily symptoms—be the pain or any other indicator—depends on his or her past experience with illness, personality and coping styles, familial and cultural norms, and current interpersonal interactions.

How symptoms are supposed and the meaning attributed to them may, in turn, powerfully influence their consequent intensity and duration, the nature and extent of help-seeking behavior, and whether the person comes to view him-or herself as sick, weakened, and deserving of disability benefits (Osterweis et al, 1987). The concept of illness behavior arrange for a useful way of understanding and describing the many psycho-social impacts that affect how people monitor their bodies, define and understand their symptoms, come to view themselves as sick and disabled, take remedial action, and use lay and professional sources of help (Mechanic, 1978). Though the background variables are not seemed associated with the bodily symptoms of the patients there may be influences of different factors on the perceptions on bodily discomforts and their management.

The threat to bodily comforts and the potential changes ensuing in lifestyle and relations with others give rise to conflicts and anxiety which each patient handles unconsciously through various defensive maneuvers (Abraham, 1980).There are people who find life satisfaction even in their disabled condition and those who want to get their life prolonged probably because there are still things they aspire to witness. Most of the things like feeling of isolation, mental happiness, interest in socializing etc. are influenced by factors like gender, education, marital status, income etc.

However, all the bodily problems and psychological problems cannot have such material solutions and there palliative care workers help by diverting the patient's attention to better things or trying to make him more productive. Alongside the paid and professional staff, palliative care depend heavily on a significant volunteer workforce to help with the care of patients and their families both in the situation of the palliative care and in the community with much care now taking place in patients' own homes (Watts, 2012).

The research reveals that the patients undergoing palliative care are suffering from various physical and mental impairments. The major aim of palliative care services is to assist the individual undergoing these difficulties and their care taking families. It is to be inferred that the palliative care is relevant in Kerala context to provide physical care and mental consolation for those who do not need care from the medical agency as their services are not relevant for patients coming under this category.

# CHAPTER 6

# SOCIO-ECONOMIC CONDITIONS OF THE BENEFICIARIES

Patients with chronic illness or disability are not alone; ordinarily they have family, and friends and they often have social relationships and responsibilities. Their disadvantaged condition may have frequently distressing effects on these relationships and responsibilities. Social interactions greatly influence a patient's capability to cope with the struggles created by their illness or disability. Disruption of interpersonal relations can also lead to psychological distress in patients and vice versa. These disruption may be harmful to the coping mechanisms themselves. They may feel isolated even if they are among their family and friends.

The inference of a long term illness, for example, diabetes or coronary illness has extensive money related and social consequences for the individual, his family and the general public. The money related results are the prompt and aberrant costs spent on the exhausted individual. Direct costs blend cost of medicines, examination charges, and other vital charges. The anomalous costs consolidate loss of productivity of both the patient and a nearby relative or relative who needs to fill the role of the overseer.

Palliative care beneficiaries are able to avail social and economic support from the agency. As the principles of palliative care ensure the active total care for the beneficiaries it is understood that they provide care as each of its beneficiaries require. Individual encounters regarding the unhealthy condition may change from person to person according to their specific social and monetary atmospheres.

This chapter attempts to analyse the social and economic conditions of the beneficiaries of the palliative care.

## 6.1 Social Interactions

Initially, families of chronically ill people frequently react to severe illness by being over-protective and fostering the ill person's dependency and a sense of diminished competence. As the disease persists, due to the demands of new responsibilities, exhausted resources, and other facets of a changing lifestyle, families also feel fatigue. There are feelings of frustration, guilt, and helplessness in the network, often leading to the withdrawal of support, particularly as the capacity of the ill person to reciprocate support is impaired. Chronic illness has profound effects on social support and the social network of both the ill person and his or her family (Tilden and Weinert, 1987).

### 6.1.1 Reduction in Social Interactions

Individuals leading an ordinary social lifestyle may have many friends and relatives with whom they share their worries and find out relaxations. A chronically sick individual may not be involved or in a position to meet with their friends. From earlier studies, existing literature, experts' opinions and researcher's observations, it is found that the social network and interactions of the patients and their families are interrupted consequent to the desperate situation.

The study enquired into the habit of visiting the relatives and friends of the persons who are under the palliative care. The respondents were asked to reveal their interest to visit their family members and friends. Analysis 6.1.1.1 shows that only a miniscule segment of the sample (4%) are very much interested to conduct such visits.  An overwhelming majority of them (76.33%) show a lukewarm interest in such social visit. Almost 20% of the sample is not at all interested in such visits. So it may be concluded that the patients are somewhat interested to interact with others even if they are their family members or friends.

### 6.1.1.1 Age and Interest in Visiting Friends and Relatives

It is assumed that age status of the patients is a deciding factor of their interest in visiting their friends and relatives. According to the analysis contained in Table 6.1.1.1, the assumption is valid. Number of companions and friendships vary with age and pattern of keeping up relations in consistently testing life circumstances additionally varies. Tolerating the life challenging constant sickness and being adjusted with the crippled circumstance isn't the equivalent with all age groups. People who are confronting a dangerous circumstance may pull back from friendships and other social relations.

**Table 6.1.1.1: Age and Interest in Visiting Friends and Relatives**

| Age (in years) | Very much Interested | Somewhat Interested | Not interested | Total |
|---|---|---|---|---|
| 20-40 | 1<br>(5.26%) | 12<br>(63.16%) | 6<br>(31.58%) | 19<br>(100.00%) |
| 40-60 | 2<br>(1.89%) | 88<br>(83.02%) | 16<br>(15.09%) | 106<br>(100.00%) |
| 60-80 | 3<br>(2.07%) | 112<br>(77.24%) | 30<br>(20.69%) | 145<br>(100.00%) |
| 80-100 | 6<br>(20.00%) | 17<br>(56.67%) | 7<br>(23.33%) | 30<br>(100.00%) |
| Total | 12<br>(4.00%) | 229<br>(76.33%) | 59<br>(19.67%) | 300<br>(100.00%) |

Chi square= 27.18, df= 6, Table Value=16.81, P≤0.01

The association is significant

Analysis in Table 6.1.1.1 shows that while 31.58% of the respondents among 20-40 age group have no interest in visiting their friends, 20% of the respondents of age between 80 and 100 is very much interested in visiting their friends. Majority among the other two age groups (83.02% among 40-60 group and 77.24% among 60-80 group) are somewhat interested in visiting their friends.

Friendship is a relationship that may persist across the entire life cycle, playing a crucial role in preserving social connectivity in late life when other relationships may be abandoned, such as with co-workers and members of the organisation. Studies have consistently shown that friendships are as significant in predicting psychological well-being in adulthood and old age as family connections. (Bleiszner et al, 2019). This might be the reason for the interest of a sizable portion of the old (20%) showing keen interest in visiting their friends and relatives.

The respondents who are not interested in such visits among the youngsters (20-40 years) is about one third (31.58%) of the group. It may be explained as consequence of their depression caused by the seriousness of the disease. Palliative care workers are able to identify such introvert behavior seen among their beneficiaries. They help both the groups appropriately through arranging possible remedies.

### 6.1.1.2 Education and Interest in Visiting Friends and Relatives

Educational attainment gives a social status for each individual in society and everyone tries to make social relationships according to their accomplished status. Maintaining friendships also has been considerably influenced by the educational status of each individual. Visiting friends and relatives and spending time with them creates a relaxing mood for each and every one in stressful period.

Chronic illness undoubtedly fabricates stressful desperate conditions for individuals and their families. But dealing with this debilitated condition differs with each individual. Educational attainment of the chronically ill people may have an influence on the level of their social interactions. On the basis of the presumption an analysis was carried out as shown in Table 6.1.1.2

**Table 6.1.1.2: Education and Interest in Visiting Friends and Relatives**

| Education | Very much Interested | Somewhat interested | Not interested | Total |
|---|---|---|---|---|
| Illiterate | 1<br>(0.78%) | 103<br>(79.84%) | 25<br>(19.38%) | 129<br>(100.00%) |
| Primary | 4<br>(3.39%) | 92<br>(77.97%) | 22<br>(18.64%) | 118<br>(100.00%) |
| Secondary | 5<br>(13.51%) | 25<br>(67.57%) | 7<br>(18.92%) | 37<br>(100.00%) |
| College | 2<br>(12.50%) | 9<br>(56.25%) | 5<br>(31.25%) | 16<br>(100.00%) |
| Total | 12<br>(4.00%) | 229<br>(76.33%) | 59<br>(19.67%) | 300<br>(100.00%) |

Chi square=17.36, df= 6, Table Value=12.6, $P \leq 0.05$

The association is significant

Analysis in Table 6.1.1.2 reveals that as educational attainment of the respondents increase, their interest in visiting friends decrease. While 79.84% of the illiterate respondents show somewhat interest in visiting their friends or relatives, only 56.25% of the respondents having college education show interest in visiting their friends. Also almost equal percentages (18.64% and 18.92%) of the respondents among ‘Primary’ and ‘Secondary’ groups show no interest in visiting any friends or relatives. Educated individuals usually keep ties of friendship when compared to those who are not that much educated.

Maintaining friendship is not that much easy for less educated individuals who may be overburdened with bread winning works while educated individuals may be settled with secured jobs. They may have also better income and mobility than the other groups.

### 6.1.1.3 Marital Status and Interest in Visiting Friends and Relatives

Like 'Educational attainment', 'Marital status' also generates a specific social recognition for individuals. Persons who remain 'Unmarried', and people who had problematic marital relations (Separated/Divorced) may have stigma and such people hesitate to maintain social relations. Though they make friendships, they couldn't maintain them. Unlike those people mentioned above, 'Married' persons though they are widows/widowers may have confidence in their social recognition and they keep so many healthy relationships which help them to tide over the strenuous life situations. With this prevision, an analysis was carried out to see whether the marital status is associated with the habit of visiting the kith and kin.

**Table 6.1.1.3: Marital Status and Interest in Visiting Friends and Relatives**

| Marital Status | Very much Interested | Somewhat interested | Not interested | Total |
|---|---|---|---|---|
| Married | 11<br>(5.85%) | 150<br>(79.79%) | 27<br>(14.36%) | 188<br>(100.00%) |
| Unmarried | 0<br>(0.00%) | 22<br>(61.11%) | 14<br>(38.89%) | 36<br>(100.00%) |
| Separated/ Divorced | 0<br>(0.00)% | 9<br>(52.94%) | 8<br>(47.06%) | 17<br>(100.00%) |
| Widow/Widower | 1<br>(1.69%) | 48<br>(81.36%) | 10<br>(16.95%) | 59<br>(100.00%) |
| Total | 12<br>(4.00%) | 229<br>(76.33%) | 59<br>(19.67%) | 300<br>(100.00%) |

Chi square=23.48, df= 6, Table Value=16.81, $P \leq 0.01$

The association is significant

Analysis in Table 6.1.1.3 shows that majority of the ‘Married’ respondents (79.79%) and ‘Widow/Widower’ respondents (81.36%) are somewhat interested in visiting their friends and sharing their concerns. When compared to the ‘Married’ and ‘Widow/Widower’ respondents, ‘Unmarried’ and ‘Separated/Divorced’ respondents who are interested in visiting their companions are less in number (61.11% and 52.94% respectively).

De Paulo and Morris (2005) argue convincingly, research conducted over the past 20 years shows that unmarried persons are viewed as less likeable and more physically unattractive, lonely, and shy than their married peers. Single people are particularly likely to be denigrated if they are deemed “responsible” for their solitary civil status. Unmarried persons often are regarded as responsible for their single status due to some characterological flaw or “blemish,” such as promiscuity, immaturity, self-centeredness, or a lack of personal discipline (Byrne and Carr, 2005). Such stigma pulls individuals on singlehood back from social interactions, especially in life challenging debilitated situations.

These revelations are in consonance with the results of the study seen in Table 6.1.1.3. The married persons are supposed to be leading a normative life and here compared to other groups, they seem to be more interested be in contact with their friends and relatives. 5.85% of them are very much interested and 79.79% somewhat interested. The total strength come to around 86%. No other group shows such a strength in the compartments who are interested in visiting their friends and relatives. The others may be feeling some sort of disgrace to face their friends in their present marital and diseased condition.

### 6.1.1.4 Family Income and Interest in Visiting Friends and Relatives

Family income is a major factor which determine individual contentment. Family income decides the standard of life of each individual in our society. Individuals facing a life challenging disease may have extra expenses in connection with the treatment and medicines. Families which have a low income may struggle to maintain the economic status of their family especially if it has a member who is chronically ill. The patients from such economically struggling families may hesitate to meet and spend time with friends. Patients from families of high income may not have such intricacies and they seem to have some interest to spend time with their friends.

The analysis shown in Table 6.1.1.4 shows the association between family income of the respondents and their interest to visit their friends and relatives in the diseased or disabled condition

**Table: 6.1.1.4 : Family Income and Interest in Visiting Friends and Relatives**

| Monthly Family Income in Rs. | Very much interested | Somewhat Interested | Not interested | Total |
|---|---|---|---|---|
| Low<br>(Below 5000) | 6<br>(2.53%) | 184<br>(77.64%) | 47<br>(19.83%) | 237<br>(100.00%) |
| Middle<br>(5000-10000) | 2<br>(4.17%) | 36<br>(75.00%) | 10<br>(20.83%) | 48<br>(100.00%) |
| High<br>(10000 and above) | 4<br>(26.67%) | 9<br>(60.00%) | 2<br>(13.33%) | 15<br>(100.00%) |
| Total | 12<br>(4.00%) | 229<br>(76.33%) | 59<br>(19.67%) | 300<br>(100.00%) |

Chi square=21.48, df=4, Table Value=13.28, $P \leq 0.01$

The association is Significant

Analysis in Table 6.1.1.4 epitomizes that majority of the respondents of low income families (77.64%), middle income families (75%) and high income families (60%) express somewhat interest in visiting friends. When combining the number of respondents who show high interest and somewhat interest, we could understand that members of high income family constitute the major portion showing high interest or moderate interest in visiting friends and relatives.

There are several ways in which social relations can be influenced by income. Money allows consumption, which is a way to gain social status and making friendships. We can conceive of a lack of money as intrinsically linked to social stigma and feelings of shame, in line with the modern perception of poverty as an inherently social phenomenon, especially in richer countries (Ohls, 2015). In turn, this can lead to exclusion from social circumstances by others or self-exclusion in order to conceal one's economic condition or to escape potentially shameful circumstances. Moreover, involvement in social life is also directly dependent on material resources and on the economic capacity to engage in organised and unorganised social activities. By increasing conflicts and stress levels within the family, economic pressure may also have more indirect effects on social ties. (Conger et al., 1994); this may affect individual’s behaviour and wellbeing, which may in turn affect friendship relations (Hjalmarsson and Mood, 2015).

#### 6.1.1.5 Nature of Disability and Interest in Visiting Friends and Relatives

Nature of disability is a significant factor in determining the intensity of physical, psychological and socio-economic struggles of patients. Disabilities of the respondents are classified according to their Disabilities due to Old Age, Disabilities due to Disease and Disabilities due to both Old Age and Disease. Disabilities due to Old Age group only have disabilities related to their age. At the same time Disabilities due to Disease category consists of youngsters and middle aged patients with chronic illness. The third category Disabilities due to both Old Age and Disease is that of aged patients with chronic diseases. Impact of disabilities may differ in these three groups. Usually the 'Diseased' group may have more anxiety, depression and hopelessness than that of the other two groups. The level of social interaction also may be less among the 'Diseased group' because of the humiliation regarding role incompletion associated with the devastating situation. Thus the nature of disability may have impacts on the interest among the patients to visit their friend s and relatives.

Analysis given in Table 6.1.1.5 reveals the association between the variables.

**Table 6.1.1.5: Nature of Disability and Interest in Visiting Friends and Relatives**

| Nature of Disability | Very much Interested | Somewhat Interested | Not Interested | Total |
|---|---|---|---|---|
| Old Age related | 1<br>(5.88%) | 13<br>(76.47%) | 3<br>(17.65%) | 17<br>(100.00%) |
| Disease related | 7<br>(2.68%) | 202<br>(77.39%) | 52<br>(19.92%) | 261<br>(100.00%) |
| Both Old Age and Disease related | 4<br>(18.18%) | 14<br>(63.64%) | 4<br>(18.18%) | 22<br>(100.00%) |
| Total | 12<br>(4.00%) | 229<br>(76.33%) | 59<br>(19.67%) | 300<br>(100.00%) |

Chi square=12.92, df=4, Table Value=9.49, $P \leq 0.05$

The association is Significant

Analysis in Table 6.1.1.5 reflects that patients with disabilities of old age alone and both old age and disease constitute the major portion of the respondents who show interest in visiting friends. The portion of respondents who show very much interest in such visits are higher among those who have only age related disabilities (5.88%) and those who have both age related and disease related disabilities (18.18%) than the group who are in young age with disease related disabilities (2.68%).Youngsters who are having chronic disease may not have interest in visiting outsiders of their family. When compared to the ‘Aged’ (17.65%) and ‘Both Aged and Diseased’ (18.18%) respondents, the ‘Diseased’ respondents are slightly high in percentage (19.92%) who are not having any interest in visiting their companions.

A recent meta-analytical literature review compared young people's social functioning with and without chronic illness and found that young people with chronic physical illness have poorer social functioning compared to healthy peers. (Pinquart &Teubert, 2011). The effects were larger for diseases associated with larger impairments in functioning than diseases with smaller impairments in functioning. Although people have fewer friends in old age, the importance they give to friendship increases. They believe friendship help them to think positively to be stable even in deteriorating physical health (Retrieved from https://courses.lumenlearning.com).

### 6.1.2 Entertaining Visitors

It is usual in our society to visit the persons who are aged or chronically ill at their homes. Some people may not have the presence of mind to entertain such visits especially in the case of chronically ill. They might have been trying to avoid such meetings and interactions. Some other people may enjoy or they may be expecting someone to enquire about their condition or sharing something about the outside happenings as they are unable to come out even from their room. This study enquired into the interest of the respondents to entertain visitors. With this understanding the data were analysed as shown in Table 6.1.2.1. It is found that except a negligible portion (6.67%) the respondents are interested in entertaining visitors at their home. 69.67%

sometimes show interest in entertaining the visitors while 23.66% often interested in the matter. In the condition of declined social interactions due to their disabled status, it could be understood that most of them may be welcoming the people who come to their home.

### 6.1.2.1 Education and Interest for Entertaining Visitors

Educational attainment makes individuals more aware of their condition as diseased or disabled and they may have the ability to balance their physical and psychological disorders with their disabled condition. Also they may know the significant role that social interactions could play in such debilitated situations. At the same time people who have low education may think in a different way. They may feel such visiting as a burden to their family and they may not be interested in sharing their experiences to them. They may try their maximum to cover up their helpless conditions. The analysis given in Table 6.1.2.1 shows the association between the educational attainment of the respondents and their interest for entertaining visitors at their residence.

**Table 6.1.2.1: Education and Interest for Entertaining Visitors**

| Education | Never | Sometimes | Often | Total |
|---|---|---|---|---|
| Illiterate | 6<br>(4.65%) | 103<br>(79.84%) | 20<br>(15.50%) | 129<br>(100.00%) |
| Primary | 10<br>(8.47%) | 74<br>(62.71%) | 34<br>(28.81%) | 118<br>(100.00%) |
| Secondary | 4<br>(10.81%) | 21<br>(56.76%) | 12<br>(32.43%) | 37<br>(100.00%) |
| College | 0<br>(0.00%) | 11<br>(68.75%) | 5<br>(31.25%) | 16<br>(100.00%) |
| Total | 20<br>(6.67%) | 209<br>(69.67%) | 71<br>(23.66%) | 300<br>(100.00%) |

Chi square=13.54, df=6, Table Value=12.59, $P \leq 0.05$

The association is significant

Analysis 6.1.2.1 reveals that entertaining visitors is increasing with the respondents' educational attainment. According to the data analysed, illiterate respondents constitute the majority (79.84%) who sometimes entertain the visitors. But among the respondents who have attained secondary school and college education almost equal proportions are interested in accepting visitors at their residence (32.43% and 31.25% respectively). It is clear that the highly educated ones are more who find happiness in entertaining visitors when compared to the illiterate respondents.

There seems to be a direct association between the level of education and interest in entertaining visitors because among those with higher education 31.25% are seen to be interested in 'always' entertaining despite being sick. This percentage declines with declining education with illiterates having only 15.50% in that category. However, this direct association with education is not seen in the case of patients who like to entertain visitors sometimes or often.

Many patients love having visitors with whom they can share memories. Some patients might have done a lot of entertaining when they were healthy that they might find it difficult to stop that practice completely. Persons with higher education may consider social interactions more important than those with lower education. However visitors who can energize the disabled from the desperate condition are always encouraged by the palliative care members as such people do the responsibility to bring back the isolated to the normal social life.

### 6.1.2.2 Marital Status and Interest for Entertaining Visitors

As marital status assigns a socially recognized role for each individual, married persons (who live with their partner and also widow/widower) show some interest in social interactions and also maintaining social relationships.

Persons who remain unmarried and those who had problematic marital relations may not have interest in social interactions and they do not encourage visitors or guest frequently to their homes.

Chronically ill patients would have in need of a marital partner who can give all types of support in such a devastating life situation. Unmarried and Separated/Divorced condition make the patients feel lonely, hopeless and depressed. However their guilt feel makes them detached from friends, relatives and other societal members. At the same time ‘Married’ and ‘widow/widower’ respondents may be surrounded by friends, relatives and other social support systems and they can manage their stressful conditions associated with disease. With this prevision an analysis was done to verify the association between the marital status of the respondents and their interest for entertaining visitors at their residence.

**Table 6.1.2.2: Marital Status and Interest for Entertaining Visitors**

| Marital Status | Never | Sometimes | Often | Total |
|---|---|---|---|---|
| Married | 8<br>(6.36%) | 128<br>(68.09%) | 52<br>(27.66%) | 188<br>(100.00%) |
| Unmarried | 5<br>(13.89%) | 23<br>(63.89%) | 8<br>(22.22%) | 36<br>(100.00%) |
| Separated/ Divorced | 4<br>(23.53%) | 9<br>(52.94%) | 4<br>(23.53%) | 17<br>(100.00%) |
| Widow/ Widower | 3<br>(5.08%) | 49<br>(83.05%) | 7<br>(11.86%) | 59<br>(100.00%) |
| Total | 20<br>(6.67%) | 209<br>(69.67%) | 71<br>(23.66%) | 300<br>(100.00%) |

Chi square=19.18, df=6, Table Value=16.81, $P \leq 0.01$

The association is significant

Analysis 6.1.2.2 shows that among the respondents who never entertain visitors, ‘Separated/Divorced’ group constitute a higher portion

(23.5%).Majority among the ‘Married’ (68.09%) sometimes show interest to entertain the visitors while the rest among them often interested in the matter. Similarly the respondents among the ‘Widow/Widower’ constitute the majority (83.05%) in the compartment of those who sometimes entertain the visitors.

Probably because they are used to entertaining, married people seem to prefer to do so even when they are sick. Married people have the smallest percentage of respondents (6.36%) who never entertain visitors. The remaining portion of them entertain visitors to their residence often and sometimes. Even though unmarried people have a higher percentage (13.89%) of respondents than married who never entertains visitors, it appears that separated or divorced people are much more reluctant to have guests because there are 23.53% of them who never want to have visitors.

Single people are in most instances reluctant to entertain guests even when they are not sick. This could be probably because most of them manage with a simple setup without any elaborate cooking arrangements. And if he/she is arranging food for the visitors, a single person may find it difficult to talk to the visitors and at the same time manage the household activities. But with married people it is generally different. They have more hands to organize things, especially if there are growing children. Because of all this, they tend to entertain more.

Though unmarried people and separated/divorced people are essentially single, there is some difference between their single-hood. Unmarried may be sometimes younger and carefree, and may be having a lot of friends. Separated people, on the other hand, have become single after having experienced sharing and companionship once so that they may be experiencing a deep loneliness. This might be leading to an aversion of having visitors at their residence. However, among those who always entertain, the percentage of divorced/separated is the highest (17.65%). Further, it should also be taken into consideration that the number of respondents is very small in the case of separated and divorced people.

### 6.1.2.3 Family Income and Interest for Entertaining Visitors

Family income determines the standard of life of each family in our society. People with disabilities due to old age and chronic illness may have lot of expenses and most of the expenses maybe unexpected. To meet those expenses, the family with a member of disabilities or bedridden may struggle. Amidst such economic struggles, the patients may feel disappointed because of their helpless situations. The diseased or impaired normally will not enjoy others' company apart from their care givers. Analysis in Table 6.1.2.3 reveals whether family income of the respondents and their interest for entertaining visitors are associated.

**Table 6.1.2.3: Family Income and Interest for Entertaining Visitors**

| Family Income (Monthly in Rs.) | Never | Sometimes | Often | Total |
|---|---|---|---|---|
| Low<br>(Below 5000) | 14<br>(5.91%) | 166<br>(70.04%) | 57<br>(24.05%) | 237<br>(100.00%) |
| Middle<br>(5000-10000) | 3<br>(6.25%) | 38<br>(79.17%) | 7<br>(14.58%) | 48<br>(100.00%) |
| High<br>(10000 and above) | 3<br>(20.00%) | 5<br>(33.33%) | 7<br>(46.67%) | 15<br>(100.00%) |
| Total | 20<br>(6.67%) | 209<br>(69.67%) | 71<br>(23.66%) | 300<br>(100.00%) |

Chi square=12.714, df= 4, Table Value=9.49, $P \leq 0.05$

The association is significant

The analysis in Table 6.1.2.3 reveals that while majority of the respondents in low and middle income families (70.04% and 79.17% respectively) show some enjoyment in the arrival of visitors to their home, only 33.33% of respondents from high income family enjoy visitors' arrival. Families having a high income may have facilities to entertain the bedridden or chronically ill patient and so they may not require visitors for time pass or to get rid of from the bored lifestyle. Unlike the high income families, low and middle income families may struggle even for the treatment expense of the ill family member and consequently they may not have facilities to entertain the diseased family member. Patients in such families expect someone to visit them and spend some time with them.

### 6.1.2.4 Nature of Disability and Interest for Entertaining Visitors

Reasons for disabled condition are different for different individuals. While sometimes age creates some major impairment in the body and mind some chronic diseases may be the cause of such devastated conditions in individuals without considering their ages. Difference in the nature of disability makes difference in the perceptions of individuals on lifestyles and behaviours. Unusual and unexpected severe illness may produce desperate individuals who would like to withdraw from normal social life and activities including interacting with visitors.

An analysis was carried out to verify the assumption that the nature of disability of the respondents and their interest for entertaining visitors are associated.

**Table 6.1.2.4: Nature of Disability and Interest for Entertaining Visitors**

| Nature of Disability | Never | Sometimes | Often | Total |
|---|---|---|---|---|
| Old Age related | 0<br>(0.00%) | 13<br>(76.47%) | 4<br>(23.53%) | 17<br>(100.00%) |
| Disease related | 20<br>(7.66%) | 185<br>(70.88%) | 56<br>(21.46%) | 261<br>(100.00%) |
| Both Old Age and Disease related | 0<br>(0.00%) | 11<br>(50.00%) | 11<br>(50.00%) | 22<br>(100.00%) |
| Total | 20<br>(6.67%) | 209<br>(69.67%) | 71<br>(23.66%) | 300<br>(100.00%) |

Chi square=11.35, df= 4, Table value=9.49,$P \leq 0.05$

The association is significant

From table 6.1.2.4, it could be understood that only the respondents from the 'Diseased' group even if they constitute a small percentage (7.66%) responded that they never entertain visitors. On the other hand, when 100% of the respondents of the other two categories sometimes or often enjoy such visitors the 'Diseased' respondents are not able to find happiness in sharing their concerns or chatting with the visitors. Aged respondents may realise or accept their end of life situations when compared to the young or middle aged respondents. People in old age may thus encourage meeting with people they are related or connected.

It is clear from the table that there is not a single old patient for whom visitors are completely unwelcome. So old people, whatever their debilities are, seem to like having visitors at least sometimes, though most of them do not like to have visitors all the time. Companionship is important for the mental health of the elderly even if they are not sick. Loneliness is even said to promote Alzheimer's disease in the old. Palliative care workers, since they understand all these problems, encourage old care-receivers to converse with and entertain more people. As people get old, their social networks tend to collapse and when they get sick also, they become very insecure without companionship. Even if there are family members at home, old care-receivers may like to have visitors with whom they can share memories or discuss topics of common interest. If there are no family members also, these visitors become extremely crucial to their survival.

The reasons for entertaining or not entertaining guests are likely to be dependent mainly on the severity of their disease. Only 7.66% of them do not want to have visitors at all. This could be either due to their introversion or the fact that able-bodied human beings do not like others to see them in a pathetic state. A significant majority (70.88%) of them prefers to have visitors sometimes and it substantiates the fact that human is always a social animal. He can identify himself only as a part of a society.

Analyses with variables namely age, gender, family size and religion were made but since association between the variables are not revealed. So the analyses are not included in the report.

### 6.1.3 Affection shown by the Family to the Impaired

If a member in a family is chronically ill, it gradually affects the family relationships. Chronic illness may disrupt the normal moorings of the family system and they may create stress on family relations. Irregular expenses, long treatment duration, interrupted economic balance etc. may negatively affect the family and the chronically ill. Family members of the chronically ill may not be able to attend the patient all the time due to the normal responsibilities. As the patients may always need a support from their family, they may feel the family is neglecting them by do not attending to them properly.

The analysis in Table 6.1.3.1 shows that majority (73.67%) of the respondents feel the affection of their family on a medium level. However respondents who feel high level of affection from their family appears higher (19.67%) than those who feel the affection from the family as poor (6.67%).

### 6.1.3.1: Education and Feeling of Affection Shown by the Family

Educational attainment of the impaired may influence their emotional strength. Usually as educational attainment increases the ability to manage the variations in emotions also increases. It is assumed that the educational background of the impaired is influencing the feeling of affection of the family towards him/her. According to the analysis shown in Table 6.1.3.1, it is revealed the sustenance of the presumption. The results show that majority of the respondents belonging to all educational categories except college educated feel that the affection by the family towards them is lukewarm. In the case of the college educated category majority (62.50%) feel that the affection by the family is very high. Another projecting result in that as educational background of the respondents increases their feeling of affection shown by the family increases.

**Table 6.1.3.1: Education and Feeling of Affection Shown by the Family**

| Education | Poor | Medium | High | Total |
|---|---|---|---|---|
| Illiterate | 8 (6.20%) | 108 (83.72%) | 13 (10.08%) | 129 (100.00%) |
| Primary | 11 (9.32%) | 86 (72.88%) | 21 (17.80%) | 118 (100.00%) |
| Secondary | 1 (2.70%) | 21 (56.76%) | 15 (40.54%) | 37 (100.00%) |
| College | 0 (0.00%) | 6 (37.50%) | 10 (62.50%) | 16 (100.00%) |
| Total | 20 (6.67%) | 22 (73.67%) | 59(19.67%) | 300 (100.00%) |

Chi square=38.65, df=6, Table value=16.81, P≤0.01

The association is significant

Members of the family of ‘Primary’ and ‘Illiterate’ respondents may be busy with earning a livelihood while members of the family of highly educated members may have better economic balance when compared to the others and there may be someone to take care of the patient. Among the more-educated, there appears to be no one who feels that their family members are not affectionate to them. And 62.50% of them are convinced that their families’ attachment is quite high.

Quite often, a person who seeks palliative care because of disease may be young or middle-aged and may be in the prime of their life. At that stage, the attachment of family members to that person is bound to be high. Studies have shown that “serious illness will routinely activate affectionate behaviours in patients and family members, due to threats such as progressive physical disability, declining capacity for self-sufficiency, increasing dependency needs and threats of separation”(Milberg & Friedrichsen, 2017).

However, barring those with college education, others in all categories seem to feel that the affection of the family is at a medium level. It is believed that palliative care workers have a role to play here. “It seems important that palliative care teams are aware of what the repertoire of attachment figures may be, in order to facilitate deactivation of the attachment system and allow creative exploration among patients and family members during palliative care” (Ibid, 2017).

#### 6.1.3.2 Marital Status and Feeling of Affection Shown by the Family

Marital status is an important factor of individuals’ identity and socio-cultural position (Coombs, 1991).Generally the protective effects related to being partnered are accredited to the emotional and financial support provided by one’s spouse, as well as health -related social control (Rendall et al., 2011) and social integration and attachment (Umberson, 1987). In the study an analysis was carried on the presumption that the feeling of affection from the family members is associated with the marital status of the impaired.

**Table 6.1.3.2: Marital Status and Feeling of Affection Shown by the Family**

| Marital Status | Poor | Medium | High | Total |
|---|---|---|---|---|
| Married | 5<br>(2.66%) | 138<br>(73.40%) | 45<br>(23.94%) | 188<br>(100.00%) |
| Unmarried | 7<br>(19.44%) | 25<br>(69.44%) | 4<br>(11.11%) | 36<br>(100.00%) |
| Separated/ Divorced | 3<br>(17.65%) | 12<br>(70.59%) | 2<br>(11.76%) | 17<br>(100.00%) |
| Widow/Widower | 5<br>(8.47%) | 46<br>(77.97%) | 8<br>(13.56%) | 59<br>(100.00%) |
| Total | 20<br>(6.67%) | 221<br>(73.67%) | 59<br>(19.67%) | 300<br>(100.00%) |

Chi square=21.71, df=6, Table Value=16.81, P≤0.01

The association is significant

The analysis in Table 6.1.3.2 shows that those who feel high level of affection from the family is more among married respondents (23.94%) and the least among unmarried ones (11.11%). It is to be understood that affection got from the partner makes the difference. Further it can be seen that next after the married respondents comes those who are in the status of widow/widower. Their opinion might be influenced by the affection they received from their deceased partner in their impaired condition or otherwise. Again another interesting fact revealed in the analysis is that the proportion of high level affection received among the divorced/separated is equal to that of the unmarried. When all these matters are taken together, the partner in marital bond is an important agent who gives affectionate consideration to the impaired person. May be they have not received the affection in their disabled condition. Still they remember the regards they got earlier. So marital status influences the responses.

Some single people may be getting help from support networks and helpful organizations even when they are not sick and this may extend to the time of sickness also. While this is not family support, such arrangements have the power of reassuring relatives and thereby making them getting involved in patient care. Unmarried people have the highest percentage (19.44%) of respondents who claim to get poor attachment from the family. These may be middle-aged people whose parents are either no more or too old to provide family support. Palliative care workers need to provide extra support to them.

#### 6.1.3.3 Family Size and Feeling of Affection Shown by the Family

Family structure and system is facing major changes in our society. Persons with severe disabilities have no way other than depending on their family members. Family size of the patient has a significant role to play in coping with the disabled condition of one of the family members. The size of the family is assumed to influence the feeling of affection received from the family members. This is because of all the members show interest in supporting the impaired, he/she will get better care and consequently the disabled will feel better treatment affection from the family. Analysis to verify the association between the size of the family of the respondents and their feeling of affection from the family was carried out.

**Table 6.1.3.3: Family Size and Feeling of Affection Shown by the Family**

| Family Size | Poor | Medium | High | Total |
|---|---|---|---|---|
| Small<br>(2-4) | 13<br>(16.67%) | 54<br>(69.23%) | 11<br>(14.10%) | 78<br>(100.00%) |
| Medium<br>(5-7) | 5<br>(3.60%) | 103<br>(74.10%) | 31<br>(22.30%) | 139<br>(100.00%) |
| Large<br>(More than 7) | 2<br>(2.41%) | 64<br>(77.11%) | 17<br>(20.48%) | 83<br>(100.00%) |
| Total | 20<br>(6.67%) | 221<br>(73.67%) | 59<br>(19.67%) | 300<br>(100.00%) |

Chi square=18.01, df= 4, Table Value=13.28, P≤0.01

The association is significant

An analysis conducted on the basis of the above presumption (Table 6.1.3.3) shows that as family size increases the respondents' feel of affection shown by the family also increase. There is not much difference in the percentage of respondents from the medium size and large size families (74.10% and 77.11% respectively) who opined that there is a satisfactory level of affection by their family members. Respondents from the small family show considerable difference in percentage (69.23%) from the other two groups.

Affection of family members with the chronically ill or aged may resolve so many psychological problems of the patients. Patients in 'Small' family may lack the attention and affection of family members and hence the perceptions of the respondents in a different pattern.

Analyses with other variables namely age, gender, nature of disability, family income, and religion were made but since association between the variables are not revealed. So the analyses are not included in the report.

### 6.1.4 Interest in Attending Family Functions/Ceremonies

Attending functions/ceremonies in the family is a matter of interest and enjoyment of members in a family. Chronic illness or impairment related to old age may reduce interest in attending such functions. The study enquired into the interest of the respondents in attending such ceremonies and to interact with relatives and family friends during their incapacitated situation.

Analysis 6.1.4.1 shows that majority (74.33%) of the respondents are somewhat interested in attending such functions. Only a negligible portion (3.67%) shows very much interest in attending family functions/ceremonies. 22% of them are not at all interested in attending such functions in their impaired condition.

#### 6.1.4.1 Marital Status and Interest in Attending Family Functions/ Ceremonies

Marital partners may give all types of support to the bed ridden patients to maintain a normal social status. Patients who are living with their conjugal partners may show interest in attending family functions and other social situations because of the confidence developed by their spouses. Unmarried patients usually fail to maintain family and social relationships when compared to married ones. Among the respondents from ‘Separated/Divorced’ and ‘Widow/Widower’ groups ‘Widow/ Widower’ patients may have more interest in attending family functions and get together programs than the ‘Separated/Divorced’ patients. Analysis given in Table 6.1.4.1 shows the association between the marital status of the respondents and their interest in attending family functions/ceremonies.

### Table 6.1.4.1: Marital Status and Interest in Attending Family Functions/Ceremonies

| Marital Status | Very much interested | Some what interested | Not interested | Total |
|---|---|---|---|---|
| Married | 9<br>(4.79%) | 147<br>(78.19%) | 32<br>(17.02%) | 188<br>(100.00%) |
| Unmarried | 0<br>(0.00%) | 20<br>(55.56%) | 16<br>(44.44%) | 36<br>(100.00%) |
| Separated/ Divorced | 1<br>(5.88%) | 10<br>(58.82%) | 6<br>(35.29%) | 17<br>(100.00%) |
| Widow/ Widower | 1<br>(1.69%) | 46<br>(77.97%) | 12<br>(20.34%) | 59<br>(100.00%) |
| Total | 11<br>(3.67%) | 223<br>(74.33%) | 66<br>(22.00%) | 300<br>(100.00%) |

Chi square=17.36, df= 6, Table Value=12.6, $P \leq 0.05$

The association is significant

Analysis 6.1.4.1 epitomizes that marital status influences the respondents' interest in attending family functions. As majority (82.98%) of 'Married' respondents (taking the 1st and 2nd columns together) shows interest in attending family functions only 55.56% of 'Unmarried' respondents (when taken the two columns together) shows interest in such functions. Compared to the percentage (79.66%) of 'Widow/Widower' group, interested respondents from the 'Separated/Divorced' are less (64.7%).

While among unmarried people there seems to be no one who is very much interested in attending family functions, there are only small portions even in other categories with similar inclination. This is probably foreseeable because sick people may not have much inclination for participating in functions even if it is his or her own family. Married patients have the highest percentage (4.79%) in this category and they also have the smallest percentage

(17.02%) without any interest in participating in family functions. People generally love to celebrate special occasions because of the way such events are filled with positivity, become milestones in life, and provide a chance to mingle with people. Many people may be retaining this attitude to family functions even when they are sick.

Even at the stage when they are living a normal life, single people may be less interested than married people to entertain other family members and get entertained themselves by participating in family functions. This difference in interest may define these people when they are ill also. The proportion of those who are 'somewhat' interested in participating in family functions are more or less the same for married people (78.19%) and widow/widowers (77.97%). This statistics accentuates the similarity between these two groups because, widow/widowers, though single, might have liked to host functions and join functions when they were not single.

#### 6.1.4.2 Family Income and Interest in Attending Family Functions/Ceremonies

Though family functions create enjoyment and pleasure, there are some expenditure to both those who conduct the event and participants. To attend a family function there are several factors to be arranged. As a prestige issue everyone will be prepared to 'show off' their own standard of life in front of other members. To be presented neatly, to purchase valuable gifts and to reach the venue, there may be lot of expenditure to the participants. Chronically ill individuals and also their families may be in the middle of a huge expenditure. In such a situation they may hesitate to make expenses for attending family functions. Others who have no financial crisis may avoid such get-togethers due to lack of interest in exposing their disabled conditions to other relatives and family friends. Naturally it is to be assumed that the income status and interest in participating in the family functions are associated.

**Table 6.1.4.2 : Family Income and Interest in Attending Family Functions/Ceremonies**

| Family Income (Monthly in Rupees) | Very much interested | Some what interested | Not interested | Total |
|---|---|---|---|---|
| Low<br>(Below 5000) | 5<br>(2.11%) | 180<br>(75.95%) | 52<br>(21.94%) | 237<br>(100.00%) |
| Middle<br>(5000-10000) | 2<br>(4.17%) | 35<br>(72.92%) | 11<br>(22.92%) | 48<br>(100.00%) |
| High<br>(10000 and above) | 4<br>(26.67%) | 8<br>(53.33%) | 3<br>(20.00%) | 15<br>(100.00%) |
| Total | 11<br>(3.67%) | 223<br>(74.33%) | 66<br>(22.00%) | 300<br>(100.00%) |

Chi square=26.37, df= 4, Table Value=13.28, $P \leq 0.01$

The association is significant

Analysis in Table 6.1.4.2 shows 26.67% of the respondents who have a high family income are very much interested in attending family functions. Family income makes an individual confident to be presented in front of other family members where they have to show good appearance. When there is no satisfactory income in the family, the members altogether will withdraw from get together and functions of huge expenses. Moreover the unexpected expenditure created by the diseased/ disabled condition may prompt the patients from low income family to avoid unwanted expenses to be created by attending such ceremonies.

The rich generally lean towards pomp, show, and participation and could retain these wishes even when they are in declining health. But when it comes to the percentages of people having no interest at all in participating in family functions, the percentages are more or less the same, in high, middle, and low income groups, ranging between 20.00% and 22.00%. This is probably due to the fact that chronic illnesses could change the perception and mindset of patients in the same way across a wide income spectrum.

Many seriously ill patients are in denial– that is they like to act as if there is nothing wrong with them. This is the way they defend themselves against the painful realities to which they will have to eventually reconcile and succumb. Sometimes family members and palliative care workers categorize denial as a dysfunctional response because patients, who are in denial, refuse to take medicines, break many restrictions imposed by the doctor, and participate in functions with scant regard to their health condition. But others see it as a healthy coping mechanism of the mind. On the other hand, some fully accept the fact of their death or prolonged incapacitation. In such cases, palliative care workers disclose the prognosis of the disease to the patient. Those, who thus accept reality completely, are generally indifferent to partaking in celebrations and may prefer to use the available time in settling family matters or unfinished businesses. This could be the mindset that is functioning as a common denominator in the patients of different income groups and discouraging them to participate in family functions/ ceremonies.

Analyses with other variables namely age, gender, education, nature of disability, family size, and religion were made but association between the variables are not revealed. So the analyses are not included in the report.

### 6.1.5 Feeling of Attachment of Wider Society

As a social being each individual maintains social relationships. In normal social life, everyone can engage and maintain such relationships. But in a diseased and disabled condition, individuals withdraw from social interactions and feel marginalised from the normal social life. The ‘’Sick Role” developed by Talcott Parsons (Parsons, 1951) is an early but pervading sociological approach aiming to explain on how society deals with sick people.

Being sick is not simply a state of fact or condition, it contains a number of expectations expressed as rights and obligations (Leys, 2010). The study enquired about feeling of attachment of society among the respondents in their disabled condition. It is found that majority (76%) among the respondents feel attachment of society on a medium level. When 6.67% feel high level of attachment of their society 17.33% feel that their society's attachment as poor.

### 6.1.5.1 Education and Feeling of Attachment of Wider Society

Education makes everyone enlightened and they feel socially recognised than the illiterates. The feel of status attached due to their education level make even chronically ill to interact with their society without any hesitation. Such individuals even though they are keeping away from normal social life due to their illness, feel their society is there to support them and considers them as a dignified social being. On the other hand the patients who are illiterate or having lower level of education may already in a feel of inferiority among the societal members. Their disabled and desperate condition make them more hesitated to interact with people outside their family and automatically feel the society is detached from them. So an analysis was conducted to find out whether the perception that the educational status of the impaired and their feeling of attachment of the society with them are associated.

**Table 6.1.5.1: Education and Feeling of Attachment of Wider Society**

| Education | Poor | Medium | High | Total |
|---|---|---|---|---|
| Illiterate | 31(24.03%) | 95(73.64%) | 3(2.33%) | 129(100.00%) |
| Primary | 18(15.25%) | 96(81.36%) | 4(3.39%) | 18(100.00%) |
| Secondary | 3(8.11%) | 25(67.57%) | 9(24.32%) | 37(100.00%) |
| College | 0(0.00%) | 12(75.00%) | 4(25.00%) | 16(100.00%) |
| Total | 52(17.33%) | 228(76.00%) | 20(6.67%) | 300(100.00%) |

Chi square=40.03, df= 6, Table Value=16.81, $P \leq 0.01$

The association is significant

It is clear from the table 6.1.5.1 that educational level of the respondents has a significant association with their opinion about the attachment of wider society to them. 24.03% of ‘Illiterate’ respondents have the opinion that the attachment of society to them in their disabled condition is poor. Nobody in the group of ‘College’ say they have poor attachment with their society. As education level of respondents increases, their feel of attachment also increases.

According to Aristotle, human is a social animal and attachment to the larger society is one of the attributes that defines his/her existence. Barring a few hermits, no human being can detach himself/herself from the human society which regularizes and lays down the ground rules for human behavior. The most-educated category apparently had good participation in the wider society because there is no one in that group with feeling of poor attachment though they are presently in an impaired condition. However, the highest percentages in all educational categories feel a medium level of attachment the larger society to them.

Those who are availing palliative care are receiving a major contribution from society because palliative care is one of the finest aspects of modern society. While 25.00% of college-educated patients and 24.32% of secondary-school-educated people show a high level of attachment from the wider society, they might be acknowledging this involvement of society in their lives.

### 6.1.5.2 Family Income and Feeling of Attachment of Wider Society

The material circumstances under which individuals develop and live have a lasting effect on their personal and social identity and affect both the way they think and feel about their social environment and the main aspects of their social actions. (Manstead, 2018). Family which has high income status will have a particular recognition in society while low income families struggle to make a status in society. Individuals from a high income family always get recognised in society easily. Socially recognized persons naturally feel the society is attached to them. Analysis shown in Table 6.1.5.2 was done to find out the association between family income of the impaired and their feeling of attachment of society with them.

**Table 6.1.5.2: Family Income and Feeling of Attachment of Wider Society**

| Family Income (Monthly in Rs.) | Poor | Medium | High | Total |
|---|---|---|---|---|
| Low (Below 5000) | 45 (18.99%) | 179 (75.53%) | 13 (5.49%) | 237 (100.00%) |
| Middle (5000-10000) | 7 (14.58%) | 38 (79.17%) | 3 (6.25%) | 48 (100.00%) |
| High (10000 and above) | 0 (0.00%) | 11 (73.33%) | 4 (26.67%) | 15 (100.00%) |
| Total | 52 (17.33%) | 228 (76.00%) | 20 (6.67%) | 300 (100.00%) |

Chi square=12.78, df= 4, Table Value=9.49, $P \leq 0.05$

The association is significant

Analysis in Table 6.1.5.2 shows that family income of the respondents and their feel of attachment of the society to them has significant association. Respondents having low family income feel poor attachment of the society while those from high family income never feel the attachment of society to them that much poor. While 26.67% of the respondents from the family of high income feel their society's attachment to them as high, only 5.49% of the respondents having low family income feel such high attachment of the society.

High income families can easily maintain mainstream social relationships. The case is different with the lower income groups. They are always neglected and excluded from the mainstream society. Their condition worsens when one of such families has a chronically ill or bedridden member. They may feel more detached from their society.

Analyses with other variables namely age, gender, nature of disability, family size, marital status and religion were made but since association between the variables are not revealed. So the analyses are not included in the report.

### 6.1.6 Loss of Social Acquaintances

Chronic disease is indeed the kind of experience that disrupts the systems of daily life and the systems of knowledge that underpin them. This brings people, their families and larger social networks face to face with the soul of their relationships in stark form, undermining usual rules of reciprocity and mutual support. (Bury, 1982). In normal social life everyone has a lot many social acquaintances in different fields of life. But when individuals are having ill-health, it constrains them from maintaining such acquaintances and they become completely depend on their family members.

The analysis given in Table 6.1.6.1 reveals that, except a minuscule portion (5.33%) of the respondents, the rest of them feel that the social acquaintances they had are losing due to their impaired condition which restricts them from normal social interactions.

### 6.1.6.1 Family Size and Feeling of Loss of Social Acquaintances

It is assumed that family size of the respondents have an impact on the maintenance of social acquaintances they had before their impaired condition. Members of larger family may not consider interactions outside the family as important because there are many to take care of the disabled member. This may lead the disabled member to feel their social acquaintances are losing. The situation in a small family is different. The disabled may not be able to interact with more members and consequently they may try to interact with people outside the family. They may naturally feel their acquaintances are maintained by interacting with members outside their family. With this presumption, analysis to find out the association between family size of the respondents and their feeling of loss of social acquaintances was carried out.

**Table 6.1.6.1: Family Size and Feeling of Loss of Social Acquaintances**

| Family Size | Very much | Somewhat | Not at all | Total |
|---|---|---|---|---|
| Small<br>(2-4) | 20<br>(25.64%) | 49<br>(62.82%) | 9<br>(11.54%) | 78<br>(100.00%) |
| Medium<br>(5-7) | 27<br>(19.42%) | 106<br>(76.26%) | 6<br>(4.32%) | 139<br>(100.00%) |
| Large<br>(More than 7) | 26<br>(31.33%) | 56<br>(67.47%) | 1<br>(1.20%) | 83<br>(100.00%) |
| TOTAL | 73<br>(24.33%) | 211<br>(70.33%) | 16<br>(5.33%) | 300<br>(100.00%) |

Chi Square=13.07, df= 4, Table Value =9.49; P≤0.05

The association is significant

From Table 6.1.6.1, it could be understood that while 11.54% of the respondents from ‘Small’ families opines that they have not at all lost their social acquaintances due to their disabled condition, only 1.20% of the members from ‘Large’ families makes the same opinion. ‘Medium’ and ‘Large’ families have more members to attend to the diseased or bedridden respondents and there may be lacking interactions with people outside their family. In ‘Small’ families, the shortage of members to stay with the diseased or bedridden member creates situations of interactions with friends and other people outside the family. Thus such people may not feel like losing social acquaintances.

In order to preserve the quality of life, individuals and families handling the difficulties of life-limiting disease need sufficient social support. Previous research reports also reveal that the social support received in palliative care interventions such as home care and community therapies is highly appreciated by the patients. In the programme, social assistance was specifically implemented. The recipients of palliative care reported high perceived levels of support and accessibility from members of the Palliative Care team, and many expressed comfort in obtaining additional help from members of the team. Notably, the team was considered by participants to be accessible either at home or at the clinic according to the convenience.

Analyses with other variables namely age, gender, marital status, education, nature of disability, family income, and religion were made but since association between the variables are not revealed. So the analyses are not included in the report.

## 6.2 Economic Struggles

Chronic illnesses are slowly becoming more prevalent worldwide. The implications and effects of these diseases differ and in several cases affect not only the patient, but the entire household. As a result of major lifestyle changes, reduced mortality rates, increased survival, and an improvement in health care in many countries, these chronic and steadily progressive diseases are becoming increasingly prevalent. Consequent implications include a higher medical bill which can lead to economic impoverishment (which is broadly defined as a process of household income and asset depletion which cause consumption levels to fall below minimum needs). Chronic illnesses have been associated with debility and this can have damaging or severe economic implications on the individual and his/her family as they normally deprive individuals of their productivity and health potentials (Okediji et al., 2017).

### 6.2.1 Economic Stability

One of the greatest burdens on the family of chronic patients is the financial cost. This can include treatment costs, transportation cost, the cost of hiring a caregiver, and adapting their home environment (Golics et al., 2013). Being economically stable is difficult for a family where such costs may create imbalance in the family economy. Unexpected and unmanageable expenses may constrain the family to maintain economic stability.

It is found in the analyses that the lion’s share (85.67%) of the respondents feel no economic stability in their life especially in the disabled condition. When 10 % of them feel somewhat stability in their economic condition only 4.33% feel their economic condition is very much stable even in the disadvantaged condition.

#### 6.2.1.1 Religious Affiliation and Feeling of Economic Stability

Way of life of individuals in different religious beliefs differs. The difference in the lifestyles of individuals in different religions may have impact on their economic and social life. While some religions give importance to economic prosperity, some others don’t have such aspirations. The economic activities of religious group may differ. In the essays on Protestant Ethics, Weber (1905) argues that religious values and traditions contributed greatly to the decline of economic traditionalism and the rise of modern rational capitalism. His study shows that the economic actions of its adherents can be influenced by a single sect of religion. Weber suggests that the Calvinist sect of the Protestant Christian faith has the greatest impact on capitalist creation (Zafirovski, 2018).

These differences in focuses strongly influence their members in maintaining the economic stability in their life. Even if the spending on medical treatment does not depend on religious ethic, the total management of family income may be influenced by the religious background.

Hence an analysis was carried out to assess the financial stability of the family of the patients belonging to different religious groups. The analysis is shown in Table 6.2.1.1.

**Table 6.2.1.1:Religious Affiliation and Feeling of Economic Stability**

| Religion | Very much Stable | Somewhat Stable | Not stable | Total |
|---|---|---|---|---|
| Hindu | 10<br>(5.03%) | 14<br>(7.04%) | 175<br>(87.94%) | 199<br>(100.00%) |
| Muslim | 0<br>(0.00%) | 6<br>(9.52%) | 57<br>(90.48%) | 63<br>(100.00%) |
| Christian | 3<br>(7.89%) | 10<br>(26.32%) | 25<br>(65.79%) | 38<br>(100.00%) |
| Total | 13<br>(4.33%) | 30<br>(10.00%) | 257<br>(85.67%) | 300<br>(100.00%) |

Chi Square= 17.98, df= 4, Table Value =13.28, $P \leq 0.01$

The association is significant

Majority of the Hindu (87.94%), Muslim (90.48%) and Christian (65.79%) respondents have opined that the economic condition of the family is not very stable due to their ill health and the spending on treatment. When considering the majority among all the three religious groups, the percentage of Christian respondents who opined about the unstable economic condition is lesser. And among the respondents who opined that they are economically very stable, Christian respondents have an upper hand though the percentage strength is only 7.89%. People who balance the income and expenditure well, may able to face a challenge which may economically affect their family. Families having no such income and expenditure balance may face economic instability frequently, especially in life challenging situations.

Financial crisis is something that no one wants for himself, but still happens in too many instances. Medical treatment is excruciatingly expensive, and can tilt the delicate economic balance of even those families that could otherwise be managing reasonably well. If the situation of the family was not good even before one of the members fell ill, then the situation would significantly affect the economic stability of the family. Majority of the respondents from all religions have acknowledged that their families have come to very difficult times financially as a result of their illness. However, Christians have lesser strength among this group (65.79%) and they have the highest percentage (7.89%) of respondents who seem to be confident of their finances, and the highest percentage (26.32%) again among those who are ‘somewhat’ stable. What we can assume is that Christian patients may probably be richer than those of other communities; or they may be getting community help via churches; or they might have wisely invested in medical insurance. The findings again reinforce the concepts of Weber on religion and economy.

### 6.2.1.2 Education and Feeling of Economic Stability

Education has been fostering the types of learning that enable individuals to better deal with and balance life affairs. It is a common expectation that higher level of education reaps higher level of financial stability to individuals (Menard, 2014). It is to be assumed that respondents who are having higher level of education may have secured jobs and payments for making savings for future. Such people may able to face sudden and unexpected expenses due to chronic illness and treatment.

Education makes us aware of the life situations and how to make a balance between our income and expenditure. The awareness getting from our education also makes us ready to face life challenging situations like chronic disease and bedridden condition of an earning member in our family. Most of the people who have lower level of education may be stunt before the unexpected tragedy came to their life in the form of chronic, life threatening illness of any one of their family.

With this assumption an analysis was carried out to verify the association between the educational attainment of the respondents and their feel of economic stability.

**Table 6.2.1.2:Education and Feeling of Economic Stability**

| Education | Very much Stable | Somewhat Stable | Not stable | Total |
|---|---|---|---|---|
| Illiterate | 1 (0.78%) | 9 (6.98%) | 119 (92.25%) | 129 (100.00%) |
| Primary | 2 (1.69%) | 11 (9.32%) | 105 (88.98%) | 118 (100.00%) |
| Secondary | 8 (21.62%) | 6 (16.22%) | 23 (62.16%) | 37 (100.00%) |
| College | 2 (12.50%) | 4 (25.00%) | 10 (62.50%) | 16 (100.00%) |
| Total | 13 (4.33%) | 30(10.00%) | 257 (85.67%) | 300 (100.00%) |

Chi Square =44.10, df= 6, Table value=16.81, P≤0.01

The association is significant

It is clear from Table 6.2.1.2 that there is a significant association between the respondents' educational attainment and their opinion about the economic stability of the family. While 92. 25% of 'Illiterate' respondents and 88.98% of the respondents having 'Primary' education opined that their families are facing economic instability, only 62.16% of the respondents having 'Secondary' education and 62.50% of the respondents having 'College' education are having similar opinion. People who are having high level of education can easily maintain the financial situation of their family when compared to people having low level of education. Among secondary-school-educated respondents, 21.62% feel that their family is economically quite well. The corresponding figure in the case of the College educated group is 12.50%. Among illiterates and primary-school-educated respondents, the percentage of those having a sound financial background is very low, being 0.78% and 1.69% respectively. Nevertheless, it is quite good to see that at least small percentages of patients, with low levels of education, have strong financial status. Free medical aid, insurance cover, and strong family help may be the reason for their better economic background.

### 6.2.1.3 Family Income and Feeling of Economic Stability

Major cause of economic instability is the low income of a family. Even if in normal life situations, members of a family of low income struggle to fulfill its basic needs by themselves. Then it is very much strain full for them to manage the expenses due to the withdrawal of earning member from his/her work because of the life threatening illness. Not only the decrease in income matters the family but also the extra expenses for the treatment of the chronically ill family member make the family economy totally unstable. With this presumption, analysis to find out whether family income of the respondents and their feel of economic stability was carried out.

**Table 6.2.1.3: Family Income and Feeling of Economic Stability**

| Family Income (Monthly in Rs.) | Very much Stable | Somewhat Stable | Not Stable | Total |
|---|---|---|---|---|
| Low<br>(Below 5000) | 3<br>(1.27%) | 11<br>(4.64%) | 223<br>(94.09%) | 237<br>(100.00%) |
| Middle<br>(5000-10000) | 1<br>(2.08%) | 15<br>(31.25%) | 32<br>(66.67%) | 48<br>(100.00%) |
| High<br>(10000 and above) | 9<br>(60.00%) | 4<br>(26.67%) | 2<br>(13.33%) | 15<br>(100.00%) |
| Total | 13<br>(4.33%) | 30<br>(10%) | 257<br>(85.67%) | 300<br>(100%) |

Chi Square=15.87, df= 4, Table Value=13.28, P≤0.01

The association is significant

It is obvious from table 6.2.1.3 that while majority (60%) of the respondents from high income family opined that their family is very much stable in its economy even if in their disabled or bedridden condition, 94.09% of the respondents from families of low income opine that their families are facing economic instability due to their ill health or bedridden condition. Majority (66.67%) of the respondents from middle income family also opines about the economic instability of their families.

Quiet according to our expectations it is seen that the higher the family income, the higher the feeling of economic security of the respondents. But the interesting fact here is that a small percentage (1.27%) of low income patients feels financially secure while a slightly bigger percentage (13.33%) of high-income patients feels economically unstable.

One possible explanation for this anomaly is that people's perception varies about what financial security is. Some people may need a significant amount of wealth to feel financially secure, especially when they no longer feel productive, and some rich people remain worried about losing their wealth. Another viewpoint is that "insecurity about wealth among the wealthy might come from a poor sense of self-worth, or an underlying sense of shame or feeling of being undeserving or incapable of owning so much wealth. Financial insecurity among the wealthy is now diagnosed and treated as a mental illness" (Shashikant, 2017).

The explanation for a small percentage of low-income patients feeling financially secure, the explanation is that they may have limited requirements. They do not need fancy cars and foreign tours to feel rich, but only enough to meet their basic needs satisfactorily. Another fact is that the sense of safety provided by the family's attitude could influence a person and make him feel financially secure. Finally, some people who show their income as low as they have limited income of their own, may be being supported fully by their children. This would surely make them feel financially secure.

Analyses with variables namely age, gender, nature of disability, marital status and family size were made but since association between the variables are not revealed. So the analyses are not included in the report.

### 6.2.2 Sufficiency of Income for Maintenance of Treatment

A chronic illness or bedridden condition of a family member may create economic imbalances in the family. The family income may not be sufficient to maintain the normal standard of life. Lower income family may struggle to manage the treatment expenses which are unexpected. They may not be able to fulfill their daily expenses also. Each one of the family may sacrifice his/her personal economic requirements to balance the total family finance.

Sufficient income is mandatory even when one is not sick, though what is sufficient income may be different for different people. Further, when an individual says that he does not have sufficient income it does not just mean that his current income is inadequate. It may also imply that he has no savings to fall back upon, that his/her future is uncertain, and that there is no guarantee of a continued income. He may also need more income to protect himself against threats like possible illnesses or natural disasters. This sort of uncertainty about income sufficiency increases very much when one becomes sick and is unable to contribute to the family income.

In order to find out the financial burden faced by the family, particularly due to the disablement of the incumbent the respondent was asked whether there is any difficult being felt to satisfy the treatment related expenses. The elicited responses are analysed as shown in Table 6.2.2.1

Analysis in Table 6.2.2.1 shows that majority (92.67%) of the respondents feel that their income is not sufficient to maintain their treatment related cost. Only a negligible portion (7.33%) of the respondents feel their income is sufficient to maintain the treatment related expenses.

### 6.2.2.1: Education and Feeling of Sufficiency of Income for Maintenance of Treatment

It is understood that educational qualification makes individuals able for better job and payment capacity and thus maintain the treatment expenses. On the other hand illiterate and people having lower educational qualification will not have a secured job and reasonable payment capacity to maintain the expenses occurred due to the treatment for either a chronic illness or disability.

We can expect a higher percentage of people with good education to have sufficient income than those with lesser education. Even if it could be so, the overall percentage of those who feel that their income is insufficient appears to be very high, being 92.67%. It could possibly mean that the illness-related mental condition has changed many people's perspective of what is sufficient income because physical disabilities can become big money drainers. Another reason for the high proportion of respondents with insufficient income is probably that the overall income level of the respondents were chosen is not high.

Analysis was done to verify whether the educational attainment of the respondents and their feel of sufficiency of income are associated.

**Table 6.2.2.1: Education and Feeling of Sufficiency of Income for Maintenance of Treatment**

| Education | Sufficient | Not Sufficient | Total |
|---|---|---|---|
| Illiterate | 5<br>(3.88%) | 124<br>(96.2%) | 129<br>(100.00%) |
| Primary | 6<br>(5.08%) | 112<br>(94.92%) | 118<br>(100.00%) |
| Secondary | 7<br>(18.92%) | 30<br>(81.08%) | 37<br>(100.00%) |
| College | 4<br>(25.00%) | 12<br>(75.00%) | 16<br>(100.00%) |
| Total | 22<br>(7.33%) | 278<br>(92.67%) | 300<br>(100.00%) |

Chi square=17.80, df= 3, Table Value=11.35, $P \leq 0.01$

The association is significant

The analysis in Table 6.2.2.1 reveals that as educational level of respondents varies, their opinion about sufficiency of income for maintenance also varies. When 96.2% of 'Illiterate' respondents and 94.92% of the respondents who are having primary education opine that the family income is not sufficient for their maintenance.75% of the respondents having 'College' education opine that family income is not sufficient for their maintenance.

As can be expected, those with higher education have the highest percentage (25.00%) of respondents who feel that they have sufficient income. This percentage decreases with decreasing education, becoming a mere 3.88% in the case of illiterates. While this situation can be understood, it is rather surprising that only 25.00% of even the higher (college) educated respondents have sufficient income. The remaining 75.00%, despite their higher education, do not appear to be able to find the sufficient financial resources for sustaining the family and meeting the expenses of the treatment. It indicates that mere education is not sufficient to ensure a satisfactory income. It is probably only a combination of assets and entrepreneurial skills besides mere education that would ensure a satisfactory income.

However, there are also illiterate people who claim to have sufficient income. It could be hereditary assets or well-earning children that give them income sufficiency. There is the viewpoint that we should not equate lack of education with lack of income or lack of initiative. Many uneducated people are quite successful in life because they are ready to take more risks. When a person is "at the rock bottom, the urge to succeed in life is very strong…people with education do not push that hard as people without education" (Yadav, 2018).

#### 6.2.2.2 Family Income and Feeling of Sufficiency of Income for Maintenance of Treatment

A family having high income can easily maintain a bedridden or chronically ill patient when compared to a low income family. A low income family may be struggling to manage even their day-to-day expenses. In between the extra expenses created by the treatment and caring of the ill family member may mess up the total economic budget of the family.

An individual's income is the money he receives in return for the goods or services he provides. Income can also be generated by investing money in a bank, in real estate, in company shares etc. The latter method is relied upon by people for augmenting their earnings or to provide themselves with an income when they are no longer able to work.

When disease strikes one member of the family, expenses increase, thereby upsetting the economic budget of the family. When the stricken person was an earning person as well, this change will be drastic and will affect the level of care that the family can provide for the patient and the patient's own mental condition. Analysis was done to check whether the family income of the respondents and their feel of sufficiency of income are associated.

**Table 6.2.2.2: Family Income and Feeling of Sufficiency of Income for Maintenance of Treatment**

| Family Income (Monthly in Rupees) | Sufficient | Not Sufficient | Total |
|---|---|---|---|
| Low (Below 5000) | 10<br>(6.32%) | 227<br>(95.78%) | 237<br>(100.00%) |
| Middle (5000-10000) | 7<br>(14.58%) | 41<br>(85.42%) | 48<br>(100.00%) |
| High (10000 and above) | 5<br>(33.33%) | 10<br>(66.67%) | 15<br>(100.00%) |
| Total | 22<br>(7.33%) | 278<br>(92.67%) | 300<br>(100.00%) |

Chi Square=22.02, df= 2, Table Value=9.21, $P \leq 0.01$

The association is significant

Analysis 6.2.2.2 reveals clearly that there is a significant association between the family income and their opinion about the sufficiency of income for their maintenance. When 33.33% of the respondents from families of high income opined that their family income is sufficient for their maintenance, only 6.32% of the respondents of low income families opined the same manner.

Those with high family income are bound to be satisfied with their financial soundness and it is clearly seen that there is a direct correlation between the level of income and satisfaction about the income. Further, even in the high-income group, only one-third of the respondents find their income sufficient. So it is understood that illnesses strain the financial resources of most people to a significant extent.

Ironically, 6.32% of low-income patients find their income sufficient. They may be satisfied with less, or may be having additional sources of support which are not counted as their income. Some low-income patients may be living in an ambience that gives them a sense of safety and this may be reinforcing their sense of income sufficiency. “People at the lower end of the income scale take more pleasure in their relationships and enjoy caring for and connecting with others” while “the positive emotions experienced by people with higher incomes are mainly focused on themselves” (Scutti, 2018).

Analyses with variables namely age, gender, marital status, nature of disability, family size, and religion were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

### 6.2.3 Economic Deterioration of the Family

Chronic illness of a family member is one of the major causes of a family’s economic deterioration. Family which depends fully on the member who fell ill be more easily deteriorate economically when compared to a family in which a non-earning member became bedridden. “Financial protection—a core element of universal health coverage—aims to ensure that people receive the health care services they require without facing financial ruin” (WHO, 2010).

The efficiency of both the sick person and a family caregiver may also be reduced by ill health, resulting in the loss of paying jobs or educational and other opportunities. Such factors seriously hinder the ability of the family to gain income in both temporary and longer-term ways. The household must mobilise resources to pay for health care, often by borrowing money, using limited savings, and selling assets when faced with ill health, especially unexpected events, which can negatively disturb the long-term economic well-being of the family, including its ability to manage with ongoing health care needs and future health issues (Essue et al., 2017).

It is found from the analysis (Table no. 6.2.3.1) that majority (72.33%) of the respondents perceive that their family is very much deteriorated economically after they got disabled. While 20.67% of them perceive their family is somewhat deteriorated economically, only 7% of them perceive their family is not at all deteriorated economically due to their disadvantaged condition.

#### 6.2.3.1 Education and Perception on the Economic Deterioration of the Family

Higher education of family members elevates the family status to a high position in the society. The individuals having higher educational qualifications may have strategies to balance the economic condition of their family and thus they may be able to protect their family from economic deterioration. Even if they have to face challenging situations, they would be easily overcome with their ability to tackle the same. People having low education level may be scared of the future of their family if they caught with a chronic disease. It is not easy for them to recover the economic imbalance created by the life threatening disease. Analysis shown in Table 6.2.3.1 was done to verify the association between educational attainment of the respondents and their perception on the economic deterioration of their family.

## Table 6.2.3.1: Education and Perception on the Economic Deterioration of the Family

| Education | Very much Deteriorated | Somewhat Deteriorated | Not at all Deteriorated | Total |
|---|---|---|---|---|
| Illiterate | 106 (82.17%) | 20(15.50%) | 3(2.33%) | 129(100.00%) |
| Primary | 86 (72.88%) | 25(21.19%) | 7(5.93%) | 118(100.00%) |
| Secondary | 19(51.35%) | 11(29.73%) | 7(18.92%) | 37(100.00%) |
| College | 6(37.50%) | 6(37.50%) | 4(25.00%) | 16(100.00%) |
| Total | 217(72.33%) | 62(20.67%) | 21(7.00%) | 300(100.00%) |

Chi Square=31.14, df= 6, Table Value=16.81, $P \leq 0.01$

The association is significant

Analysis in Table 6.2.3.1 reveals that educational level of the respondents has an influence on their opinion about the economic deterioration of the family consequent on the prolonged illness of a family member. While 82.17% of the 'Illiterate' respondents opine that their family is very much economically deteriorated, only 37.50% of the respondents of 'College' education level has the same opinion.

As we have already seen, when illness subdues one member of the family, the economic impact of it on the whole family can be quite severe. The patient himself would be extremely conscious of it, but the extent to which it affects him may be influenced by his level of education. As expected, the highest percentage of patients (25.00%), who feel that the economic condition of the family has not deteriorated at all, belong to the highly-educated category. The percentage is declining progressively with the level of education is decreasing and only 2.33% of illiterates confirming the same. This can be attributed to their mental courage or to owning assets that can compensate for a reduced monthly income.

### 6.2.3.2 Family Income and Perception on the Economic Deterioration of the Family

As family income decreases, the possibility to be deteriorated economically increases. High income family may easily manage the expenses due to the chronic illness condition of one of its members. At the same time, a low income family may incur debt from various sources for the treatment expenses. If the member who fell ill was one of the earning members in the family, withdrawal of that member from working and earning might seriously affect the economic balance of the family.

With this presumption, an analysis was carried out to verify the association between family income of the respondents and their perception on the economic deterioration of the family.

**Table 6.2.3.2: Family Income and Perception on the Economic Deterioration of the Family**

| Family Income (Monthly in Rupees) | Very much Deteriorated | Somewhat Deteriorated | Not at all Deteriorated | Total |
|---|---|---|---|---|
| Low<br>(Below 5000) | 180<br>(75.95%) | 46<br>(19.41%) | 11<br>(4.64%) | 237<br>(100.00%) |
| Middle<br>(5000-10000) | 33<br>(68.75%) | 13<br>(27.08%) | 2<br>(4.17%) | 48<br>(100.00%) |
| High<br>(10000 and above) | 4<br>(26.67%) | 3<br>(20.00%) | 8<br>(53.33%) | 15<br>(100.00%) |
| Total | 217<br>(72.33%) | 62<br>(20.67%) | 21<br>(7.00%) | 300<br>(100.00%) |

Chi Square=54.42, df= 4, Table Value=13.28, P≤0.01

The association is significant

The analysis in Table 6.2.3.2 shows that family income and the respondent’ opinion about the economic deterioration of the family is very much associated. While majority (75.95%) of the respondents from low income family see that their family is economically deteriorated after their diagnosis and treatment for the disease, majority (53.33%) of the respondents from high income family opines that their family income not at all deteriorated after the diagnosis and treatment for the serious illness.

Chronic diseases have thus been found to inflict high and devastating costs on patients and their households. The lack of appropriate coping mechanisms points to the need for policymakers to expand access to specialised services and to increase formal health insurance coverage in order to improve the substantial economic effects of chronic diseases on the households as a whole.

The task for palliative care staff in the developing world is to build a framework for long-term care and palliative care that is culturally and socio-economically relevant and suitable and available to most people who need it. Network Neighbourhood in Palliative Care (NNPC) groups usually work attached with the existing Palliative Care services in their area. To check up on the patients seen by the Palliative Care team, volunteers from these organisations make daily home visits. They consider and discuss a number of non-medical concerns, including financial issues, patients in need of treatment, coordinating community awareness events, and raising funds for Palliative Care services. Financial support by providing medicines free of cost, monthly kit of rice and provisions, arranging other accessories like wheel chair, water bed, airbed etc., the agency try to reduce the expenses associated with the long term care of the disabled.

Analyses with variables namely age, gender, marital status, nature of disability, family size, and religion were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

## Summary

Social interactions for a human being is indispensable. Among individuals who are leading a normal social life may sometimes be disabled with some chronic illness or old age related problems. Consequently the social interactions of such persons may be interrupted. The analyses on the interest of making social interactions were done in the first section of the chapter.

It is well understood that a good portion of the patients have interest in making social relationship and maintaining the existing ones. They are also having the feel that they are losing their social acquaintances due to their lack of interactions due to the disabled condition. Most of them are somewhat interested in visiting friends and entertaining visitors at their home. Some of them feel guilt to face their friends and discuss their desperate condition.

Similarly financial circumstances of an individual and the family may be affected due to the impaired condition of one of the members in the family. Analyses were done to find out how the respondents perceive their economic stability in the midst of the disadvantaged condition, their perception on the economic deterioration of the family after they get impaired and their feel of sufficiency of income to maintain the treatment related expenses.

It is found that most of them perceive that their economic stability is lost. Larger portion of the respondents feel their income as insufficient to maintain the expenses and almost all of them opined that their family is economically deteriorate due to the huge expenses associated with the treatment and medications.

Palliative Care is availed by the beneficiaries to reduce such economic burdens and to get social support. Principles of palliative care oblige them to provide the type of care as the beneficiary requires. Active total care envisioned by the agency may be fulfilled only if the actual type of care required by the beneficiaries is revealed.

# CHAPTER 7

# PERCEPTIONS ON THE STRESS OF CARE GIVERS

In Kerala's Palliative Care system, the responsibility of caring the patients are shared by family members and volunteers who include medical professionals, counselors and supporting good Samaritans. The patients who require palliative care obviously suffer from physical pain as well as mental agony. Most of them are usually victims of diseases like cancer, heart complaints, kidney failure, paraplegia, Parkinson's disease or old-age-related complications. Many of these diseases last for long and also require expensive medical care.

The term 'family caregiver' denotes an unpaid family member, friend, or neighbour who provides care to an individual who has an acute or chronic illness and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Reinhard et al., 2008).

Caregivers spare a considerable amount of time interacting with their care receivers, while assisting them in various activities. Family caregivers frequently feel unprepared to provide care, have insufficient expertise to provide appropriate care, and receive no support from the official providers of health care. Family caregivers can be unfamiliar with the type of care they need to provide or the amount of care required due to insufficient knowledge and capacity. Family caregivers may not know when community services are needed, and then they may not know how to access and best use the resources available. As a consequence, caregivers frequently overlook their own health care needs to assist their member of the family, causing the health and well-being of the caregiver to deteriorate.

Twenty-five years of research have shown that there can be tension in the work of family care giving. The stress can affect both the caregiver and the recipient of treatment adversely. Family members may be challenged to recognise the willingness or capacity to provide care, but studies have shown that caregivers with poor health or low-income or dysfunctional conditions may have the most limited ability to provide the necessary care. They may also not understand the quality level and might not provide the care as required. Here is the demand arises for a care giving system like palliative care.

Palliative care considers care for the family very crucial as the competent and confident informal caregivers constitute the essential part of Palliative Care Service. Through the different aspects of assistance in care giving, Palliative care reduces the stress and strain of family care givers. Some of the families may not have economic stability to maintain the expenses created in association with the disabled status of the patient. Palliative care offers economic support to them. In some other cases, where the families are economically stable, they may in need of nursing assistance. There also palliative care is a solution. If any of the patients are in psychological distress, the family may need counselors to give emotional support to their family member. The well co-ordinated team of palliative care is always prepared to offer each and every requirement of the beneficiaries.

The chapter deals with the analyses of the perceptions of the patients on the stress of their family care givers in the process of caring. Analyses are being done using the background variables Age, Gender, Marital Status, Religion, Education, Nature of Disability, Family Income and Family size.

## 7.1 Perceptions on the Family Stress by the Patients

The patients require intensive care from their families. Even for partially satisfying the requirements, the family members have to strenuously struggle. These struggling members are motifs of sacrifices for the palliative patients and this feeling in turn aggravate their mental stress. The physical pain endured by the patients naturally redoubles. So the patients as well the family members are victims of the condition.

According to Charles Horton Cooley, individuals develop their concept of self by observing how they are perceived by others, a concept Cooley named the “looking – glass self”. Using social interaction as a form of mirror, to evaluate their own worth, beliefs and actions, people use judgments they obtain from others. Patients are exposed to two realms of torment. They share a major anxiety in illness equal to their own distress about death, experience of pain or loss of dignity in the midst of the suffering experienced by their family caregivers (Loscalzo and zabora, 1998).

### 7.1.1 Perceptions on the Sacrifices Made by the Family Members

The terminus of life is exigent for both patients and their families. Terminally ill patients who are the recipients of care from other family members can experience that their caretakers are waiving a lot in caring for them. An earlier study defined that this type of feelings among the patients as a multifaceted construct arising out of dependence and the resulting annoyance and worry which then lead to depressing feelings of censurability at being responsible for the caregivers’ adversity.

It is evident from the analysis in Table 7.1.1.1 that 74% of the respondents feel that their family members are sacrificing their personal affairs for taking the responsibility of caring the diseased. Only 15.67% of them don’t feel that their family members do some sacrifices for them and another 10% has no opinion.

### 7.1.1.1 Marital Status and Perceptions on the Sacrifices made by the Family Members

Marital status and living arrangements, along with mid-life and older age shifts, have consequences for the physical, psychological and social wellbeing of a person. In particular, if a person who is disabled because of old age or a persistent disease may need special care from his/her primary care giver. Married patients living with their spouse may receive all type of care they expect when compared to the respondents in the categories of unmarried, divorced/separated and widow/widower. Also the caregivers in such cases may be comfortable with caring their intimate partner rather than caring a distant relative. With this presumption an analysis was carried out to find out the influence of the marital status of the respondents on their perception on the sacrifices made by their care givers.

**Table: 7.1.1.1: Marital Status and Perceptions on the Sacrifices Made by the Family Members**

| Marital Status | Feel about the sacrifices | Don't feel about the sacrifices | No opinion | Total |
|---|---|---|---|---|
| Married | 147<br>(78.19%) | 34<br>(18.09%) | 7<br>(3.72%) | 188<br>(100.00%) |
| Unmarried | 18<br>(50.00%) | 6<br>(16.67%) | 12<br>(33.33%) | 36<br>(100.00%) |
| Separated/ Divorced | 11<br>(64.71%) | 2<br>(11.76%) | 4<br>(23.53%) | 17<br>(100.00%) |
| Widow/ Widower | 47<br>(79.66%) | 5<br>(8.47%) | 7<br>(11.86%) | 59<br>(100.00%) |
| Total | 223<br>(74.33%) | 47<br>(15.67%) | 30<br>(10.00%) | 300<br>(100.00%) |

Chi square= 36.84, df= 6, Table Value=16.81 P≤0.01

The association is significant

Analysis in Table No. 7.1.1.1 shows that significant portions of widow/widowers (79.66%) and married respondents (78.19%) feel that their caregivers are making tremendous sacrifices by taking care of them. In a study done on patients receiving palliative care in rural Kerala, it was found that 43.00% of them were widows or widowers (Thayyil & Cherumanalil, 2012). This is a significant percentage of care recipients who does not get spousal support though many of them could be having caregivers from children or grandchildren. This group has the highest percentage of members who are acutely conscious of the sacrifices others are making for them. Loss of a spouse affects different people in different ways – for some it is the loss of power, some have financial problems because of it, some are angered by society’s condescending attitude, and some ache for the companionship and shared joys. Whatever it is, they are already deprived in one way or other, and an additional embarrassment by taking the help of others is the last thing that probably most of them want.

In the case of married people, the dynamics of the marriage changes significantly when one of the partners become disabled and dependent on the other for daily survival. Many shared practices and socialization pleasures will thus have to be sacrificed. This can be very painful for both and the person who is the patient will be doubly burdened by the absence of these pleasures and the guilty feelings that he or she is the cause of the other person’s suffering also. In the case of completely bed-ridden patients, the type of care they require, which include feeding, changing soiled diapers can be physically and emotionally tiring for the caregiver and will proportionately increase the guilty feelings of the dependent patient.

Respondents in the categories of unmarried and divorced/separated have comparatively lesser percentages(50% and 64.7% respectively) among people who are conscious of the sacrifices of friends and family members are forced to make for them. But even their percentages are not very low.

#### 7.1.1.2 Family Size and Perceptions on the Sacrifices Made by the Family Members

The family forms the rudimental unit of care for every individual; it is in the family setting that every individual receives primary attention whenever an affliction is discovered. The members of the family are regarded as demanding participants in the care of the patients. Family functioning becomes a consequential factor in determining the quality of care carried out by informal caregivers. Most patients find it edifying to have their beloved ones around to care for them and to consort them through their rejuvenating process. However there are patients who feel that their loved ones are sacrificing a lot in caring for them. Family size may be a factor in engendering such a feeling among the patients.

The analysis given in Table 7.1.1.2 reveals the association between the family size of the respondents and their perception on the sacrifice of their care givers.

**Table: 7.1.1.2: Family Size and Perceptions on the Sacrifices made by the Family Members**

| Family size | Feel about the sacrifices | Don't feel about the sacrifices | No response | Total |
|---|---|---|---|---|
| Small<br>(2-4) | 41<br>(52.56%) | 17<br>(21.79%) | 20<br>(25.64%) | 78<br>(100.00%) |
| Medium<br>(5-7) | 111<br>(79.86%) | 22<br>(15.83%) | 6<br>(4.32%) | 139<br>(100.00%) |
| Large<br>(More than 7) | 71<br>(85.54%) | 8<br>(9.64%) | 4<br>(4.82%) | 83<br>(100.00%) |
| Total | 223<br>(74.33%) | 47<br>(15.67%) | 30<br>(10.00%) | 300<br>(100.00%) |

Chi Square= 36.54, df=4, Table Value=13.28, P≤0.01

The association is significant

It is obvious from Table No. 7.1.1.2 that bigger the size of the family, higher the percentage (85.54%) of respondents who feel that their family is making too many sacrifices by caring for them. This percentage continues to decrease with decreasing size of the family, becoming 79.86% in the case of respondents belonging to medium-sized families and 52.56% in the case of respondents belonging to small-sized families.

Care giving in larger families could be a complex affair mainly because everyone, including children, may have to make adjustments to the new atmosphere. Further, most family members would be unprepared for the new role that is unexpectedly thrust upon them and may not have sufficient medical knowledge to handle the situation. Besides, accumulating demands and costs of continuing care will also have adverse effects on personal and social lives of the family members. Additional problems arise when family members disagree on the type of care that is to be provided and the way in which it should be done (Schulz & Eden, 2016). All these could lead to emotional stress for most of the patients in large families. Small families could generally be nuclear families within which the need for adjustments between family members is generally limited. This will reduce tension for the patient so far as the family is on a sound footing financially.

Analyses with variables namely age, gender, education, nature of disability, family income, and religion were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

### 7.1.2 Perception on the Physical Strain of Care givers

Becoming an informal caregiver for an incapacitated family member is often a chronically stressful experience that can become inundating and may even become precarious to the caregiver's own health. There is no doubt that it is disquieting to have a close family member who is afflicted with a chronic illness or infirmity. Caregivers undergo many physical ailments like acid reflux, headaches, pain, tendency to develop serious illness, and have greater levels of obesity and body pain. Studies reveal that caregivers have reduced immunity power, which causes frequent infection. The physical strain of care giving has an influence on the physical health of the caregiver, explicitly when providing care for someone who cannot move him/herself out of bed, walk or bathe without assistance.

A frequently overlooked quandary for many caregivers is the physical strain of care giving. In earlier studies caregivers who experience physical strain are more likely than those with financial, emotional or social strains. Such physical strains of caregivers are customarily understood by the care recipients and most of them express their helpless situation with extreme mental agony.

There is no doubt that the physical strain of the caregivers may vary depending on the stage of illness. In the later stages of illness, this physical strain of the caregivers can increase and disturb the activities and schedule of a household. In a survey by the National Family Caregivers Association (2000), more than half of the family caregivers provided help with activities of daily living and 85 percent of the care receivers were fully dependent on their caregiver for this assistance (Ibid, 2016).

Among the respondents, 12.67% is very much conscious about the physical strain of the care givers.  While majority (69%) of them somewhat conscious about the physical strain of their care givers, 6.67% of them perceive no physical strain for the caregivers and 11.67% has no response.

### 7.1.2.1: Gender and Perception on the Physical Strain of Care Givers

Everywhere in the world, women are the transcendent providers of intimate care for family members with chronic medical circumstances or disabilities including the elderly. It has been suggested that women have many social and cultural criteria to take on the role of a family caregiver. Studies have found the women caregivers experience more preponderant psychological and physical constriction than men caregivers. Consequently there would be gender difference in the perceptions on the physical strain of caregivers. An analysis showing the association between the gender of the respondents and their perception on the physical strain is given in Table 7.1.2.1.

**Table 7.1.2.1: Gender and Perception on the Physical Strain of Care givers**

| Gender | Very much Concerned | Somewhat Concerned | No strain | No response | Total |
|---|---|---|---|---|---|
| Male | 14<br>(10.29%) | 107<br>(78.68%) | 5<br>(3.68%) | 10<br>(7.35%) | 136<br>(100.00%) |
| Female | 24<br>(14.63%) | 100<br>(60.98%) | 15<br>(9.15%) | 25<br>(15.24%) | 164<br>(100.00%) |
| Total | 38<br>(12.67%) | 207<br>(69.00%) | 20<br>(6.67%) | 35<br>(11.67%) | 300<br>(100.00%) |

Chi Square=11.79, df= 3, Table Value=7.82, $P \leq 0.05$

The association is significant

According to Table No. 7.1.2.1, slightly larger portion (14.63%) of women than men (10.29%) is ‘very much’ conscious of the fact that their family caregivers have to undergo serious physical strain by caring for them. While 78.68% of the male respondents state their caregivers are having some strain, only 60.98% women come under this category.

This difference could be due to the fact that many women are accustomed to doing household chores that they do not see caregiving as too strenuous a job. This could also be the reason for 9.15% of them saying that caregiving is not a strenuous job at all. Overall, men appear to be more conscious of the strain of the caregivers. One of the reasons for this could be their embarrassment about being dependent on others.

### 7.1.2.2: Marital Status and Perception on the Physical Strain of Care givers

Marital status is a paramount social factor correlated with human health and longevity. In many studies, married adults show better health status than their unmarried counterparts. Marital cessation is a potential aggravator that changes major physical and psychological control systems in divorced and widowed individuals. These vicissitudes make those people more vulnerable to poor physical and noetic health.

Though the pain and strain of the caregivers are similar in the case of married patients and the other categories, the patients perceive the sufferings of their caregivers in different manners according to their marital status. Patients who are cared by their spouse may have a guilty feeling that they can't help their partner in fulfilling their responsibilities. Married patients may be more focused on the strain of their spouse. At the same time the other categories of respondents feel themselves as a burden to the caregivers and to the family as a whole. The analysis shown in Table 7.1.2.2 reveals whether the marital status of the respondents and their perception on the physical strain of their care givers are associated.

**Table 7.1.2.2: Marital Status and Perception on the Physical Strain of Care givers**

| Marital Status | Very much Concerned | Somewhat Concerned | No strain | No response | Total |
|---|---|---|---|---|---|
| Married | 22<br>(11.70%) | 143<br>(76.06%) | 13<br>(6.91%) | 10<br>(5.32%) | 188<br>(100.00%) |
| Unmarried | 6<br>(16.67%) | 14<br>(38.89%) | 3<br>(8.33%) | 13<br>(36.11%) | 36<br>(100.00%) |
| Separated/ Divorced | 1<br>(5.88%) | 10<br>(58.82%) | 0<br>(0.00%) | 6<br>(35.29%) | 17<br>(100.00%) |
| Widow/ Widower | 9<br>(15.25%) | 40<br>(67.80%) | 4<br>(6.78%) | 6<br>(10.17%) | 59<br>(100.00%) |
| TOTAL | 38<br>(12.67%) | 207<br>(69.00%) | 20<br>(6.67%) | 35<br>(11.67%) | 300<br>(100.00%) |

Chi Square=42.36, df= 9, Table Value=21.67, $P \leq 0.01$

The association is significant

Analysis 7.1.2.2 shows that more unmarried people (16.67%) and widow/widowers (15.25%) are ‘very much’ concerned of the physical strain others have to undergo for caring them, than married (11.70%) people. The reason for this could be that people who are single, whether by choice or otherwise, are not used to demanding help from others so that when they have to accept it they become extremely conscious of it.

However, when it comes to the opinion that caregivers’ job is ‘somewhat’ strenuous, the percentage of unmarried people (38.89%) is way behind that of widow/widowers (67.80%) and married people (76.06%). This can probably be explained by the fact that married people and widow/widowers have the experience of taking help from others, especially the spouse, so that they do not feel that the help being rendered is very strenuous.

### 7.1.2.3: Family size and Perception on the Physical Strain of Care givers

Family size has significant implications on quality of life including health, nutrition, education of children, convivial status of families as well as their faculty to adequately cater for the desiderata of their families. When size of a family increases, it faces difficulties to manage the basic requisites. Then there is no doubt if there is an incapacitated member in a large family engenders more imbalances than that in a small one. But in the case of physical strain, large families may easily manage with large number of care givers while small families struggle to offer the physical support required. Table 7.1.2.3 analyses the association between the family size of the respondents and their perception on the physical strain of their care givers.

**Table 7.1.2.3: Family size and Perception on the Physical Strain of Care givers**

| Family size | Very much Concerned | Somewhat Concerned | No strain | No response | Total |
|---|---|---|---|---|---|
| Small (2-4) | 7<br>(8.97%) | 38<br>(48.72%) | 9<br>(11.54%) | 24<br>(30.77%) | 78<br>(100.00%) |
| Medium (5-7) | 21<br>(15.11%) | 100<br>(71.94%) | 9<br>(6.47%) | 9<br>(6.47%) | 139<br>(100.00%) |
| Large (More than 7) | 10<br>(12.05%) | 69<br>(83.13%) | 2<br>(2.41%) | 2<br>(2.41%) | 83<br>(100.00%) |
| Total | 38<br>(12.67%) | 207<br>(69.00%) | 20<br>(6.67%) | 35<br>(11.67%) | 300<br>(100.00%) |

Chi Square=47.49, df=6, Table Value=16.81, $P \leq 0.01$

The association is significant

According to Table No. 7.1.2.3 also, overall only a very small percentage (12.67%) of the respondents feels that caregivers are put to 'very much' physical strain. But among them, those belonging to medium-size households have the largest percentage (15.11%) who feels that the physical strain is very high. The majority appears to feel that the physical strain is limited, and in this category, respondents from large families top the chart with 83.13%, followed by those in medium-size families (71.94%) and then by small-sized families (48.72%). In large-size families, the task of caregiving may be shared by the members so that the physical strain of each member may not be very high. That could be the reason for patients in large families feeling that there is only limited strain on caregivers.

In small-size families, rather surprisingly, 30.77% of the respondents have expressed no opinion at all. It could probably be due to the fact that some of them were too sick to be interested in participating in the interview. Patients who have a terminal disease and are aware of their condition, also may not be keen on giving their opinion as to what extent the caregivers are struggling.

Analyses with variables namely age, education, nature of disability, family income, and religion were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

### 7.1.3 Anxiety about the Future of Children

The most heartbreaking thing for a sick parent is always the effect of chronic illness on children. It is also important not to throw too much pressure on kids, depending on them to assist you or supervise a younger sibling. Parents with children of school age may be more frustrated than those who have adult off-springs. Parents may be more anxious about the proper management of their children's studies and health when they are not able to supervise in their disadvantaged condition. If they have unmarried young adults, the anxiety may be about finding a suitable marital alliance for them.

Parental chronic ailment is upsetting for children and adolescents and may have some significant impact on children's conformance and performance. Not only younger children and adolescents, unmarried younger adults additionally face major physical and psychological tensions due to a chronically ill family member. Respondents who are having children in younger ages shared more apprehensiveness about the future of their children than those who are having espoused adult children. It is conspicuous that parents with children who didn't consummate their edification or didn't get a secured job and didn't espouse and settle may have solicitousness about how to make them safe in the incapacitated condition.

From the analyses it could be understood that 38.32% of the respondents are always worried about the future of their children. Almost equal portion (34.58%) opines that sometimes they are worried about the future of their children. While 15.89% of them are often anxious about the future of their children, only 11.21% of them are never worried about their children.

### 7.1.3.1 Education and Anxiety About the Future of Children

Children without parental support would surely be very insecure and vulnerable. Even if the family is financially secure, such children may lack emotional support and proper guidance. When the illness or death of a parent leads to financial deprivation as well, the plight of the orphaned child becomes quite precarious. There may be a sense of hopelessness and failure surrounding such children and this could lead to them becoming underachievers in school. Unless such children are accepted to a good orphanage or have relatives to take charge of them, they will be in a highly vulnerable social situation.

A parent who becomes incapacitated or is confronting the specter of death would only be too conscious of this frightening scenario his debility is likely to lead to. Even if the patient has got money, he would plan to deposit it in such a way that it becomes available to the children in a timely fashion. If he/she does not have the necessary finances, they would plan the next best alternative like seeking the help of a kind relative or an NGO that will take care of the child. These thoughts will create a real turmoil in the patients' mind, added to the sorrow that they will not be there to witness the important milestones in their children's lives.

However, the percentage of people who are 'always' anxious about their children's future is only 38.32% and those who are 'often' worried is only

15.89%. This means that human mind has some coping mechanism to at least partially ward off such upsetting thoughts.

**Table 7.1.3.1 : Education and Anxiety about the Future of Children**

| Education | Always worried | Often worried | Sometimes worried | Never worried | Total |
|---|---|---|---|---|---|
| Illiterate | 22<br>(24.44%) | 14<br>(15.56%) | 47<br>(52.22%) | 7<br>(7.78%) | 90<br>(100.00%) |
| Primary | 38<br>(47.50%) | 15<br>(18.75%) | 20<br>(25.00%) | 7<br>(8.75%) | 80<br>(100.00%) |
| Secondary | 16<br>(50.00%) | 4<br>(12.50%) | 3<br>(9.38%) | 9<br>(28.13%) | 32<br>(100.00%) |
| College | 6<br>(50.00%) | 1<br>(8.33%) | 4<br>(33.33%) | 1<br>(8.33%) | 12<br>(100.00%) |
| Total | 82<br>(38.32%) | 34<br>(15.89%) | 74<br>(34.58%) | 24<br>(11.21%) | *214<br>(100.00%) |

Chi Square=34.67, df= 9, Table Value=21.67, $P \leq 0.01$

The association is significant

**86 respondents are either unmarried or having no children. They are not considered for this analysis.*

It is seen in Table No. 7.1.3.1 that the better educated a person is, the more concerned he or she is about the future of their children because half the number of respondents among both secondary-school-educated and college-educated respondents are seen to be persistently anxious about the future of the children. While the percentage of primary-school-educated people who have such anxiety is 47.50%, the percentage of illiterate people in the category is still less, being only 24.44%. Illiterate people, most of whom belongs to the underprivileged segments of the society, generally have “lower expectations of work and education” (Katz et al, 2007). This could be one of the reasons that illiterate people are less anxious about their children’s future.

However, the authors also say that "'Resilience' and 'plasticity' (the ability to undo psychological or social damage) can counteract the effects of poverty at any point in the child's lifetime" (Ibid, 2007). So, many people even when steeped in the culture of illiteracy and poverty, may have high hopes for their children. This mindset explains the fact that 52.22% of even illiterate respondents worry about the future of their children. Among the respondents who are never anxious about their children's future, the highest percentage (28.13%) is that of secondary-school-educated people. This is slightly difficult to explain except through the postulate that these respondents could be having enough family or financial security or that their children are already grownup and independent.

#### 7.1.3.2 Family size and Anxiety About the Future of Children

Large families are advocated by some people because children growing up in large families are unlikely to be pampered. As a result such children develop better social skills, are more independent, can make compromises easily and can adjust well with others. Children growing up in nuclear families may be slightly pampered but smaller families tend to be more financially sound so that parents can afford better educational opportunities for children, children get better parental attention, and these help children to become better achievers.

The indications for detrimental consequences because of a large size of families include a more diminutive portion of resources (time, income and/or pabulum) among the family members; constrained access to public resources (health care and inculcation), unequal distribution of resources among family members and gender defined roles. Such an influence of the size of the family will be more when one of the parents is chronically ill. Analysis shown in

Table 7.1.3.2 shows the association between the size of the family of the respondents and their anxiety about the future of their children.

**Table 7.1.3.2: Family size and Anxiety About the Future of Children**

| Family size | Always worried | Often worried | Sometimes worried | Never worried | Total |
|---|---|---|---|---|---|
| Small (2-4) | 12 (33.33%) | 3 (8.33%) | 8 (22.22%) | 13 (36.11%) | 36 (100.00%) |
| Medium (5-7) | 45 (40.18%) | 18 (16.07%) | 43 (38.39%) | 6 (5.36%) | 112 (100.00%) |
| Large (More than 7) | 25 (37.88%) | 13 (19.70%) | 23 (34.85%) | 5 (7.58%) | 66 (100.00%) |
| Total | 82 (38.32%) | 34 (15.89%) | 74 (34.58%) | 24 (11.21%) | * 214 (100.00%) |

Chi Square= 28.40, df =6, Table Value=16.81, P≤0.01

The Association is significant

**86 respondents are either unmarried or having no children. They are not considered for this analysis.*

Analysis 7.1.3.2 reveals that the respondents from medium-sized and large-sized families (40.15% and 37.88% respectively) are ‘always’ more anxious about the future of their children than those from small families. Further, 36.11% of the respondents from small families are seen to be ‘never’ anxious about the future of their children. In the case of medium and large families, the corresponding percentage is 5.36% and 7.58% respectively (never anxious group). Overall, it is clear that in Small families, the ailing members are less worried about the future of their children.

When resources like money, time, and energy are shared among the members of large families, each person’s share is likely to be quite small. A situation like a debilitating disease in the family further reduces these limited resources, especially when the ailing person is the earning member. As such, there will be tension in the entire family about these already scanty resources as well as the future scenario and this will obviously reflect on the sick individual also. However, in small families also, despite the comparatively better security measures, 33.33% of the patients are ‘always’ seen to be worried about the future of their children. This is because many people consider that parental rapport and guidance are extremely important for growing children.

### 7.1.3.3 Nature of Disability and Anxiety About the Future of Children

The diseases that necessitate palliative care fall under a wide spectrum. Cardiac diseases, different types of cancer, Parkinson’s disease, Alzheimer’s disease, COPD, kidney-related problems, dementia, liver ailments, stroke, neurological diseases, rheumatoid arthritis, and general deterioration of health as a result of old age, are all problems that may require palliative care. Though any one of these problems could make a person dysfunctional, the type of help required by the patient may differ for different diseases. Some people may be mentally fully alert, though physically unable to be productive in any way while in the case of others, their mental faculties would have been affected to the extent that they are unable to focus properly on the problems encountered by others because of the situation.

In the case of old people who are taking palliative help, their children are likely to be settled in life so that they would never be a cause of anxiety for the patient. But young or middle-aged people may have children who still need a lot of guiding and emotional support to find their way forward. Such patients are likely to be very anxious about the future of their children. An analysis was done to find out the association between the nature of disability of the respondents and their anxiety about the future of their children as shown in Table 7.1.3.3.

**Table 7.1.3.3 : Nature of Disability and Anxiety About the Future of Children**

| Disability | Always worried | Often worried | Sometimes worried | Never worried | Total |
|---|---|---|---|---|---|
| Old age related | 2<br>(15.38%) | 3<br>(23.08%) | 6<br>(46.15%) | 2<br>(15.38%) | 13<br>(100.00%) |
| Disease related | 77<br>(41.62%) | 31<br>(16.76%) | 60<br>(32.43%) | 17<br>(9.19%) | 185<br>(100.00%) |
| Both old age and disease related | 3<br>(18.75%) | 0<br>(0.00%) | 8<br>(50.00%) | 5<br>(31.25%) | 16<br>(100.00%) |
| Total | 82<br>(38.32%) | 34<br>(15.89%) | 74<br>(34.58%) | 24<br>(11.21%) | * 214<br>(100.00%) |

Chi Square=17.1.42, df=6, Table Value=12.59, $P \leq 0.05$

The association is significant

**86 respondents are either unmarried or having no children. They are not considered for this analysis*

The analysis in Table 7.1.3.3 shows that in the case of those who are not old and have become incapacitated due to some illnesses, 41.62% are ‘always’ worried about the future of their children and 32.43% are ‘sometimes’ worried about it. This is only to be expected because when people become disabled or out of action in middle age or earlier, they would be quite anxious about who would protect and support their children. However, it is quite stimulating to see that 9.19% are ‘never’ worried about this matter because it hints at the fact that they have a healthy financial and family support system in place or that their children are quite mature and self-confident to manage on their own even at a young age.

However, no significant majority among the respondents appear to be ‘always’ or ‘often’ worried about the future of their children. And surprisingly, it is respondents who require palliative care as a result of a combination of old age and disease who have the largest percentage (50.00%) worrying ‘sometimes’ about the future of their children. Since these respondents are old, we have to presume that some of them have children who are not properly settled in life or have not been successful the way their parents wanted them to be. Again, among people who have only old-age-related problems also, there is 46.15% who ‘sometimes’ worry about the future of their children. However, the number of respondents in both these categories are much smaller compared to those require palliative care due to diseases. As such, too much significance cannot be attributed to these groups.

Analyses with variables namely age, gender, marital status, family income, and religion were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

### 7.1.4 Feeling on Others’ Disturbed Mental Peace

In the face of everyday pressures, anxieties, fears, disruptions, and disorder, harmony, inner peace, or peace of mind is a state of being at peace physically, emotionally, and spiritually. It actively keeps our minds at ease, regardless of external factors, including what people can think or say about us. Sometimes, taking care of the person with chronic disability makes the care giver feels worthy by providing love and comfort. Sometimes, it can be frustrating also. Each day passes with new tasks. It is unpredictable what will be next because the prognosis takes over a long period of time.

The major part of the burden for family care givers is created by the changing roles they must perform in a family structure as a consequence of a partner’s, parent’s, sibling’s or child’s terminal illness. The pressure caused by such a condition creates feelings of high anxiety, confusion, anger, frustration and loss. Though the majority of caregivers are considering such situations as worthy, the patients or the care receivers are in fact very much concerned with their caregiver’s stress, the pain they are taking for caring them.

Though the percentage of respondents who always being concerned about the mental peace of their care givers is low (20 %), a considerable portion (57.67 %) of them are really worried about the disturbed mental peace of care givers. While 19% of the respondents are often worried about the disturbance they create to the mental peace of their care givers, only 3.33% of them are never worried about the same.

### 7.1.4.1 Gender and Feeling on Others' Disturbed Mental Peace

It may be impossible to remedy the incapacitation, but realizing how to cope can minimize the mental and emotional impact of illness. An earnest health quandary can disrupt all aspects of life, whether it is a chronic or life threatening illness or attenuating injury. Both the victim and the family may experience inundated by bursts of arduous emotions- from tension and agony to abstruse woefulness and depression. However the incapacitated member may worry about the perturbed tranquility of the other family members. Gender difference in emotional consistency has already been conspicuous in earlier studies. Here the perceptions on the mental peace of other family members withal is analysed on the substratum of the respondents' gender.

**Table 7.1.4.1: Gender and Feeling on Others' Disturbed Mental peace**

| Gender | Always feel | Often feel | Sometimes feel | Never feel | Total |
|---|---|---|---|---|---|
| Male | 42 (30.88%) | 21 (17.1.44%) | 68 (50.00%) | 5 (3.68%) | 136 (100.00%) |
| Female | 18 (10.98%) | 36 (21.95%) | 105 (64.02%) | 5 (3.05%) | 164 (100.00%) |
| Total | 60 (20.00%) | 57 (19.00%) | 173 (57.67%) | 10 (3.33%) | 300 (100.00%) |

Chi Square=19.01, df= 3, Table Value=11.34, P≤0.01

The association is significant

*Note: No member from the third gender was in the sample.*

From Table 7.1.4.1, it can be seen that there are more male respondents (30.88%) compared to their female counterparts (10.98%)who are ‘always’ worried about the way the palliative care scenario is affecting the mental peace of others. This is probably because women are more “biologically wired to pay attention to different things than men are” (Lewis, 2009). This may explain why women are not ‘always’ thinking of the same problem, because even while she is sick, as long as she is mentally alert a woman may shift her attention to organizing immediate necessities like cleaning the house or getting provisions or getting children’s homework done. This also explains why when it comes to the ‘sometimes’ category, women patients are seen to be of a much higher percentage (64.02%) than men patients (50.00%).Women are conscious of how the mental peace of others is affected by the debilitating disease and resultant scenario, but many of them think of other things also so that they probably focus on this only sometimes. Men, on the contrary, may remain more obsessed by or more narrowly focused on specific concerns.

### 7.1.4.2 Education and Feeling on Others’ Disturbed Mental Peace

Highly educated individuals may additionally have the facility to cope with major life-challenging situations and to fortify their family in sundry ways. The emotional support needed is paramount to chronically incapacitated individuals and their family. The feel of affected tranquility of other family members may additionally vary with the inculcative procurement of the respondents. Analysis in Table 7.1.4.2 reveals the association between the educational qualification of the respondents and their feel of others’ disturbed mental peace.

**Table 7.1.4.2: Education and Feeling on Others' Disturbed Mental Peace**

| Education | Always feel | Often feel | Sometimes feel | Never feel | Total |
|---|---|---|---|---|---|
| Illiterate | 26<br>(20.16%) | 26<br>(20.16%) | 76<br>(58.91%) | 1<br>(0.77%) | 129<br>(100.00%) |
| Primary | 22<br>(18.64%) | 22<br>(18.64%) | 73<br>(61.86%) | 1<br>(0.84%) | 118<br>(100.00%) |
| Secondary | 5<br>(13.51%) | 2<br>(5.41%) | 24<br>(64.86%) | 6<br>(16.21%) | 37<br>(100.00%) |
| College | 1<br>(6.25%) | 2<br>(12.50%) | 11<br>(68.75%) | 2<br>(12.50%) | 16<br>(100.00%) |
| Total | 54<br>(18.00%) | 52<br>(17.33%) | 184<br>(61.33%) | 10<br>(3.33%) | 300<br>(100.00%) |

Chi Square=24.34, df=9, Table Value=21.67, P≤0.01

The association is significant

It is clear from Table 7.1.4.2 that illiterate care-receivers have the highest percentage (20.16%) of members who are 'always' worried that the peace and wellbeing of others are disturbed by having a patient in the house who needs help for coping with his daily life. They are followed by those with primary-level education (18.64%), then those with secondary-school-level education (13.51%), and finally by those with higher education (6.25%). It is clearly seen that lesser the education, more the consciousness among respondents about disturbing the peace and equilibrium of family members.

However, when it comes to worrying 'sometimes', the percentage is in the reverse order with 68.75% of respondents with higher education worrying about their family members maintaining their equanimity despite the stress. This percentage is followed by secondary-school educated, then primary-school educated, and then illiterate people with 64.86%, 61.86%, and 58.91% respectively, feeling so. So, obviously, this is a matter of concern for most people who are in need of palliative care, even though there is a very small percentage (less than 1.00%) of illiterate people and those with primary education who are 'never' bothered about it.

### 7.1.4.3 Nature of Disability and Feeling on Others' Disturbed Mental Peace

Disabilities due to old age, chronic disease and old age with disease are different. Similarly the perceptions or feelings of the respondents may vary with the nature of incapacitation. Caregivers of elderly may have some emotional strains and that may be different from those who take care of a chronically ill. Above all, the physical and emotional strains faced by the caregivers of 'Both aged and diseased' ones may not be able to compare with other categories. The care recipients' nature of incapacitation engenders different perceptions on the caregivers' mental peace affected by an incapacitated family member. With this presumption analysis was carried out to reveal the association between the nature of disability of the respondents and their feeling on others' disturbed mental peace.

**Table 7.1.4.3: Nature of Disability and Feeling on Others' Disturbed Mental Peace**

| Disability | Always Feel | Often feel | Sometimes feel | Never Feel | Total |
|---|---|---|---|---|---|
| Old age related | 3<br>(17.65%) | 6<br>(35.29%) | 8<br>(47.06%) | 0<br>(0.00%) | 17<br>(100.00%) |
| Disease related | 50<br>(19.16%) | 49<br>(18.77%) | 157<br>(60.15%) | 5<br>(1.92%) | 261<br>(100.00%) |
| Both Old age and Disease related | 5<br>(22.72%) | 4<br>(18.18%) | 8<br>(36.36%) | 5<br>(22.73%) | 22<br>(100.00%) |
| Total | 58<br>(19.33%) | 59<br>(19.67%) | 173<br>(57.67%) | 10<br>(3.33%) | 300<br>(100.00%) |

Chi square=29.82, df= 6, Table value=16.81, P≤0.01,

The association is significant

Analysis 7.1.4.3 shows that when it comes to the nature of disability, those who suffer from a combination of old-age deterioration and other diseases have the highest percentage (22.72%) of respondents who ‘always’ worry about the loss of peace they are causing to other family members. The other two categories, namely those suffering from only disease and those whose problems are only geriatric, have 19.16% and 17.65% people respectively in the category of ‘always’ worrying. The higher percentage could be because of the fact that they are doubly burdened due to old age and the disability caused by the disease. But even this percentage is not very high so that we can presume that most patients are not unduly worried that they are causing tension to the other family members.

The highest percentage (60.15%) of people, among all the categories, who are worried about the loss of equanimity for family members are those who are not old and require palliative care because of some serious illness. This is easily explainable because being a victim of debilitating diseases in one’s prime is a very discomforting experience and the patient, besides having to go through the physical agony, is bound to be embarrassed about the tension he/she causes to others because of the situation. However, even among them, there is a small 2.00% who ‘never’ worry about the tension they are causing to others. It could probably be sheer indifference that leads to such attitudes. Or maybe these people are quite brave that they could not be feeling that others are tensed.

Analyses with variables namely age, marital status, family size, family income, and religion were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

### 7.1.5 Worry About the Disturbance Faced by Children

Family members in general suffer greatly from the consequences of a complicated illness of one among them. Children in these families may lack care when compared to children in normal families. Children in different ages face different adverse impacts due to the precarious situation in their family. No proper attention could be provided to the children by that particular family and it negatively affects children's health, education and socialization.

Chronic physical illnesses are intricate, lengthy and arduous to treat. People proceeding with this type of diseases often experience impaired physical and social functioning as well as truncated salubrity. Because of these issues, the impact of physical illness habitually reaches beyond an individual to his or her immediate family. Caring of offspring will be challenging in such a situation. Thinking how to better support children of a parent with a chronic illness can avail minimize the stress of a chronically ill parent. Children in the family, where there is a chronically ill or bedridden member, need not to be a parent, also may have some difficulties to manage with.

However, 44.33% of the respondents opined that sometimes they feel the children in their family face disturbances due to the incapacitated parent and the situations developed thereby. 19.33 % of them always worry that their disease and stepping back from parental roles creating confusions and stress among their children while 18.67% often worry about the same. Only 17.67% of the respondents say they never worry about their children being disturbed due to their diseased condition.

### 7.1.5.1 Gender and Extent of Worry About the Disturbance Faced by Children

Parenting styles are different according to gender. Mothers conventionally expect their children whether a boy or a girl assisting them in household activities and they train them to do such things. Unlike Mothers, Fathers mostly are fascinated to play with them and concerned about their studies and future activities. Similarly if a Mother becomes incapacitated, the mostly affected area in that family is the household tasks. And if it is a father is incapacitated, it affects the family economy. Consequently the perceptions of the respondents on the crises faced by the children vary according to their gender.

**Table 7.1.5.1: Gender and Extent of Worry About the Disturbance Faced by Children**

| Gender | Always worry about | Often worry about | Sometimes worry about | Never worry about | Total |
|---|---|---|---|---|---|
| Male | 42<br>(30.88%) | 25<br>(18.38%) | 56<br>(41.17%) | 13<br>(9.56%) | 136<br>(100.00%) |
| Female | 16<br>(9.75%) | 31<br>(18.90%) | 77<br>(46.95%) | 40<br>(24.39%) | 164<br>(100.00%) |
| Total | 58<br>(19.33%) | 56<br>(18.67%) | 133<br>(44.33%) | 53<br>(17.67%) | 300<br>(100.00%) |

Chi Square=26.99, df=3, Table Value=11.34, P≤0.01

The association is significant

*Note: Here 'Children' not only include the respondents' own children but also the children in the family in which the respondent is included. Thus the unmarried respondents and those who have no children are also included in the analysis*

The analysis in Table 7.1.5.1 shows that a much larger percentage of males(30.88%) than females(9.75%) are 'always' concerned about the unsettling effects on children when a normal family equation gets disrupted by one of the family members being in need of palliative care. And there are only

9.56% of male patients who are ‘never’ concerned about this problem whereas there are 24.39% females who are not bothered about this problem at all.

This may appear a little surprising because the general viewpoint is that women are more concerned about children than men are. However, involvement of fathers in children’s upbringing can promote their self-confidence and social skills and “even physically absent fathers can establish high-quality relationships with their children” (Jessee & Adamsons, 2018). Probably because of the gender stereotyping still prevalent in the society, a male parent is the hero and role model for many children as he gives them emotional and physical security. Men probably reciprocate these feelings even if they may not be prone to outward displays of affection and that is why they are more conscious than women about the disconcerting effect that a palliative care setup can have on children.

#### 7.1.5.2 Religion and Extent of Worry About the Disturbance Faced by Children

Studies have shown that different religions have their own concepts on different life aspects. Withal it is kenned that child birth and rearing are consequential life events according to every religion. Obligations of parents and that of children are generally constructed according to the religion in which the family believes. While some religions are pronatal, some others promote celibacy. However the religious credences influence the family in child care also. These religious differences of respondents have an impact on their opinion about the crises faced by the children in their family.

**Table 7.1.5.2: Religion And Extent of Worry About the Disturbance Faced by Children**

| Religion | Always worry about | Often worry about | Sometimes worry about | Never worry about | Total |
|---|---|---|---|---|---|
| Hindu | 32<br>(16.08%) | 23<br>(11.56%) | 98<br>(49.25%) | 46<br>(23.12%) | 199<br>(100.00%) |
| Muslim | 17<br>(26.98%) | 20<br>(31.75%) | 24<br>(38.09%) | 2<br>(3.17%) | 63<br>(100.00%) |
| Christian | 3<br>(7.89%) | 10<br>(26.32%) | 20<br>(52.63%) | 5<br>(13.16%) | 38<br>(100.00%) |
| Total | 52<br>(17.33%) | 53<br>(17.67%) | 142<br>(47.33%) | 53<br>(17.67%) | 300<br>(100.00%) |

Chi Square=26.96, df=6, Table Value=16.81, P≤0.01

The association is significant

*Note: Here 'Children' not only include the respondents' own children but also the children in the family in which the respondent is included. Thus the unmarried respondents and those who have no children are also included in the analysis*

According to Table No. 7.1.5.2, Muslims have a higher percentage of respondents than the other two religions, among those who 'always' remain worried about the unsettling effect on children when a member of the family falls seriously ill. But this percentage is only 26.98% and among Muslims themselves, there are higher percentages of respondents who are 'often' worried or 'sometimes' worried.

And Muslims have the smallest percentage of respondents (3.17%) in the category of people who never worry about the matter. So, overall, Muslim patients appear to be highly conscious of the negative effects of the situation on the children.

However, the highest percentages of respondents in all religions belong to the category of people who sometimes worry about the situation. In the case of Christians it is more than half (52.63%), in the case of Hindus it is almost half (49.25%), and among Muslims it is 38.09%.These patients may probably having some resources for taking care of the children so that they do not have to be extremely worried about their children.. And finally there are 23.12% of Hindus and 13.16% of Christians who never appear to be bothered about the matter. Some of these families may be childless and others may be having a good support system that frees the patients from focusing on the issue.

### 7.1.5.3 Family Size And Extent of Worry About the Disturbance Faced by Children

It is discussed earlier the importance of family size in caring and rearing of children. Children in 'Large size' families lack so many things when compared to those in 'Medium size' and 'Small size' families. The difficulties the children face will be double when one of their family members is incapacitated due to chronic illness, ill health due to old age or both. Respondents from large families may be of course consequently concerned about the difficulties, scarcity of resources and lack of fortification in case of the children in their family. Analysis shown in Table 7.1.5.3 shows the association between the size of the family of the respondents and their opinion about the disturbance faced by children.

**Table 7.1.5.3 : Family Size And Extent of Worry About the Disturbance Faced by Children**

| Family size | Always worry about | Often worry about | Sometimes worry about | Never worry about | Total |
|---|---|---|---|---|---|
| Small (2-4) | 8 (10.26%) | 11 (14.10%) | 31 (39.74%) | 28 (35.89%) | 78 (100.00%) |
| Medium (5-7) | 12 (8.63%) | 18 (12.95%) | 80 (57.55%) | 29 (20.86%) | 139 (100.00%) |
| Big (More than 7) | 22 (26.51%) | 14 (16.87%) | 33 (39.76%) | 14 (16.87%) | 83 (100.00%) |
| Total | 42 (14.00%) | 43 (14.33%) | 144 (48.00%) | 71 (23.67%) | 300 (100.00%) |

Chi Square =22.24, df= 6, Table Value=16.81, P≤0.01

The association is significant

*Note: Here 'Children' not only include the respondents' own children but also the children in the family in which the respondent is included. Thus the unmarried respondents and those who have no children are also included in the analysis.*

It is clear from table 7.1.5.3 that the highest percentage (26.51%) of respondents who worry constantly about the disruption in children's life by having a patient in the family belong to large families. This is probably because the shared resources in large families become further attenuated when there is a sick individual in the family so that the patient becomes very worried about the negative fallout on it on the children. This problem may be limited in smaller families so that there is only 10.26% among them who constantly worry about this problem about the children and 35.89% never worry at all. In some cases the children may be grown up or capable enough to handle the situation without confusion.

Analyses with variables namely age, education, nature of disability, family income, and marital status were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

### 7.1.6 Feeling of Self as a Burden

While several studies have explored the stress of caregivers, very few studies have concentrated on people receiving treatment in a palliative care environment. Patients with terminally ill cancer who are the beneficiaries of such treatment might believe they are a burden to others. The sense of self-perceived burden was described in a previous study as a multidimensional construct arising from the feelings of dependency and the resulting distress and worry of the care recipients, which then leads to negative feelings of guilt at being responsible for the caregiver's hardship (Akazawa, et al., 2010).

Nonetheless, therapeutic experts frequently underestimate oneself saw trouble experienced by critically ill disease patients despite the fact that the apparent feeling of burden has been seen as a significant factor in accomplishing a decent demise in terminally ill patients in both Western and Eastern societies. Emotional discomfort and feelings of remorse may also occur beyond the physical suffering of a chronic illness.

It is found clear from the analyses that majority (61.33%) of the respondents says that they feel themselves as burdensome for their care givers. While 24.67% of them very much feel about the burden they create for their care givers, a very small portion (14%) not at all feel he/she is a burden for their family.

### 7.1.6.1 Gender and Feeling of Self as a Burden

Women have typically surmised the caregiver role and provide more family care giving than men. Consequently in situations where women are care recipients, the self-perceived burden may be more among women when compared to men care-recipients. With this presumption, an analysis was carried out to find out the association between the gender of the respondents and their feel of self as a burden.

**Table 7.1.6.1: Gender and Feeling of Self as a burden**

| Gender | Very much Feel | Some what feel | Not at all feel | Total |
|---|---|---|---|---|
| Male | 25<br>(18.38%) | 85<br>(62.50%) | 26<br>(19.12%) | 136<br>(100.00%) |
| Female | 49<br>(29.88%) | 99<br>(60.37%) | 16<br>(9.76%) | 164<br>(100.00%) |
| Total | 74<br>(24.67%) | 184<br>(61.33%) | 42<br>(14.00%) | 300<br>(100.00%) |

Chi square=8.69, df=2, Table Value=5.99, P≤0.05

The association is significant

*Note: No member from the third gender was in the sample*

The analysis in Table No. 7.1.6.1 shows that only 18.38% of male care-receivers feel that they are ‘very much’ a burden to their families whereas 29.88% of female care-receivers feel so. This is only to be expected since women in most families are not used to receiving help or being cared for but only in providing help and care to others. It is a behavioral pattern that is probably instinctive or something gender stereotyping has trained them to accept. But among those who are ‘somewhat’ worried about being a burden to others, there is not too much difference between the strength of males and females. This shows that all women do not have the characteristics that gender stereotyping attributes to them.

Overall picture clarifies that there are more female respondents (90.25%) than male respondents (80.88%) who feel remorseful about being a burden on others. Nevertheless, it is to be noted that a significant portion of men also feel sorry about being a burden to others so that this feeling should be considered less of a gender-related trait than an innate human sensitivity.

### 7.1.6.2 Education and Feeling of Self as a Burden

While persons with better education feel mentally strong because of their knowledge about the treatment options and prognosis the illiterates may feel mentally strong because of the total ignorance of the seriousness of the disease they have. It is assumed that the educational attainment of the impaired is influencing their feel of self as a burden. Analysis given in Table 7.1.6.2 was carried out to verify the assumption.

**Table 7.1.6.2: Education and Feeling of Self as a Burden**

| Education | Very much feel | Some what feel | Not at all Feel | Total |
|---|---|---|---|---|
| Illiterate | 24<br>(18.60%) | 94<br>(72.87%) | 11<br>(8.53%) | 129<br>(100.00%) |
| Primary | 39<br>(33.05%) | 62<br>(52.54%) | 17<br>(14.41%) | 118<br>(100.00%) |
| Secondary | 8<br>(21.62%) | 18<br>(48.65%) | 11<br>(29.73%) | 37<br>(100.00%) |
| College | 3<br>(18.75%) | 10<br>(62.50%) | 3<br>(18.75%) | 16<br>(100.00%) |
| TOTAL | 74<br>(24.67%) | 184<br>(61.33%) | 42<br>(14.00%) | 300<br>(100.00%) |

Chi square=20.48, df= 6, Table Value=16.81, P≤0.01

The association is significant

According to Table 7.1.6.2, when it comes to educational categories, primary-school-educated people have the highest-percentage (33.05%) who feels that as care-receivers they are ‘very much’ a burden to the rest of the family. Ironically, both illiterates and highest-educated category have the same strength (nearly 19.00%) who feel the same way. However, the number of respondents who have higher education is $^1/_8$th of that of illiterate people and this has to be taken into account while considering their percentage.

Among those who feel ‘somewhat’ that they are a burden to the family, illiterates top the chart (72.87%). College-educated people also have a significant percentage (62.50%) who feels the same way. The difference probably is that illiterate people are more worried about becoming an economic burden to the family by draining the financial resources, the more-educated think of being a burden to others by depriving them of their social obligations and opportunities for relaxing and entertaining themselves.

### 7.1.6.3 Family Size and Feeling of Self as a Burden

As family size of the ill varies their feelings about their perished condition also varies. Larger families are generally more resource-strapped than smaller ones. As such, when a person becomes incapacitated the whole family would invariably become upset. This worry will be reflected on the patient also and he would become guilt-ridden for being the cause of all the trouble that the family has to take. The family dynamic can change intensely when a member of the family suffers from a chronic illness. A chronic disease has a monumental effect not only on the development of the person suffering from it, but also on the family members and relationships of the individual. These changes in turn affect the physical and psychological status of the diseased. Table 7.1.6.3 shows the association between the size of the family of the respondents and their feeling of self as a burden.

**Table 7.1.6.3: Family Size and Feeling of Self as a burden**

| Family Size | Very much feel | Some what feel | Not at all Feel | Total |
|---|---|---|---|---|
| Small (2-4) | 20 (25.64%) | 38 (48.72%) | 20 (25.64%) | 78 (100.00%) |
| Medium (5-7) | 31 (22.30%) | 92 (66.19%) | 16 (11.51%) | 139 (100.00%) |
| Large (More than 7) | 23 (27.71%) | 54 (65.06%) | 6 (7.23%) | 83 (100.00%) |
| Total | 74 (24.67%) | 184 (61.33%) | 42 (14.00%) | 300 (100.00%) |

Chi square=14.29, df= 4, Table Value=9.49, $P \leq 0.05$

The association is significant

Analysis 7.1.6.3 shows that among the respondents of small-size families, 25.64% not at all feel that they are a burden to the rest of the family.

While 48.72% of them somewhat feel that they are burdensome to others, another 25.64% is very much worried about the burden they are creating for their care givers. In the case of medium-size families only 11.51% of the respondents has not at all having a feel that they are becoming a burden to others in some way or other. In large families when only 7.23% don't feel that they become burden to others, majority (61.33%) of them somewhat feel that they are a big liability to their families and 24.67 % has a deep sense of feeling the same.

Thus larger the family is, the more the proportion of the diseased members who feel that they create burden for their families. This may be because of the huge responsibilities of the family members due to the larger family size may create more strain on the caregiver.

Thus the care receivers in larger families may have more worry about the burden created by themselves on the care givers.

Analyses other variables namely age, marital status, nature of disability, family income, and religion were made but since association between the variables are not revealed. So the details of analyses are not included in the report.

## Summary

Human being may have to face a stage when palliative care becomes mandatory. While that is in itself a painful experience, an additional burden for many is witnessing the struggles their relatives go through because of the altered situation that causes significant emotional, material, and financial challenges.

Among the respondents, widows, widowers, and married people are seen to be comparatively more conscious than the unmarried about the sacrifices their caregivers have to make. Similarly, respondents of larger families are more acutely aware of this sacrifice than those of smaller families. Coming to the question of the strain to which caregivers are put, men appear to be more conscious of it than women; widow/widowers and married people appear to be more aware of it than unmarried people; and members of large families appear to be more so than the rest.

Many patients are worried about the future of their children, better-educated people, younger people, and those from smaller families being more so. Other things that palliative care recipients worry about are the mental peace of family members who are the primary caregivers, general disturbance that the children of the family have to encounter, and the extent to which care-receivers become a burden to others.

Family caregivers have consistently require the need for the following: education to prepare them for their role, about how to respond to the challenges (physical, social, spiritual, and psychological) of the role, and about how to access resources (internal and external) to assist them to maintain optimal psycho-social well-being (Hudson and Payne, 2011). Palliative Care principles include ‘Attitude to Care’ which promises the co-ordinated care of the team to support the family care givers also whenever they require. Planning routine home- and community-based services, and deciding what private and public initiatives may be available, is one of the most critical aspects of navigating the system.

Supporting the family in the care giving process also become indispensable as the care recipients are more worried about the strain of their care givers. The perceptions of the patients on the stress and strain of their family care givers in various aspects have already been discussed above. It is also found that their physical and mental agonies double according to the increase in the care givers’ burden. Thus to assist the family in caring the disabled should be one of the prime aims of the palliative care agency.

# CHAPTER 8

# SUPPORT FROM PALLIATIVE CARE AGENCY

More than a decennium ago the World Health Organization (WHO) made an ecumenical call for all countries to consider Palliative Care as a public health quandary and include it in their health agendas. Since then an incrementing number of health systems across the world commenced to look into the escalating unmet desiderata of the frail elderly and terminally ill people and many agree with the WHO that palliative care is indeed a public health matter.

In developed countries, end-of-life care provision is facing so many challenges due to socio demographic transmutations in the cessation-of-life context and health care system constraints. These challenges have led to palliative care being on public and regime agendas across the developed countries as an increasingly consequential public health issue. In India, among the total population who are in need of Palliative Care, less than 2% are currently being catered to. Despite its limited coverage, Palliative Care has been contemporaneous in India for about 20 years. Obstacles in the growth of palliative care in India are many and not only include aspects like population density, poverty, geographical diversity, restrictive policies concerning opioid prescription etc. However India has reasons to be honored in that it has overcome several hurdles and last two decades have seen profound changes in the mind set of health care providers and policy makers with respect to necessity of palliative care in India (Khosla et al., 2012).

The State of Kerala maintains 90% of the country’s palliative care programmes though it has only 3% of the country’s population. This is characterised by a considerably voluminous number of home care accommodations which have extensive coverage. This habitation predicated provision relies on the vigor of family support and the ebullience of volunteers. Most of the families prefer to care for the ill person throughout their illness. To fortify the families who care the bedridden or chronically ill doted ones, Palliative Care takes a crucial role. Palliative Care agencies provide support through the service of Medicos, Nurses, Volunteers and also Medicines. Sundry needs from the care recipients however put Palliative Care in a struggle to meet all those desiderata.

This chapter discusses the beneficiaries' perceptions on the services provided by the agency and their satisfaction with the services of Doctors, Nurses, Volunteers, Medicines etc. Also the association between the perception and the background variables like Age, Gender, Religion, Marital status, Education, Family size, Family income and Nature of Disability, is examined through cross analyses. Analyses that show no association between variables are given as frequency tables.

### 8.1 Reason to Avail of Palliative Care

Modern medicine has magnified the number of older adults with chronic illness. Albeit the current generation of older people is less incapacitated than its predecessors, the probability of functional dependency, cognitive impairment and living with advanced chronic illness increases with age. Health care providers will be needed to provide appropriate care for these patients. Palliative Care utilizes a team approach to address the requirements of the patients and their families. This approach requires the interdisciplinary effort of health care professionals, volunteers and the community to address the physical, psychological, convivial, spiritual and practical ancillary needs of patients and their families.

It is conspicuous from earlier chapters that patients, who are the beneficiaries of Palliative Care has different convivial, economic, cultural and edifying backgrounds. Availing palliative care may be for different reasons for these patients. Since palliative care provides variants of accommodation, the patients can choose them according to their particular requisite. Analysis given in Table 8.1 shows the reasons of the beneficiaries to avail of the palliative care.

**Table 8.1: Reason to Avail Palliative Care**

| Reason | Frequency | Percentage |
|---|---|---|
| Reduce economic burden of the family | 173 | 57.67% |
| Get nursing assistance | 82 | 27.33% |
| Get psychological relief | 7 | 2.33% |
| All the above | 38 | 12.67% |
| Total | 300 | 100% |

Analysis 8.1 indicates that the highest percentage (57.67%) of the respondents is seeking palliative care support to reduce economic burden. Studies have found that by “integrating palliative care into curative care practices earlier in the disease trajectory, chronically ill patients nearing the end of life report improved satisfaction with care and demonstrate less acute care use resulting in lower costs of care” (Brumley et al, 2004). Though only 27.33% of the respondents have said that they are relying on palliative care for nursing assistance, help in nursing is a very important aspect of palliative care as palliative care can be availed of along with the treatment done to cure the disease.

It can be availed of as soon as the problem is diagnosed, throughout the treatment, during the follow-up stage, if any, and even at the final stage of life. Psychological assistance, which involves counseling, giving emotional support to the patient by being gentle and empathetic, and treating the patient as a special individual, is also a crucial aspect of palliative care but among the respondents of this study, only 2.33% appear to need such emotional support. It is possible that in Kerala, family support system is good enough for patient comfort so that they do not seek too much psychosocial assistance from outside Care givers.

## 8.2 Type of Care Getting from Palliative Care Agency

Even though home predicated care is the backbone of acceptable and cost efficacious palliative care, it is being provided to hospital patients withal. There can be three models of palliative care which is being offered to the needy patients. First one is general palliative care at home, which is accessible, available, affordable, acceptable and felicitous for patients with perdurable illness. It is conventionally being offered at the terminal stage only. Second is palliative care at home which partially consummates the desiderata of the patient. Auxiliary accommodations like counseling, physiotherapy and spiritual care are customarily unavailable. Access to nearby health care institution and adequate conveyance facility are preferable. Third model is palliative care in a hospital, which is costly and inconvenient to the patient and caregivers in some aspects. But it is the only model where the advanced accommodations of palliative care i.e, palliative radiation, surgery, chemotherapy, special palliative care for children etc. can be practiced. In the study an enquiry was carried out to know what type of Palliative Care is preferred by the respondents.

It is found that majority (58.67%) among the respondents are availing of both home based and institution based care as they require. When 30.33% of them avail only institution based care, 11% of them completely depending on the home based care of the agency.

### 8.2.1 Education and Type of Care Availed of

Respondents' education and knowledge attainment make them perceive their debilitated situation and the appropriate type of care they need. Timely access of care may be significant in getting quality care for the needy. Home based care or institution based care alone is not possible for everybody who are availing palliative care. Lower level of education may create individuals who are incapable of making timely decisions about the type of care they need at a particular time. Similarly higher level of education helps people to access the most effective type of care at a particular time. An analysis was done to verify the association between the educational qualification of the respondents and the type of care they availed from the agency.

**Table 8.2.1: Education and Type of Care Availed of**

| Education | Home based | Institution based | Both | Total |
|---|---|---|---|---|
| Illiterate | 16 (12.40%) | 22 (17.05%) | 91 (70.54%) | 129 (100.00%) |
| Primary | 9 (7.63%) | 46 (38.98%) | 63 (53.39%) | 118 (100.00%) |
| Secondary | 5 (13.51%) | 18 (48.65%) | 14 (37.84%) | 37 (100.00%) |
| College | 3 (18.75%) | 5 (31.25%) | 8 (50.00%) | 16 (100.00%) |
| Total | 33 (11.00%) | 91 (30.33%) | 176 (58.67%) | 300 (100.00%) |

Chi Square=22.63, df= 6, Table Value=16.81, $P \leq 0.01$

The association is significant

It is evident from Table 8.2.1 that there are comparatively more respondents (58.67%) availing both home-based and institution-based care. Only 30.33% availing institution-based care and11.00% availing home-based care. A significantly high percentage (70.54%) of illiterate people are seen to avail of both home-based and institution-based palliative care, followed by primary-school-educated (53.39%) and college-educated (50.00%). College-educated respondents have the highest percentage (18.75%) who make use of home-based care and secondary-school-educated have the highest percentage (48.65%) who make use of institution-based care.

The knowledge or awareness about the availability of the services of the agency may influence the choice of the respondents in the type of care they avail of. The knowledge about the service may influenced by the educational attainment of the respondents as better educated respondents may enquire more about the different services available from the agency.

### 8.2.2 Nature of Disability and Type of Care Availed of

The difference in disability demands different models of care from the palliative care agency. It is estimated that over 20 million people world over require palliative care at the end of life every year. They are mainly adults over 60 years old. The largest number of adults in need of end-of - life palliative treatment live in low- and middle-income countries. People with non-communicable diseases account for about 90 percent of the end-of - life palliative care burden. The diseases are cardio vascular diseases, cancer, kidney failure etc.

The present study includes a significant number of paraplegic patients also. The analysis in Table 8.2.2 shows that the nature of disability of the respondents and the type of care availed of by them are associated.

**Table 8.2.2: Nature of Disability and Type of Care Availed of**

| Disability | Home based | Institution based | Both | Total |
|---|---|---|---|---|
| Old age related | 4<br>(23.53%) | 5<br>(29.41%) | 8<br>(47.06%) | 17<br>(100.00%) |
| Disease related | 19<br>(7.28%) | 83<br>(31.80%) | 159<br>(60.92%) | 261<br>(100.00%) |
| Both age and disease related | 10<br>(45.45%) | 3<br>(13.64%) | 9<br>(40.91%) | 22<br>(100.00%) |
| Total | 33<br>(11.00%) | 91<br>(30.33%) | 176<br>(58.67%) | 300<br>(100.00%) |

Chi Square=33.58, df= 4, Table Value=13.28, $P \leq 0.01$

The association is significant

It could be understood from Table 8.2.2 that majority among ‘Diseased’ (60.92%) respondents avail both home based and institution based care. 47.06% of the aged people also come under this category. But the highest portion (45.45%) among ‘Both Aged and Diseased’ avail of home-based care. It may be because of the reason that the respondents in that category may be in terminal stage and for them, institution-based care may be impossible or useless.

Analyses with other variables namely age, gender, marital status, family size, family income and religion were made but since association between the variables are not revealed. So the details of analyses are not given here.

### 8.3 Frequency of Doctor’s Visit

Palliative Care physicians/doctors understand the value of making time for commiseration in the midst of a crisis. It is understood that patients who avail of palliative care are in different desiderata of care. While some patients need special care some others are not in such requisites. Patients’ contentment with the quality of care and thus patient autonomy is prominent in palliative care. Doctors' presence and consolation words may have paramount role in management of the active total pain of the patients.

The analysis in the study shows that 32.33% of the clientele perceive that they are visited by doctors regularly, 17.33% frequently, 21.67% occasionally and 28.67% rarely. It is revealed that almost 50% of the care receivers feel they are attended to by the doctors at the appropriate times prescribed by them. So the attention given by the doctors is not underestimated. The occasionally and rarely group may not be deserving serious medical attention.

### 8.3.1 Perceptions of Religious Groups on Frequency of Doctor's Visit

Religious affiliation may influence the perceptions of the impaired about various matters. Some religious beliefs make dominance over the concepts of doctors and their treatments considering them as secondary. Due to prodigious number of patients turning to their belief and faith during strenuous times, it is vital for health care professionals to be empathetic and do what they can do to accommodate a patient's needs to be sure that they receive the best possible care. It is paramount that providers offer the opportunity for patients to discuss their cultural and religious notions, so that treatments can be adjusted if needed. Analysis shown in Table 8.3.1 verifies the association between the religious affiliation of the respondents and their perception on the frequency of doctor's visit to them.

**Table 8.3.1: Perceptions of Religious Groups on Frequency of Doctor's Visit**

| Religion | Regularly | Frequently | Occasionally | Rarely | Total |
|---|---|---|---|---|---|
| Hindu | 68<br>(34.17%) | 36<br>(18.09%) | 44<br>(22.11%) | 51<br>(25.63%) | 199<br>(100.00%) |
| Muslim | 11<br>(17.46%) | 6<br>(9.52%) | 15<br>(23.81%) | 31<br>(49.21%) | 63<br>(100.00%) |
| Christian | 18<br>(47.37%) | 10<br>(26.32%) | 6<br>(15.79%) | 4<br>(10.53%) | 38<br>(100.00%) |
| Total | 97<br>(32.33%) | 52<br>(17.33%) | 65<br>(21.67%) | 86<br>(28.67%) | 300<br>(100.00%) |

Chi Square=28.33, df= 6, Table Value=16.81, P≤0.01

The Association is significant

From Table 8.3.1, it can be understood that while 47.37% of the 'Christian' and 34.17% of the 'Hindu' respondents opine that doctors visit them regularly or frequently, only a small portion (17.46%) of the 'Muslim' respondents opines that their doctor visit them regularly. Nearly half (49.21%) of the 'Muslim' respondents says that they are visited by the doctor rarely.

May be respondents among the Muslim religion do not require more visits from the doctor like those from the other religious groups. Usually Islamic beliefs refuse the withholding or life sustenance treatments and this may be the reason for many of them do not expect doctors to manage their pain or to give medicines.

### 8.3.2 Perceptions of Educational Groups on Frequency of Doctor's Visit

Satisfaction with the frequency of the doctor's visit may be varied with the knowledge about the treatment methods and options. And this knowledge depends on the educational attainment of the beneficiaries. On the basis of the awareness about the schedule of visit by the health professionals, patients feel the doctors visit and treat them regularly, frequently, occasionally or rarely.

The analysis given in Table 8.3.2 verifies the association between the educational attainment of the respondents and their perception on the frequency of doctor's visit to them.

**Table 8.3.2: Perceptions of Educational Groups on Frequency of Doctor's Visit**

| Education | Regularly | Frequently | Occasionally | Rarely | Total |
|---|---|---|---|---|---|
| Illiterate | 19<br>(14.73%) | 20<br>(15.50%) | 34<br>(26.36%) | 56<br>(43.41%) | 129<br>(100.00%) |
| Primary | 43<br>(36.44%) | 29<br>(24.58%) | 22<br>(18.64%) | 24<br>(20.34%) | 118<br>(100.00%) |
| Secondary | 19<br>(51.35%) | 3<br>(8.11%) | 9<br>(24.32%) | 6<br>(16.22%) | 37<br>(100.00%) |
| College | 16<br>(100%) | 0<br>(0.00%) | 0<br>(0.00%) | 0<br>(0.00%) | 16<br>(100.00%) |
| Total | 97<br>(32.33%) | 52<br>(17.33%) | 65<br>(21.67%) | 86<br>(28.67%) | 300<br>(100.00%) |

Chi Square=39.18, df= 9, Table Value=21.67, P≤0.01

The association is significant

From the above Table 8.3.2, it is clear that there is a strong association between level of education and the opinion about doctor's visits. Among the highly-educated respondents, 100.00% say that doctors come regularly. This is followed by 51.35% of secondary-school educated, 36.44% primary-educated, and 14.73% of illiterate respondents.

Considering the workload that palliative care doctors have to take up, regular visits to each patient is difficult. India's largest home-based palliative care programme 'CanSupport' is caring for 2600 cancer patients at any given time. The organization works in a slightly different way from Kerala's community-based palliative care networks. Whatever it be, the members "visit the homes of approximately 80-85 patients with advanced cancer every week"

(Khosla et al, 2012). In such a setup, it is not possible to visit every patient regularly. Nevertheless, it is still a bit difficult to explain how more educated people get more regular visits.

### 8.3.3 Nature of Disability and Perception on the Frequency of Doctor's Visit

Longer life expectancy, along with alterations of terminus of life morbidity poses great challenges in ascertaining health care access for the aging population. Palliative care is recommended and should be provided based on the requirements of the patients, categorically the most vulnerably susceptible populations, such as older people. Disabilities are categorized in the study as 'Old Age related', 'Disease related' and 'Both Age and Disease related'. Among the three categories two of them include the aged population. Needs and prospects also may be different for the three categories. Analysis was carried to find out the association between nature of disability of the respondents and their perception on the frequency of doctor's visit to them.

**Table 8.3.3: Nature of Disability and Perception on the Frequency of Doctor's Visit**

| Disability | Regularly | Frequently | Occasionally | Rarely | Total |
|---|---|---|---|---|---|
| Old age related | 2<br>(11.76%) | 2<br>(11.76%) | 7<br>(41.18%) | 6<br>(35.29%) | 17<br>(100.00%) |
| Disease related | 91<br>(34.87%) | 47<br>(18.01%) | 52<br>(19.92%) | 71<br>(27.20%) | 261<br>(100.00%) |
| Both age and disease related | 4<br>(18.18%) | 3<br>(13.64%) | 6<br>(27.27%) | 9<br>(40.91%) | 22<br>(100.00%) |
| Total | 97<br>(32.33%) | 52<br>(17.33%) | 65<br>(21.67%) | 86<br>(28.67%) | 300<br>(100.00%) |

Chi Square= 9.93, df= 6, Table Value=12.59, $P \leq 0.05$

The association is significant

The analysis in Table 8.3.3 reveals that when 34.87% of the respondents who are facing disabilities due to disease only perceive that they are visited by the doctor regularly, respondents who have age related disabilities and those who have both age related and disease related disabilities are comparatively lesser (11.76% and 18.18% respectively). Similarly, among the respondents who perceive the doctor’s visit to them as rare, diseased young respondents are lesser (27.20%) when compared to the old diseased and the old (40.91% and 35.29% respectively).

It could be understood that the doctors’ attention is given on a priority basis to the diseased person while that given to the old and the old diseased is lesser. This may be due to the reason that old or old age coupled with disease is a natural phenomenon in the life of a person. This does not require much medical attention.

Though much of the nursing duties like feeding, bathing, and supporting are done by such healthcare providers like nurses, nursing assistants, and other volunteers, it is the sight of the doctor that gives a special confidence to patients. They feel reassured by communicating with the doctor and clarifying their doubts. Probably because of it, most care-receivers prefer to see the doctor quite often.

Patients who are fighting against specific diseases are generally visited quite frequently by doctors because doctors themselves prefer to track the improvement of the patient and his response to the treatment scenario. It will also help the doctor to chart the prognosis of that specific disease. Old age palliative care is slightly different because old people mostly have problems related to chronic illnesses and general deterioration which require long-term care programmes for which regular doctor’s visit is not needed. So doctors must be making infrequent visits to geriatric patients. This could be the reason for old-age patients' complaint that doctors visit them only occasionally or rarely.

Analyses with other variables namely age, gender, marital status, family size and family income were made but since association between the variables are not revealed. So the details of analyses are not given here.

### 8.4 Frequency of Nurse's Visit

The role of a nurse in palliative care is distinct from other specialties. A nurse doesn't have a single role in palliative care. Instead, it is a series of roles geared towards providing support to both patients and families during one of their most arduous times. These roles are in addition to the traditional responsibilities required to be fulfilled by nurses, such as evaluating symptoms and carrying out treatment plans.

Availability of nurses and the quality of care provided by them are crucial in the case of chronically ill or bedridden elderly. The satisfaction of the recipients is that much important in palliative care and therefore each and every one in the team of care providers should be prepared for the same.

It is evident from Table 8.4.1 that majority of the respondents are of the opinion that nurses visit regularly (62.33%). 26.67% of them feel that the visit is frequent. 6.67% feel that visit is occasional and the rest (4.33%) feel that the visit is rare.

#### 8.4.1 Perceptions of Religious Groups on the Frequency of Nurse's Visit

Health care and religious notions are considered as intertwined aspects. The prospects from the patient of different religious credence are in fact making challenges for nursing professionals especially in the case of terminally ill or bedridden elderly. Managing care giving to patients without hurting their credence and perceptions demands extra skills from the component of palliative care nurses. Contentment with the nurses' visit also may be varied with the religious background of the patients. With this presumption, an analysis was made to check whether the perceptions on the frequency of nurse's visit are varied with the religious affiliation of the respondents.

**Table 8.4.1: Perceptions of Religious Groups on the Frequency of Nurse's Visit**

| Religion | Regularly | Frequently | Occasionally | Rarely | Total |
|---|---|---|---|---|---|
| Hindu | 124<br>(62.31%) | 56<br>(28.14%) | 13<br>(6.53%) | 6<br>(3.02%) | 199<br>(100.00%) |
| Muslim | 49<br>(77.78%) | 10<br>(15.87%) | 2<br>(3.17%) | 2<br>(3.17%) | 63<br>(100.00%) |
| Christian | 14<br>(36.84%) | 14<br>(36.84%) | 5<br>(13.16%) | 5<br>(13.16%) | 38<br>(100.00%) |
| Total | 187<br>(62.33%) | 80<br>(26.67%) | 20<br>(6.67%) | 13<br>(4.33%) | 300<br>(100.00%) |

Chi Square=22.11, df= 6, Table Value=16.81, $P \leq 0.01$

The association is significant

However, Muslim respondents seem to have the highest satisfaction level with 77.78% of them getting regular visits from a nurse. If you add the percentage (15.87%) of those who are satisfied with frequent visits of nurses as well, overall more than 93.00% of them are getting satisfaction from nurse visits. Hindu respondents come second with 62.31% of them getting regular visits and 28.14% of them getting frequent visits from nurses. Christian respondents come last with 36.84% of them getting regular visits and another 36.84% getting frequent visits.

The reason for higher portion among Muslim respondents perceive they are regularly visited by the palliative care nurses can be attributed to the active involvement of the Muslim community in palliative care in northern parts of Kerala, an act which has gained universal attention. “While this case of Islamic activism in palliative care is a product of Salafi reformism, the multi-religious context and the secular public domain in Kerala offer an interesting backdrop for the articulation of Islamic activism and charity” (Fountain et al, 2015).

In the case of Christians, the number of respondents who feel the nurses visit them regularly is quite low (36.84%). In Christian families, there may be trained nurses to cater to the needs of the patients. So their requirement may be the advice from the doctors. Since they are satisfied with the service of the doctors, they are not much concerned about the service of the nurses.

### 8.4.2 Perceptions of Educational Groups on the Frequency of Nurse’s Visit

Patients’ education makes them capable to avail of their facility providers including nurses on their requisite. Uneducated patients may lack the awareness or feel the services are not available according to their requisite. Education matters to health firstly through direct effects on the people that engage in it and secondly because its impact on the sentience of services provided. One of the paramount health responsibilities is health service utilization. Education makes individuals to efficiently utilize the services in terms of the communication with health professionals, utilization of preventive treatments, compliance with advice etc.

It is assumed that the educational attainment of the impaired and their perception on the frequency of nurse’s visit are associated. An analysis was carried out to find out the association between the educational attainment of the respondents and their perception on the frequency of nurse’s visit to them.

**Table 8.4.2: Perceptions of Educational Groups on the Frequency of Nurse's Visit**

| Education | Regularly | Frequently | Occasionally | Rarely | Total |
|---|---|---|---|---|---|
| Illiterate | 96<br>(74.42%) | 17<br>(13.18%) | 11<br>(8.53%) | 5<br>(3.88%) | 129<br>(100.00%) |
| Primary | 65<br>(55.08%) | 40<br>(33.89%) | 6<br>(5.08%) | 7<br>(5.93%) | 118<br>(100.00%) |
| Secondary | 17<br>(45.95%) | 16<br>(43.24%) | 3<br>(8.11%) | 1<br>(2.70%) | 37<br>(100.00%) |
| College | 9<br>(56.25%) | 7<br>(43.75%) | 0<br>(0.00%) | 0<br>(0.00%) | 16<br>(100.00%) |
| Total | 187<br>(62.33%) | 80<br>(26.67%) | 20<br>(6.67%) | 13<br>(4.33%) | 300<br>(100.00%) |

Chi Square=22.18, df= 9, Table Value=21.67, P≤0.01

The association is significant

Analysis 8.4.2 explicitly shows that 56.25% of the respondents in the category 'College' say nurses are visiting them regularly and the rest of them say that they are visited by the palliative care nurses frequently. Among the remaining three categories, the majority (74.42%) of the beneficiaries in the Illiterate category say they get regular nurse visits and the portion of the respondents in the other two categories who opine they get regular visits by the nurses are roughly the same (ranging between 45% to 55%). Overall, most patients appear to be satisfied with the frequency of nurse's visit.

Most palliative care units have specific rules regarding nurse visits. Depending upon the patients' medical condition, nurses make weekly, bi-weekly or tri-weekly visits to assess the situation, report to the doctor and get his feedback on further treatment. In cases where the patients have medical insurance covering, the insurance company may require a nurse's report at least once in a fortnight to release payment. Though most palliative care nurses make visits based on the patient's condition and the agency's rule, there are also agencies which allow nurse visits according to the patient's wish. As the condition of the patient improves, the frequency of nurse's visit may decrease. Because of all these rules, most patients get sufficient number of visits from their palliative care nurses.

Analyses with other variables namely age, gender, marital status, family size and family income were made but since association between the variables are not revealed. So the analyses are not included in the report.

### 8.5 Psychological Support by Volunteers' Interaction

Traditionally, caring for the elderly and the diseased has embodied a major facet of voluntary activity. It has been found that including volunteers in palliative care is a positive contribution to genuinely ill patients. The volunteers are to be trained and chartered by the agency. It is understood that volunteer contributions transcend the mere bodily discomforts. Many of the patients revealed the emotional care they received from the volunteers. The unpaid service of the volunteers makes their involution informal. And this informality may equip them to offer maximum psychological and convivial support to the beneficiaries rather than physical or economic.

Volunteers played a major role in the early days of the palliative care movement. They remain to be involved in the provision of palliative care, both in the community and in institutional settings. Although family and trained caregivers provide the majority of end-of-life care, volunteers take up numerous roles, for example, assisting with recreational and social programmes, visiting patients, carrying them out and providing companionship and assistance. These tasks are recognised as core to providing quality palliative care. Previous studies show that volunteers can certainly influence the quality of care for both the patient and those close to them by decreasing stress, offering practical and emotional support and providing a bond to the community (Vanderstichelen et al., 2018).

According to the analysis in the study, 66.67% of the respondents get enough psychological support from the volunteers through chatting with them, 21.33 % get relief from their stress by volunteers' listening to their sorrows.12 % opines that they get released from their mental distress by sharing their concerns with the volunteers.

### 8.5.1 Religious Affiliation and Perceptions on Psychological Support Received

The constructive emotional function of religion has been well accepted but the evidence has not been convincing. Religious belief is expected to reduce psychological distress, especially depression, anxiety and associated physiological symptoms. Religion is thought to ease, relieve pain and suffering, provide faith and meaning and help people cope with problems (Ross, 1990).

Different religions have different concepts on pain and suffering. According to Hinduism suffering, both mental and physical is thought to be part of the unfolding of Karma and is the consequence of past inappropriate action that occurred either in one's current life or in a past life (Whitman, 2007). Islam is a theocentric tradition in which the all-powerful God exercises limitless power in managing all aspects of creation, including wellness and illness, whether individual or collective (Fitzpatrick et al., 2015).In Christianity, it is an accolade to suffer because it is a minuscule bit of what Christ suffered and it is a way of sharing his suffering. Only Christianity delivers this approach to suffering because Jesus Christ grieved and died for humanity.

Different religious beliefs about pain and suffering may lead to different psychological attitudes among the respondents. Here it is assumed that the psychological support provided by the Palliative Care Volunteers is viewed differently on the basis of different religious beliefs of the respondents.

An analysis based on this prevision was carried out in Table 8.5.1.

**Table 8.5.1: Religious Affiliation and Perceptions on Psychological Support Received**

| Religion | Psychological Support by Chatting | Psychological Support by Listening | Psychological support by Sharing | Total |
|---|---|---|---|---|
| Hindu | 127<br>(63.82%) | 46<br>(23.12%) | 26<br>(13.07%) | 199<br>(100.00%) |
| Muslim | 56<br>(88.89%) | 4<br>(6.35%) | 3<br>(4.76%) | 63<br>(100.00%) |
| Christian | 17<br>(44.74%) | 14<br>(36.84%) | 7<br>(18.42%) | 38<br>(100.00%) |
| Total | 200<br>(66.67%) | 64<br>(21.33%) | 36<br>(12.00%) | 300<br>(100.00%) |

Chi Square=21.87, df=4, Table Value=13.28, P≤0.01

The association is significant

It could be understood from Table 8.5.1 that while majority (66.67%) of the respondents opines that volunteers' interaction is limited to chatting with them, a considerable percentage (36.84%) among the 'Christian' respondents says that volunteers do listen to their concerns rather than mere chatting. While majority of the Hindu respondents (63.82 %) and Muslim respondents (88.89%) opine that the volunteers do chat with them to reduce their mental agony, only 44.74% of the Christian respondents feel that mere chatting with the volunteers helps them to reduce their tensions.

Culture, whether religious or ethnic, has a role to play in palliative care because illness and death is viewed in different ways in different cultures. Some live in the belief that there is always some sort of a hope beyond death and others live in the belief that what we achieve in the present life are the only things we achieve. They do not see any meaning and purpose in life beyond that. There is a big conflict in all human beings' minds about all these things when they are suffering, and being able to share these things with the volunteers would soothe them a lot. However, for effective listening on the part of volunteers, the care-recipients should ideally have interesting ideas and experiences to share.

### 8.5.2 Education and Perceptions on Psychological Support Received

Educational status and perceptions on the psychological care given by the volunteers of the Palliative Care are assumed to be associated. Generally people with more educational qualification may have higher incomes. Since highly educated people have higher incomes, they can afford the economic challenges demanded by the debilitated condition. They may be upset about the physical and psychological burden they have created for their family members. They may be also incapable of managing the psychological distress resulting from the isolated condition in the family where others are busy with their own works. In case of such patients, palliative care may be meaningful if it provides the needed psychological support. Volunteers' support is therefore more important for those who expect psychological support above all other services.

Similarly in the case of respondents who are not that much educated, they may be unaware of the non-medical services available with the palliative care team. For such patients and families volunteers may directly or indirectly interfere to provide the same. Psychological support is included in the non-medical services offered by the agency.

Analysis shown in Table 8.5.2 verifies the association between the educational attainment of the impaired and their perceptions on the psychological support provided by the palliative care volunteers.

**Table 8.5.2: Education and Perceptions on Psychological Support Received**

| Education | Psychological Support by Chatting | Psychological Support by Listening | Psychological support by Sharing | Total |
|---|---|---|---|---|
| Illiterate | 101<br>(78.29%) | 20<br>(15.50%) | 8<br>(6.20%) | 129<br>(100.00%) |
| Primary | 75<br>(63.56%) | 26<br>(22.03%) | 17<br>(14.41%) | 118<br>(100.00%) |
| Secondary | 20<br>(54.05%) | 12<br>(32.43%) | 5<br>(13.51%) | 37<br>(100.00%) |
| College | 4<br>(25.00%) | 6<br>(37.50%) | 6<br>(37.50%) | 16<br>(100.00%) |
| Total | 200<br>(66.67%) | 64<br>(21.33%) | 36<br>(12.00%) | 300<br>(100.00%) |

Chi Square=26.95, df= 6, Table Value=16.81, $P \leq 0.01$

The association is significant

It is obvious from Table 8.5.2 that while majority (78.29%) of ‘Illiterate’ respondents says volunteers are only chatting with them, majority among the ‘College’ category opines that volunteers’ interaction extends to listening and sharing. 37.50% of them enjoy the listening mentality of volunteers and 37.50 % are happy with them for sharing their psychological tensions.

As has been already pointed out, palliative care is as much about emotional and psychological healing of the patients and their family members as the physical healing and pain relief of the patient. Since doctors and nurses are assigned specific roles to play in palliative care, it mostly falls to the lot of the volunteers to provide psychological support. Giving psychosocial support by just talking or chatting, which is a form of counseling is easy and most people get the advantage of it. People with higher education, may be because of their better knowledge level, might be able to induce the volunteers to listen to their opinions and enter into a mutually beneficial give-and-take conversation. That could be the reason why volunteers are listening to and sharing with more educated people.

Analyses with other variables namely age, gender, marital status, nature of disability, family size and family income were made but since association between the variables are not revealed. So the analyses are not included in the report.

### 8.6 Financial Support Receiving from the Agency

Particular barriers to the integration of palliative care in low-resource settings include lack of cognizance by policy makers, health professionals and the public of what palliative care is and the benefits it can offer patients and health systems. Supplemental barriers include cultural and convivial credence about death and dying, a misconception that palliative care is only for patients with cancer for those in their last days or weeks of life etc.

It is obvious that care giving process not only put physical, psychological or social strain on the family, it also creates tremendous economic stress to meet the expenses incurred by the precarious situation. Table 8.6 reveals that above 50% of the respondents avail themselves of the service of palliative care to reduce the economic burden of the family. Thus it is understood that Palliative Care agency provides financial support to their beneficiaries.

**Table 8.6: Financial Support Receiving from the Agency**

| Support | Frequency | Percentage |
|---|---|---|
| Free medicine | 191 | 63.67% |
| Rice and Provisions | 47 | 15.67% |
| Others* | 62 | 20.67% |
| Total | 300 | 100% |

** Others include Waterbed, Airbed, Walker, Wheel Chair, Crutches, Diapers, Oxygen equipment etc.*

Palliative care agencies are supposed to help those with serious illness and to improve the quality of life of people living with life threatening conditions. This volunteer agency is providing assistance both physically and morally to the needy. Poor social and economic background compels most of the patients to approach the agencies. Palliative agencies provide medicines, medical equipment, and personal assistance top up to the situation.

In Kerala model palliative care, there is a lot of involvement of the civil society and the public and funding is mostly managed through donations. Table No. 8.6 shows that different types of financial help are provided by the palliative care units based upon the patients' requirements. Medicines appear to be the primary need for most patients and majority (63.67%) of the respondents are getting free medicines from palliative care providers. Of the remaining, 15.67% are seen to be in need of food and other provisions. The remaining 20.67% get medical devices and supplies like water bed, air bed, walker, wheel chair, crutches, diapers, oxygen equipment etc. through palliative care agencies according to their need.

## 8.7 Medical Treatment Other than Palliative Care

Modern palliative care may be given alongside treating the underlying condition, contrary to what many people assume, and can be expected from the time of diagnosis. Similarly, alongside palliative care, treatment aimed at disease control may be needed right up to the time of death.

Palliative care can be secondary at any stage of illness and is best provided from the point of diagnosis. In integration to upgrading quality of life and availing with symptoms, palliative care can benefit patients understand their culls for medical treatment. Along with medicinal treatment, palliative care may be specified and it does not rely on prognosis. Or the palliative care team could remain with increasing focus on comfort care.

It is found that majority (78.67%) of the beneficiaries are not availing other medical treatments. This may be because of their satisfaction with the services provided by the palliative care.

### 8.7.1 Religious Affiliation and Availing of Treatments Other than Palliative Care

The supposed role of God in disease and recovery has a significant impact on people's health care attitudes and habits  People's religious values contribute to certain beliefs and behaviours in health care that are substantially different depending on the faith of the person (Rumun, 2014).  Based on the difference in the beliefs, people may have different attitude towards different treatment methods. On the basis of this presumption, analysis to find out the association between religious affiliation of the impaired and their availed of medical treatment other than palliative care was carried out.

**Table 8.7.1: Religious Affiliation and Treatments Other than Palliative Care**

| Religion | Availing | Not Availing | Total |
|---|---|---|---|
| Hindu | 39<br>(19.59%) | 160<br>(80.40%) | 199<br>(100.00%) |
| Muslim | 6<br>(9.52%) | 57<br>(90.48%) | 63<br>(100.00%) |
| Christian | 19<br>(50.00%) | 19<br>(50.00%) | 38<br>(100.00%) |
| Total | 64<br>(21.33%) | 236<br>(78.67%) | 300<br>(100.00%) |

Chi Square=24.19, df= 2, Table Value=9.21, $P \leq 0.01$

The association is significant

Analysis 8.7.1 reveals that the majority (80.40%) of the Hindus and 90.48% Muslims are not availing any medical treatment other than that getting from Palliative Care. Similarly 50% of the Christians are not availing other medical treatments. However 50% of the category is undergoing some other treatment along with palliative care.

The reasons for not taking any treatment other than palliative care may be different for different people. Irrespective of the religion to which they belong to, some aged people may not require any additional medical aid because they may not be a victim of any specific disease other than the one for which Palliative Care is required. There is no major religion of the world that disapproves of medical treatment but there are religious sects that ask its members to refuse certain types of treatment. For example, members of the religion called Jehovah’s Witness refuse blood transfusion. Then there are those who refuse medicines containing animal fats, alcohol etc. Steroids are also anathema to many. There are even isolated cases where prayer is used as a healing therapy instead of medicines but it can never be prescribed by a doctor and categorized as a form of treatment. Anyhow, the medical world offers plenty of treatment options nowadays that it is highly unlikely that people have to refuse treatment on ethical grounds or on the basis of religion. And none of the respondents in this case belongs to such isolated groups with special medical preferences. If they are not undergoing any medical treatment, it is simply because they do not need it. Whatever the religious background of the beneficiaries, it is understood that only if they have enough payment capacity, they can approach a paid service other than palliative care.

### 8.7.2 Education and Availing of Treatments Other than Palliative Care

Educational attainment of a person influences him/her in lot many aspects of life. Health and health care are also considered as important aspects influenced by individuals’ educational attainment. Individuals who have a high level of education may be aware of the treatment options well when compared to individuals with low level of education. In the case of illiterate respondents or those who have a lower educational qualification, there may be lack of knowledge about the treatment options when undergoing palliative care. This may restrict them from choosing any other medical treatment other than the palliative care.

An analysis was done to reveal whether the educational attainment of the respondents and availing of other medical treatment are associated.

**Table 8.7.2: Education and Availing of Treatments Other than Palliative Care**

| Education | Availing | Not Availing | Total |
|---|---|---|---|
| Illiterate | 9<br>(6.98%) | 120<br>(93.02%) | 129<br>(100.00%) |
| Primary | 23<br>(19.49%) | 95<br>(80.51%) | 118<br>(100.00%) |
| Secondary | 17<br>(45.95%) | 20<br>(54.05%) | 37<br>(100.00%) |
| College | 15<br>(93.75%) | 1<br>(6.25%) | 16<br>(100.00%) |
| Total | 64<br>(21.33%) | 236<br>(78.67%) | 300<br>(100.00%) |

Chi Square=44.66, df=3, Table Value=11.34, P≤0.01

The association is significant

From Table 8.7.2, it is obvious that the higher the level of education, the more the proportion of people who are availing treatments other than palliative care. Among those with college education and more, 93.75% are seen to be taking treatments besides palliative support. Among secondary-school-educated, the corresponding figure is 45.95%, among primary-school-educated it is 19.49%, and among illiterates it is 6.98%.Those with higher education belong to the privileged strata of society and thereby would have access to all types of medical care while it would be difficult for the underprivileged to avail of the same level of expert medical help.

### 8.7.3 Family Income and Availing of Treatments Other than Palliative Care

Chronic disease and incapacitation may have negative, even devastating, socio-economic impacts on people and their families. Internationally, there is a well-established association between low socio economic situations, poor health and salubrity and an incremented risk of mortality among those with serious health conditions. Palliative care is availed of by most of the respondents to avoid the economic burden caused by the ill health and cognate expenditure. Since palliative care offers support by providing accommodations free of cost, most of the beneficiaries from low and middle income families never endeavor to access any other curative treatment other than palliative care.

Analysis shown in table 8.7.3 reveals the association between the family income of the impaired and availing of other medical treatment by them.

**Table 8.7.3: Family Income and Availing of Treatments Other than Palliative Care**

| Family Income | Availing | Not Availing | Total |
|---|---|---|---|
| Low<br>(Below 5000) | 32<br>(13.50%) | 205<br>(86.49%) | 237<br>(100.00%) |
| Middle<br>(5000-10000) | 18<br>(37.5%) | 30<br>(62.5%) | 48<br>(100.00%) |
| High<br>(10000 and above) | 14<br>(93.33%) | 1<br>(6.67%) | 15<br>(100.00%) |
| Total | 64<br>(21.33%) | 236<br>(78.67%) | 300<br>(100.00%) |

Chi Square=18.87, df= 2, Table Value=9.21, $P \leq 0.01$

The association is significant

It is evident from Table 8.7.3 that 21.33% of the sample avail medical treatment in addition to palliative care. Those who avail only palliative care is 78.67%. Among the high-income group families 93.33% respondents are availing of additional medical help. The corresponding figures in the case of the middle-income groups are respectively 37.5% and 13.50%.This difference can surely be attributed to the ability of higher-income groups to pay for good medical help and probably also to their knowledge of new treatment options that are becoming available. As against this, low-income families are forced to restrict their treatment only to palliative care due to lack of financial resources.

Analyses with other variables namely age, gender, marital status, family size and nature of disability were made but since association between the variables are not revealed. So the details of the analyses are not given here.

### 8.8 Service Availability on Request

It is an established fact that palliative care is a necessity in the present-day society. Patients and their family members generally get the contact details of palliative care units from hospitals or doctors. However, for palliative care to be effective, it should be easily accessible and adequately available. Sometimes, in crowded cities, especially in low-resource countries, there may be too many patients who need palliative care and the number of palliative care workers may not be sufficient to cater to everybody's needs. Likewise, in rural areas there may not be functional palliative care units all the time.

Study endeavoured to analyse the availability of palliative care team on request of its beneficiaries. It is natural that the accommodation may be blocked due to the unavailability of health care team for expeditiously increasing infirm individuals.

**Table 8.8: Service Availability on Request**

| Response | Frequency | Percentage |
|---|---|---|
| Always | 103 | 34.33% |
| Often | 158 | 52.67% |
| Sometimes | 39 | 13.00% |
| Total | 300 | 100% |

The analysis in Table No. 8.8 shows that for the majority of the respondents (52.67%) palliative care is available quite ‘often’, though not always. Only 34.33% informed to have been able to ‘always’ avail palliative care. Those who have got it only ‘sometimes’ is a small portion (13.00%).

In some cases, people may not be aware of the existence of such a service while in other instances they may not have any faith in the utility of such a service. Some patients may need special, disease-specific palliative care and there may not be enough volunteers with commensurate skill for managing it. Finally, in many areas there may be a general shortage in the number of palliative care workers.

### 8.9 Satisfaction with the Service of the Doctor

Palliative care units consist of doctors, nurses, and volunteers. Each of them has their own role to play in alleviating the pain of the care-recipient and it is the cumulative action of all that leads to minimizing the discomfort of the patient. However, for palliative care to work, the patient has to be satisfied with the performance of all.

Patient satisfaction level is the degree to which a patient is gratified with the care he or she gets. Along with pain relief, symptom control etc., this gratification of a patient is a strong indicator of a doctor’s performance ability. It is a measure of the quality of care and helps a palliative care doctor to get insights into various aspects of palliative care like pain management and patient empathy. Since many palliative care patients do not expect a return to normalcy, the personal touch and physical relief that a doctor is able to provide is of extreme importance to them.

**Table 8.9: Satisfaction with the Service of the Doctor**

| Response | Frequency | Percentage |
|---|---|---|
| Highly Satisfied | 80 | 26.67% |
| Satisfied | 186 | 62.00% |
| Not Satisfied | 34 | 11.33% |
| Total | 300 | 100% |

Patient satisfaction is one of the main criteria for measuring a doctor's performance and planning of further care. Patient satisfaction can be measured by the patient's own responses to the doctor, his or her cheerfulness, the way he or she interacts with all healthcare providers in the group, the family members' opinion about the patient's attitude, and the increasing confidence of the patient. According to Table No. 8.9, 62.00% of the respondents are satisfied with the performance of the doctor and only 26.67% are highly satisfied. Then there are 11.33% who are not satisfied with their doctors' performance at all.

Lack of satisfaction in doctor's performance may sometimes arise from the family's situation itself. In families where the patient is very much worried about the financial situation or the future of the children, palliative care is unlikely to have any effect on him/her and he/she would feel dissatisfied with the doctor's performance. In some other cases, patients expect the doctors to ward off their suffering as if by magic and are unhappy when it does not happen. Condescending attitude of the doctor, poor quality of care because of the doctor's lack of experience, and absence of timely help are other things that make patients dissatisfied. But the fact that nearly 89.00% are, by and large, satisfied with the service of the doctor shows that most palliative care units are functioning very well.

### 8.10 Satisfaction with the Nursing Service

The quality and adequacy of health care services can be measured based on views and satisfaction of patients and their relatives (Merkouris et al., 2013). Patients' satisfaction with the care received from nurses has become established as the most important predictor of the overall satisfaction with the services provided by the agency (Goh et al., 2017). Doctors are more of decision-makers and it is the nurses who put their advice into practice and interacts with the patient. So patient's satisfaction with the nurse is a very crucial factor for the healing process in palliative care.

**Table 8.10: Satisfaction with the Service of Nurse**

| Response | Frequency | Percentage |
|---|---|---|
| Highly Satisfied | 96 | 32.00% |
| Satisfied | 194 | 64.67% |
| Not Satisfied | 10 | 3.33% |
| Total | 300 | 100% |

From Table No. 8.10 it can be seen that the portion of patients (32.00%) who are highly-satisfied by the performance of nurses is more than that of those highly-satisfied by the performance of doctors (26.67%). In the 'satisfied' category also, there are 64.67% who are satisfied with nurses' services while the corresponding percentage is only 62.00% in the case of doctors.

As a result, palliative care recipients who are not satisfied with the service of nurses are only 3.33%.

A nurse-patient relationship is therapeutic and it is something more than mere treatment. To be effective, a nurse needs to establish a distinctive perspective with a patient and this must be based on an understanding of not only that patient's medical problem but also his or her beliefs, fears, preferences, and cultural attitudes. Respect for the patient, empathy, and a genuine interest in curing the patient must define that relationship. If a nurse's attitude to a patient incorporates all these, that relationship will be highly beneficial for the patient. It is probably because of the uniqueness of this relationship that many patients easily bond with a nurse. From the analysis in the table, we are prompted to believe that most of the relationships palliative care patients have with nurses are very healthy.

### 8.11 Satisfaction with the Medical Care of Palliative Care Team

Palliative care units always work as a team, with no rules of hierarchy among them. They work with strong bonds and good communication between team members.  All palliative care units need not necessarily have the same number or same type of service providers. Besides a doctor and nurse, a team may consist of care-providers with varying skills like nursing assistants, social workers, dietitian, pharmacist, speech therapist, respiratory therapist, and physiotherapist. Motivational speakers and counselors may also be part of some such teams. All these skills are used in different combinations, depending upon the needs of the patients. Thus patients' satisfaction with the medical care provided by the agency was analysed.

**Table 8.11: Satisfaction with the Medical Care of Palliative Care Team**

| Response | Frequency | Percentage |
|---|---|---|
| Highly Satisfied | 97 | 32.33% |
| Satisfied | 190 | 63.33% |
| Not Satisfied | 13 | 4.33% |
| Total | 300 | 100% |

What a patient essentially expects from a palliative care team is the removal of pain and other distressing physical problems, caring and compassionate behavior, timely care and response to his/her problems, and friendly interaction with not just the patient but his/her routine caregivers and other family members. A patient’s overall satisfaction with the team’s services will depend upon the extent to which they are able to deliver all these. However, their main evaluation yardstick about their medical care is bound to depend on the team’s ability to reduce pain and discomfort. In many cases, palliative care providers are able to provide pain relief by integrated team work and holistic care but not always so.

According to Table No. 8.11, nearly two-thirds of the respondents (63.33%) are satisfied with the medical care provided by palliative care units but only about one-third (32.33%) are highly satisfied. A small percentage (4.33%) is not satisfied at all. One main reason for this dissatisfaction could be that there was no alleviation in their physical suffering despite medication. Further, palliative care providers may sometimes be constrained to stick to certain standards of care and best medical practices which the patient may not approve of, because of his/her situation.

## 8.12 Satisfaction with the Medicine Provided

Patients' satisfaction on the medicines given depends on many factors. Some people, especially those who are in too much discomfort, may expect immediate results from taking a medicine. When they fail to get it, they lose faith in that medicine. Some are afraid of medicines' side effects because they themselves might have experienced or witnessed negative reactions ensuing from it. Yet others may not understand why a particular medicine is being administered. Those who are suffering from a combination of health issues might be taking too many medicines and this may create an aversion in them towards medicines. Prohibitive cost of a medicine, mistrust of the person who forces him/her to take it, and fear of developing dependency on medicines, are the other reasons that may create lack of satisfaction among patients in the medicine provided.

Palliative care workers take all these aspects into consideration while prescribing medicines to care-recipients. Further, when palliative care is provided at home, certain methods of drug administration may not be possible or practical. Analysis was done to verify the satisfaction of the patients with the medicines provided by the palliative care agency.

**Table 8.12: Satisfaction with the Medicine Provided**

| Response | Frequency | Percentage |
|---|---|---|
| Highly Satisfied | 47 | 15.67% |
| Satisfied | 223 | 74.33% |
| Not satisfied | 30 | 10% |
| Total | 300 | 100% |

The proper use of medicine is fully integrated into the idea of palliative care. In fact it can even be called the foundation of palliative care. The fast growth of palliative care units and society's acceptance of the service are attributed to the "integration of palliative care into mainstream medicine, an aging population, and an increasing emphasis on improving patient care" (Wentlandt et al, 2016). According to Table No. 8.12, nearly three-fourths (74.33%) of the respondents are satisfied with the medicines provided for palliative care while 15.67% are highly satisfied with it. However, 10.00% is not satisfied with the medicine. May not be it is working properly in the patients. Many drugs like morphine, barbiturates, propofol, are there to lessen pain and nervousness of patients and every patient may not like it.

## 8.13 Satisfaction with the Service of Volunteers

The staffing profile of Palliative Care is centred on a multidisciplinary approach to care with nurses, doctors, health care assistants, social workers, physiotherapists, chaplains and a range of complementary therapists working together to support the individual needs of range of patients (Scott et al., 2009). It has been found that including volunteers in palliative care is helpful contribution to seriously ill patients. The volunteers are to be skilled and stimulated by the agency. It is understood that volunteer contributions transcend the purely physical problems. Many of the patients revealed the emotional care they received from the volunteers they interacted with. The unpaid inclusion of the volunteers makes their involution informal. And this informality may equip them to offer maximum psychological and convivial support to the beneficiaries rather than physical or economic.

**Table 8.13: Satisfaction with the Service of Volunteers**

| Response | Frequency | Percentage |
|---|---|---|
| Highly Satisfied | 95 | 31.67% |
| Satisfied | 195 | 65.00% |
| Not Satisfied | 10 | 3.33% |
| Total | 300 | 100% |

Those who join palliative care units as volunteers do so because of a genuine interest in helping others. These volunteers may work in hospitals helping in the care of seriously ill patients, may provide palliative care at home, and may also counsel the patient's family members. Many of them have the basic training to provide patient care like feeding, cleaning, can give advice and emotional support to frightened patients, and train family members on how to interact with the patient. Some of the volunteers even continue to maintain contact with the family during the period of bereavement to help them find closure. There are also general volunteers and volunteers with special skills and the services the two groups provide will be different.

According to Table No. 8.13, 65.00% are partially satisfied, 31.67% are highly satisfied, and 3.33% are not satisfied with volunteer services. These percentages are more or less the same as that of patients' service satisfaction with nurses. So, there could possibly be many similarities between palliative-care receivers' relationship with nurses and their relationship with volunteers in the service.

## 8.14 Satisfaction with the Time Spent by the Team

The needs and the distress caused by the debilitated condition are better understood by the palliative care team members as they are able to spend time and their services can be utilized both during treatment and also at the end of life (Devi, 2011). For any health care professional, dealing with symptoms of any unpleasant, debilitating, life-limiting disease is a difficult challenge. As a team method, Palliative Care offers an answer and has a crucial role to play in treating such patients. Palliative care allows the patient and the family to communicate with each other and health care providers better. It helps them identify the priorities and set goals for the future that can lead to a meaningful, satisfactory life for both the patient and the family.

**Table 8.14: Satisfaction with the Time Spent by the Team with the Clientele**

| Response | Frequency | Percentage |
|---|---|---|
| Satisfied | 250 | 83.33% |
| Not Satisfied | 50 | 16.67% |
| Total | 300 | 100% |

There are patients who may need palliative care for years and there are others who may need it for a couple of weeks. In many cases, palliative care is availed of near the end of life and comes to an end with the death of the patient. Some patients need palliative care occasionally for changing a catheter or getting injections. Some may need them daily for getting their bath or for help with their walking. There are still others who may need frequent administration of pain medication, counselling, emotional support etc. and they may like the palliative care workers to be with them for longer durations.

Each palliative care unit may have many patients to care for so that too often they do not have enough time to spend with each patient. However, here again, respondents of Kerala by and large (83.33%) appear to be contended with the time that palliative care workers are spending with them. There is only 16.67% who apparently want the service providers to spend more time with them. Increasing the number of palliative care units in the area is the only solution for it.

### 8.15 Satisfaction with the Overall Services

Palliative Care offers relief from pain and other upsetting symptoms, affirms life and regards dying as a natural course, according to the WHO. It has no objective of hastening or delaying death. It tries to integrate the psychological and spiritual aspects of patient care. Palliative Care offers a support system to help patients live as actively as possible until death and to help the family cope with during patient's illness and in their own bereavement. All these intentions should be made practical and the patients and family are to be satisfied with the services provided by the agency.

**Table 8.15: Satisfaction with the Overall Services**

| Response | Frequency | Percentage |
|---|---|---|
| Highly Satisfied | 48 | 16% |
| Satisfied | 223 | 74.33% |
| Not Satisfied | 29 | 9.67% |
| Total | 300 | 100% |

Pain-relieving is not the only aim of palliative care. It is an integrated, holistic system that addresses not just the physical problems of the patient but the emotional and logistical aspects of the patient's problems as well. Further, it also focuses on the emotional wellbeing of the family members who are the primary caregivers of the patient. Encouraging meaningful interaction of the patient with his family, friends, and society; helping the patients and their family members in making choices; providing financial help to care-receivers who require it; and giving basic medical training to family members so that they can do many of the care-related jobs themselves are some of the things that palliative care services focus on.

So, a patient's satisfaction with the success of a palliative care agency will reflect a satisfaction in all these types of services they are providing. Of course, different patients may be satisfied with different aspects of the service. Table No. 8.15 shows that 74. 33% of the respondents are satisfied with the overall services while 16.00% are highly satisfied too. The remaining 9.67% are seen to be not satisfied. This may due to different reasons such as their expectations about the services were different, service providers had faltered, and the patient's situation was such that no amount of palliative care could help him.

### 8.16 Perceptions on the Despondent Life in the Absence of Palliative Care Agency

Palliative care can enable people to be comfortable at the interruption felt in their lives and simplify their concerns and that of their families sanctioning them to relish their time together. The varied aspects of care provided by the agency make it that much consequential among the beneficiaries. Subsequently the absence of such an agency may engender marginally despondent situation in the lives of the care recipients and their families. Palliative care is not only for the final days. An individual may receive palliative care for many years, months, weeks or days, depending on their circumstances. It is available for every one regardless of age, culture, background, notions etc. For those with a serious life-constraining condition, palliative care can make it a more positive experience. It is found that the lions share (82%) of the beneficiaries perceive the absence of the palliative care agency make them feel that their life is despondent and only 18% of them do not perceive their life becomes despondent in the absence of the agency.

### 8.16.1 Education and Perceptions on the Despondent Life in the Absence of Palliative Care Agency

Patients with higher educational qualification automatically have good jobs and incomes to afford the bedlam created by the precarious situations. Similarly those with lower educational attainment may struggle to handle the disturbed household matters and may in need of support from agencies like palliative care. If there are no such supporting agencies, their life may be full of hurdles. An analysis was done to find out whether the educational attainment of the impaired and their feel of despondent life in the absence of the agency are associated.

**Table 8.16.1: Education and Perceptions on the Despondent Life in the Absence of Palliative Care Agency**

| Education | Make Life Despondent | Does not Make Life Despondent | Total |
|---|---|---|---|
| Illiterate | 119<br>(92.25%) | 10<br>(7.75%) | 129<br>(100.00%) |
| Primary | 94<br>(79.66%) | 24<br>(20.34%) | 118<br>(100.00%) |
| Secondary | 25<br>(67.57%) | 12<br>(32.43%) | 37<br>(100.00%) |
| College | 8<br>(50.00%) | 8<br>(50.00%) | 16<br>(100.00%) |
| Total | 246<br>(82.00%) | 54<br>(18.00%) | 300<br>(100.00%) |

Chi Square=25.94, df=3, Table Value=11.34, P<=0.01

The association is significant

It is explicitly revealed in analysis 8.16.1 that the educational attainment of the respondents and the feel of despondent life in the absence of palliative care agency are inversely associated. While 92.25% of the ‘Illiterate’ respondents cannot think life in their impaired condition without palliative care, only 50% of the ‘College’ category feel the same.

Absence of palliative care is seen to significantly reduce the quality of life, especially for illiterate people who belong to the lower strata of the society. Because of the limited resources to which they have access to, without the help of palliative care, they may find it difficult to recover from illnesses or have a peaceful death. Since more educated people may have the necessary resources to procure help even if there are no palliative care agencies, they may not feel the pinch of the system’s absence to the same extent. For example, in all parts of Kerala, there are agencies which provide ‘home nurses’ for the sick. These nurses are to a certain extent a substitute for palliative care but they are expensive and everybody will not be able to afford their services.

Analyses with other variables, namely, age, gender, marital status, family size, nature of disability, religion and family income were made but since association between the variables are not revealed. The details of the analyses are not included in the report.

### 8.17 Opinion About Improving the Services

In many developing countries, health care providers struggle to provide palliative care with inhibited resources and efforts are underway to address the concrete desideratum for palliative care by establishing a sodality of palliative care workers and some local volunteer organizations and international organizations fortifying palliative care works. However the fortification and sustained efforts from the local regimes and international stakeholders are very crucial and critical. As voluntary services, palliative agencies are passing through many hurdles. Financial assistance, transportation facilities, lack of serving members, etc. are some of the important issues they are facing. These are the hindrances in their smooth services which also affect their goal.

**Table 8.17: Opinion about Improving the Services**

| Opinion | Frequency | Percentage |
|---|---|---|
| Improvements necessary | 22 | 7.33% |
| No specific improvements necessary | 278 | 92.67% |
| Total | 300 | 100% |

However, respondents in Kerala appear to be quite satisfied with the available palliative care services because 92.67% are of the opinion that no specific improvement is required. However a meager portion (7.33%) feel that improvements in the service can be brought about.

Palliative care can, first of all, be improved by better dissemination of information about the different services that are provided. For example, some are under the wrong impression that palliative services can be provided only for terminally ill patients. Such erroneous impressions should be removed. More funding is necessary for palliative care agencies so that the units can offer better remuneration for their workers. Such a situation will attract more and better talents to the service. Doctors should refer patients for palliative care as early as possible and family members should be involved in the decision-making process of palliative care workers.

## Summary

Palliative medicine itself has become a field of medical specialty and unlike other specialists, palliative care doctors are trained in symptom management, providing of psycho-social support to patients and their families, and will have good communication skills, and ethics-based decision-making skills. Besides a doctor and nurse, a palliative care team may incorporate nursing assistants, social workers, dietitian, pharmacist, speech therapist, respiratory therapist, and physiotherapist, and even motivational speakers or counselors. That is not to say that all palliative teams will consist of all these specialists. Depending upon the care-recipients' varying needs, palliative care teams may use many of these skills in different combinations.

Most palliative care teams incorporate someone who is an expert in providing psychological support. Some palliative care teams may even have clinical psychologists as members, but other teams may have volunteers who are resourceful communicators and are able to find creative solutions for patients' problems. Where patients need material or financial help, they may find resources to arrange for it, and in cases where the patients' agony is totally unrelated to financial or structural problems, they will try to find innovative ways for healing his/her mind.

Palliative care focuses primarily on reducing pain and ensuring the comfort of the patient. This is where palliative care providers differ significantly from mainstream doctors whose primary focus is on fighting and subduing the disease. Palliative medicine is not designed to fight the disease till the last. It is designed to heal the mind and to that extent it may let the disease take its course if that will be more painless for the patient. Because of that, palliative care providers are often forced to take crucial ethical decisions while providing their services.

The socio-economic support provided by the palliative care agency help the beneficiaries in maintaining their social relationships and balancing their family finance. The time spent with the beneficiaries to offer social support by the palliative care team console the patients and their families who are most of the time detached from the society. Financial assistance arranged by the agency through free medicines, regular home visits, giving medical accessories free of cost also save the disabled and their family from economic deterioration.

Palliative Care is actually every one’s responsibility to the community. Voluntary service associated with palliative care may produce more team members to offer social support to the marginalized group. Similarly, to provide effective financial support to the needy, Palliative Care itself to be funded properly either through the State or through private sponsors.

Interacting with nurses and other staff in the hospital environment is among the main obstacles for family members, as the patient is "discharged to the family." In view of the more than two decades of research that records the possible risks of family care, health practitioners' lack of specific attention to care givers is a significant gap in health care. Care givers are unrevealed patients themselves, due to their physically and emotionally exhausting work as caregivers and decreased exposure to their own wellbeing and health care, with significant adverse physical and mental health effects. Declines in physical health and premature death among caregivers in general have been reported (Reinhard et al., 2008).

Family caregivers are often considered as “secondary patients,” who require and ought to have support and guidance. Research contributing to this caregiver-as-client perspective focuses on how to safeguard family caregivers’ health and wellbeing, because their care giving responsibilities consign them at high risk for harm and negative consequences. And also the family caregivers are unpaid caterers who frequently need help to be trained how to become capable, harmless volunteer workers who can better assist their care recipients in managing the stressful situations. It is found from the analyses that most of the beneficiaries are getting the service of palliative care agency whenever they require and they recognize the support as a relief in easing the care burden of their family care givers.

It is also important to note that the frequent visit of doctors to provide directions in medications and diet make the patients and care givers confident in continuing the treatment. Assistance by the nurses in bodily care of the disabled is considered as much valuable as it reduces a considerable amount of physical strain of the care givers. The importance of keeping the patient free of tension arising from the increasing stress of their care givers is also considered by the agency. Even though the beneficiaries in the study reported less physical, emotional, and financial strain because of the frequent interventions of the agency in providing the required assistance, this problem should be fully addressed because it is as important a part of palliative care as medical treatment. Unless there are extensive and continuous efforts to advance services and wherewithal for family caregivers, by governments, health authorities, and research councils, palliative care will fail to deliver upon its core function of adequately supporting the patient along with the family (Hudson and Payne, 2011).

# CHAPTER 9

# CASE STUDIES

Qualitative research usually focus on the way of individuals interpret and understand their experiences in social life. By conducting interviews, observations and case studies, researchers execute qualitative studies to provide a detailed understanding into individual behaviours, attitudes, emotions and experiences. Qualitative research does not include statistical analysis and empirical calculation (Brink, 1993). Recently the emphasis on qualitative research is increasing and it is considered as indispensable in social science research. However, qualitative research assists and reinforces the findings of quantitative research which is apparently based on statistical tests and consequent inferences. Thus mixed method is more preferred by new social scientists as the results of the study to be recognised by the entire research community. There are number of methods in qualitative research like ethnography, discourse analysis, case study, open-ended interview, participant observation, historical research etc. (Cibangu, 2012).

Case study is a popular method among the researchers who are doing qualitative studies. A case study is usually a study of a single case or a small number of cases (Rebolj, 2013).While most of the quantitative studies are none other than testing hypotheses, here case studies may generate hypotheses. Researcher collects the minute details about the cases to elucidate extensive information on each case. After gathering sufficient data from the selected cases they are analysed based on the specific objectives of the study. When inferences are obtained from the analysis and interpretations, the researcher will be able to verify them with the results obtained through statistical inferences.

The chapter discusses three specific cases selected from the field of research. Each case is unique in nature and they reflect the sufferings of the individuals who become chronically ill or disabled and also the process of overcoming their struggles through appropriate interventions by Palliative Care Agency.

## Case 1

Palliative Care is referred to by many people as end-of-life care also, either by choice or by mistake. While the two phrases are not exactly synonymous, substituting one for the other is probably not a big mistake. Those who use both in the same sense cannot be faulted because in most cases people start requiring palliative care when they reach the final stage of their lives. When doctors show their helplessness about introducing any fresh treatment regimen for a patient, because of the incurable or debilitating nature of the disease, the patient and his/her family gets the message. They understand that the patient's time on earth is limited. For some families such a situation may even have grave financial implications because the patient may be a young, earning member of the family. Nevertheless, they do their best to reconcile with the situation and introduce palliative care to minimize the patient's suffering.

However, it is erroneous to think that all palliative care requirements happen at the end of people's lives. Many people rely on palliative care for serious diseases like cancer. Though some do die, some cancer patients get cured and return to life. And there is another category of patients who have not reached the last stage of life, but still suffer from physical disabilities for which there is no cure. They need another type of palliative care. Their problem may not have a cure and they may not have any hope of returning to an active, productive life, but then it is not the fag end of their life also. Such patients need palliative care of a unique type for building a confidence with which they can face the long years ahead. Palliative care will have to be a constant presence in the lives of such people. There is a spiritual aspect to palliative care and it is probably this facet of the discipline that comes into play in the treatment of such patients.

It is difficult to correctly define what the spiritual facet of palliative care is because spirituality has a wide range of connotations, based on individual perceptions and social settings. However, in the context of palliative care, the spiritual aspect of care can be considered successful if caregivers are able to solve the problem of the existential dilemma of a patient. When palliative care providers can convince even a most unproductive patient that the world still needs him or her, it becomes a great success of palliative care.

The case of Muhammed (name changed) is an example of how the spiritual facet of palliative care can work wonders even for a patient who feels that he has hit rock bottom. Muhammed was a popular Karate instructor, who had got a black belt at the age of 16, and since then had been training others. He was apparently one of the first 10 black-belt holders in India. In April 2000, when he got married at the age of 29, like every young man, he was full of hopes and dreams for future. But just one year into his marriage, while coming home after a class, he fell into a pit and sustained a spinal injury. The world turned upside down for him and his 18-year-old wife Rasia (name changed) from that day.

For about a year, Muhammed got himself treated in a hospital in Perinthalmanna. He underwent a surgery and was in the ICU for 22 days after the surgery. Later he was shifted to Calicut Medical College Hospital. Muhammed and his wife went from hospital to hospital and doctor to doctor, hoping for a miracle cure. But the verdict of everyone was more or less the same – Muhammed would never be able to walk again in his life. It was a heart-breaking avowal that no human being would ever like to hear, especially in the prime of one's life. But he had to accept it. Besides enduring the physical pain and disability, Muhammed went through immense mental agony also, thinking about the suffering of his young wife. He even advised her to leave him and start a new life elsewhere, but she refused to leave him. Despite her young age, she turned out to be a tower of strength, exceeding all his expectations. She stood beside him like a rock. Nothing could break her spirits and her love for him. So eventually he accepted her faith in him and life, and realized that she would be his life and love and support for the rest of his life.

Their families were also very supportive, despite the fact that there was some confusion in the beginning. They too had to go through a lot of financial difficulties and mental agony. They helped both Muhammed and Rasia in every way with whatever resources they could. To protect his body from further deterioration, they saw to it that he was turned around frequently from one posture to another. This ensured that he never developed a single bedsore despite being bedbound for years.

It was while undergoing treatment at Calicut Medical College for his problem that he heard about the Institute of Palliative Medicine (IPM) in Kozhikode. He was at the hospital in connection with the treatment for paraplegics. Muhammed contacted Dr Suresh Kumar who was one among the first few of the Palliative Care initiatives. He was admitted at IPM for 15 days as it is the usual period for every patient referred to IPM. Muhammed was one of the early admissions at IPM. IPM was inaugurated only on 15th January 2004 and Muhammed got admitted there on 28th January 2004.

After their first stay at IPM, Muhammed and Rasia returned home with a new sort of satisfaction and inexplicable energy. However, they came back to IPM after three months. The second visit widened Muhammed's horizons better because during that visit the doctors persuaded him to attend a neighbour's wedding. At the wedding venue, while mixing with other people, for the first time after the accident Muhammed realized that he had been missing friendships and human company tremendously. This realization led to his seeking more human contacts. Then onwards Muhammed and Rasia started returning to IPM after every 3 months. Every time they came, they felt more energetic and hopeful with a conviction that mere physical disability is not the end of everything good in life.

Muhammed says that the love that the IPM people have given him is constant. He feels permanently indebted to them as they have made him believe in the immense beauty and goodness of life despite all the punishments it may mete out. Muhammed and Rasia consider the members of IPM as their family members. Over the time, Muhammed and Rasia have become like ordinary couples, enjoying life by going out or watching movies together. They go to visit friends and attend weddings of relatives. Both of them are now helping others in similar predicaments to reconcile with the inevitable and not to lose faith in life by finding joy in the positive things that life still holds out.

At home, Rasia is the primary care giver for Muhammed. They still visit IPM frequently to renew and strengthen the bonds they have woven there. These visits also give Rasia some respite from her daily caregiving responsibilities because at the institute she gets help in caregiving. When someone asked Rasia whether the people of IPM were like their family, she replied that they were not 'like their family' but their family itself which they have to visit regularly.

Muhammed addresses Dr Suresh Kumar as 'Sureshji'. Dr Anil, Dr Shabir, and Dr Anwar are the other few names mentioned by Muhammed.

"IPM is very different from ordinary hospitals", Muhammed says with delight. "Everyone at IPM is equal whether it is a doctor, nurse, volunteer or even a patient. We will not feel as a patient", he adds. According to Muhammed, IPM is his second home. He says he gets sleep only at IPM except his home. That is the extent of attachment and support he has got from IPM. Muhammed shares the happiness and psychological support IPM has given to him and his family to energize from his desperate situation.

Muhammed continues to be incapacitated and cannot move by himself or feed himself. He needs help for everything. But the ambience in the palliative care centre has changed his spirits and his outlook on life. He is immensely happy with the home-like ambience of the centre where the doctors, nurses, and other staff behave as if they are one large family, something like the joint families that were common in erstwhile Kerala. The family near IPM where Muhammed and Rasia attended a wedding for the first time after the tragedy, continues to visit them whenever they are at IPM. The electric wheelchair provided by IPM helped a lot to move around; he says. Medicines required for him are being provided by IPM. Medicines are also given during each visit by the team to his home. Doctors had also regularly visited his home. Muhammed proudly opines that he could make many important acquaintances only because of the contact at IPM. Megastar Mammootty had spent one hour with Muhammed and his family in an occasion. He also got a chance to speak a few words and share the stage with Great Singer KJ Yesudas which is a dream of every Malayali. Thus Muhammed is also now a celebrity among the Palliative Care Community. He substantiates that he would not be alive if he had not reached IPM. These words are enough to represent the attempt and support of Palliative Care to integrate the bedridden patients back to their normal social life.

If Muhammed's story is the story of the immense capabilities of palliative care, it is also the story of exquisitely beautiful, undying love. Rasia was only 18 with limited experience of life when the tragedy struck. But she faced the catastrophe with unparalleled presence of mind and fortitude and never even once gave a chance to make Muhammed feel that he was imposing on her or was a burden to her. If he couldn't move his arms or legs, she became his arms and legs that gave him mobility. They became not just two bodies and one heart like it is generally said about lovers but became one body and one heart. It was almost as if they melted into each other. There was no existence for one without the other. It is the story of the power of love to conquer everything. It is the story of how beautiful relationships can be woven out of even the gravest misfortunes. It is a love story beyond parallels, one that we rarely see in real life, though we may read a lot of such things in Rumi's poetry or Takazhi's novels.

We see welfarism at its best in the above instance. A welfare state is a system in which the state takes care of the health and well-being of its people, especially those who are in some type of need. Under such a system, the state ensures opportunities for all and equitable distribution of wealth through redistribution. Institute of Palliative Medicine (IPM) may not be fully state-sponsored but it is a typical example of how a society takes care of its individuals who are in need. IPM is a World Health Organisation Collaborating Centre for community participation in palliative care and long-term care. It is a training and research arm of Kerala's Pain and Palliative Care Society (PPCS) located within the Government Medical College of Kozhikode and has come to be known as ‘Kerala model’ where local people and authorities collaborate in the process of welfarism. IPM not only provides care for even for long-term patients but also works for creating empathetic, concerned groups of people who are able to understand the suffering of others and also understand that it is their duty to join in the effort to alleviate that suffering.

## Case 2

Like most of the Indian middle class housewives, Santha (name changed) has all along been a hardworking woman. She had married young but her mother had trained her well in household chores even at a young age. Her husband Gopalan (name changed) cultivated a piece of land he had inherited and though the family was not rich, the income from the farm was enough to keep them in reasonable comfort. When Santha came to her marital home as a young bride, she lived with her husband and in-laws in an extended family. She shared all the housework with her mother-in-law.

Over the years, she gave birth to 2 girls and had a family of her own. And as her in-laws aged, and died later, she had the additional job of caring for both of them. Rest became some forgotten luxury for her. And as the girls grew up, expenses increased. Her younger daughter wanted to take dance classes. Such classes cost money but Santha did not want to refuse permission and discourage her daughter. The income from the farm was not sufficient for any extras and Santha started thinking of ways to augment the income.

She joined a woman's collective to get a loan. When the loan was sanctioned, she bought a cow which soon produced enough milk to provide her with an extra income. But the cow significantly increased her workload. Still Santha never grumbled because she belonged to a generation of women raised on a diet that a woman's primary duty was to ensure the welfare of her family. She never felt that she required time for herself. "It was very rarely that any of us saw my mother sitting down," one of her daughters said. "And even on the rare occasions we saw her sitting, she would either be stitching new clothes or mending old ones."

After her daughters got married and moved to their new homes, Santha's workload did decrease a bit but there were other problems. For the second daughter's wedding, they had to take a loan to meet the wedding expenses. So now Santha had to find ways to repay it. She had already bought another cow but now she decided to raise some chicks too to augment the income. Her small poultry business worked well, and soon she was able to sell eggs too, besides milk.

One day, as she bent to pick up eggs from the chicken coop, she felt a shooting pain in her abdomen. But it disappeared soon so she didn't think anything much about it. But a week later, the pain came again when she was stirring something in the kitchen. This time it did not disappear fast as it did the first time, but still after four or five minutes, it went away. However, in the next six months, it reappeared a few times and each time it was more intense than the previous time. Once it came when she was sitting on her haunches and milking the cow. And the pain was so sharp that she screamed, lost her balance, fell down and the milk pail slipped from her hands and hit against a stone. Her husband came out hearing the commotion. He tried to help her up and had a difficult time to somehow raise her from the ground and get her inside. He made her lie down but her pain did not disappear fully. On the advice of a neighbour, she took some painkillers and slept fitfully that night.

Next morning, Gopalan took Santha to a nearby clinic and the doctor instantly sensed that her problem was not simple. He referred her to the Medical College Hospital. The doctor there prescribed a series of tests first of all – x-rays, blood tests, ECG, MRI scan and ultrasound. Gopalan's and Santha's world turned upside down from that day.

First of all, the Medical College Hospital was so far away that making the trip every day was not easy. Gopalan had no vehicle of his own so that they had to travel by public transport. The buses were so crowded that Santha often did not even get a place to sit. And there was no direct bus from their home to the hospital. They had to change the bus at one place and often wait there for another 15 or 20 minutes for the connection bus. Often they had to wait long at the hospital till their turn came and then return all that way back after that.

There was a private hospital near their home but it was very expensive. So they could not afford it. But one day Santha was so tired to take the bus journey that Gopalan tried to hire an auto-rickshaw. But autos did not go all the way from his village to the medical college hospital because of some rules regarding area licenses. So he had to hire three different autos by the time they reached the hospital and it turned out to be very expensive also.

There was another type of problem at home. Santha was too weak to milk the cow or clean the chicken coop. Gopalan did not have much expertise in doing these jobs. Nor did he have time to spare for it after his farm work. The first few days a friendly neighbour came and helped the family. After that Gopalan now and then got some outside help to do the job. That became another expense and the job was mostly not done satisfactorily.

Then there was the problem of household chores. One of Santha’s daughters came and stayed for a few days and did all the housework. But she had some job in a private company and if she took too much leave, she was sure to lose her job. So she rushed back after a few days. The other daughter was not in a position to help because she had two small children who needed constant attention.

Finally the test results came and when they took it to the doctor they were in for another shock. Santha had ovarian cancer. According to the doctor, she had to first undergo a surgery that would involve hysterectomy (removal of uterus) and oophorectomy (removal of ovaries). Then they would decide the treatment regimen based upon the biopsy results. The doctors told them that the treatment would involve at least six or seven cycles of chemotherapy, spread out over several months. The family understood that Santha would have to be in and out of hospitals for a long time. Because they could get much of the treatment done at the Medical College Hospital, the treatment was not going to be very expensive. But, what about the care after the surgery? What about the care in-between chemotherapy cycles?

After the surgery, one of Santha's cousins came to stay with her in the hospital for providing care during the post-operative days. But the lady had her own personal problems and told Santha that she would not be able to help for more than a week. But she told Gopalan about the palliative care centre near their village and asked him to contact them. He did so, and in response, one person from the unit came to meet Santha and Gopalan at the hospital. They took their home address and promised to come as soon as Santha was out of the hospital.

Once Santha was discharged from the hospital, Santha's daughter came to stay with her even though she herself had two small children. However, a few members of the palliative care team also reached there instantly. They told them that though they would not be able to remain full time, if Gopalan can be at least a partial caregiver, they could help enough to relieve Santha's daughter and let her go back to her job and family.

They told Gopalan that they would give him basic training in caring for the patient – like how to help her get up, how to give her a sponge bath, and what medicines to give during emergencies. Since Santha was only recovering from the surgery, they said that she would heal soon and would not need any special help at that stage. Gopalan agreed to everything since it would solve the problem at least temporarily.

However, Santha's problems were not restricted to her own pain and discomfort. Like the average Indian wife and mother, her own aches and pains were her last priority. She was more worried about her cows and chicken because even one day of neglect may affect the animals negatively. And income from her cows and chicks was imperative for repaying the loans. So, she couldn't feel the instant relief that Gopalan felt when the palliative team members spoke.

One member in the team noticed that Santha was not as relieved as Gopalan. This member – a young woman – was not a health care professional but only a volunteer. It is important to note in this context that many of the volunteers involved in palliative care work are there because of their own experiences in the field of death and disease, being witness to the sufferings of their family members or friends. As such, they are sensitive to even a slight change of expression on a patient's face. So this young woman said that she would like to talk to Santha separately.

Once they were alone, the woman asked Santha what was worrying her. Initially, Santha was reluctant to talk but on prodding, admitted to her worries about her cows and chicken. The woman told Santha that their team had many volunteers and she would talk to them to see anyone of them can do the job, though she herself was not adept at handling such things. This surprised Santha because she had thought that palliative care people only cleaned or fed or changed the catheters of the patient. She never thought they would milk the cow for her. But the team member told her that palliative care was not just medical care. She explained that though a palliative team might be composed predominantly of healthcare professionals, there were always social workers and volunteers among them. It is an interdisciplinary team catering to the economic, emotional, psychosocial and spiritual needs of the patient. She also explained that they catered to the emotional needs of not just the patient but the family as well because the anxiety and pain of the patient and the caregiving family members affect each other. So, to ensure the patient's comfort, they have to ensure the comfort of the family as well.

After two days, that lady reported back and said that she had arranged for a volunteer to take care of Santha's entire business. This included not just the care of the animals. The volunteer had even arranged for Santha's customers to come and collect their eggs and milk themselves at least till Santha became fit enough to take it to them as she used to do. Santha became extremely relieved to hear that. As a result her healing process was faster than anticipated.

However, recouping from surgery was only the first stage of her treatment. Once she was fit enough to withstand chemotherapy, she was readmitted to the hospital. By then she had become so friendly with the palliative care team that she started phoning them whenever she had a problem. And when the doctor suggested an intra-peritoneal chemotherapy, she requested that she be allowed to have a member of the palliative care team holding her hand when the doctors did the procedure. However, the doctors later cancelled the idea.

The doctors suggested six cycles of chemotherapy. There was about three weeks respite after every cycle. After every cycle, once she was back home, the palliative care team members came to visit her and encouraged her to take interest in something else, instead of thinking only about cancer. They asked her what else she was interested in other than doing housework. Santha had become so focused on her family and household chores for decades that she had forgotten whether she had any other interests at all. On their prodding, she admitted that she liked to draw motifs of flowers and leafs and could draw geometrical designs very fast. So they asked her to try her hand at making patterns for textile designing and got some of her patterns uploaded on textile designing groups on Pinterest and Facebook. When she saw the likes and positive comments that her work elicited from some unknown people in other continents, she was completely taken aback because she had never tried to be part of any venture or any group in a life that was completely confined to her home and devoted to her family's needs.

After 6 cycles of chemotherapy, the doctor told her that her cancer was in partial remission. She understood that it did not mean that she was totally cancer-free but that her cancer was at least not growing. The doctor told her that she could take a break from treatment and submit herself to quarterly check-ups to decide she would need any further treatment. Meanwhile, the palliative team members kept on telling her encouraging stories about famous people like Olympic gymnast Shannon Miller, actress Kathy Bates etc. who survived ovarian cancer and returned to very active lives.

Santha has started doing housework once more, and in her new schedule she keeps apart a little time for drawing designs and posting it at social networking sites where like-minded people gave feedback to her. She knows that future is uncertain but then whose future is certain? She has learned to live for each day, finding joy in the good things that the day gives. She is grateful to the palliative care team that introduced the new philosophy into her life. And the biggest change in her life is that she is now volunteering for a palliative care team.

Social welfare programmes, which provide benefits to the elderly, neglected, work-injured, dependent survivors etc., are an absolute necessity for any country whether these programmes are state-sponsored or not. A level of minimum help has come to be expected as the government’s responsibility, especially with regard to certain types of problems but in most countries the consensus is that public responsibility should extend to that section of the society which needs help in one form or other. The initiative for Kerala’s palliative care system has come from the government itself and some of the senior doctors in charge of it are government doctors. However, the functioning and funding of it is mainly done through the help of the public, through donation and volunteer help. Community-based palliative care service is a shining example of community welfarism where local community is involved in the planning, resource mobilization, management, service delivery, and evaluation of the project. And in this particular case, quite interestingly Santha herself is now contributing to the success of community welfarism.

## Case 3

Devaki Amma (name changed) has always been a loner and mostly kept away from the general hurry-burry of the small town in which she lived. She is an unmarried woman and lived with her parents till they die. Her father died when she was about 40 years old and her mother died seven years later. After that she continued to live alone in her parents' house. She has a brother who is twelve years younger to her. But after he got employed and married, he moved away and built a new house of his own a few kilometres away.

Devaki Amma had taken Montessori training and had a job in a children's school most of her life. She had a way with children so her employer was happy to keep her. She was an excellent raconteur and children never got tired of hearing her anecdotes. Since it was a private school, there was no age restriction on working and she was allowed to continue till she was almost 70 years old. But after that the family which owned the school felt that it was time to retire her and employ someone younger to do the job. However, she was not entirely jobless even after that because some people in the locality sent their small children to her house to teach them alphabets and basic mathematics. She also kept herself busy in her kitchen garden. It yielded very well and she sold a lot of vegetables.

Though she lived alone, she strictly followed tradition. Every evening, she kept a lighted wick at the altar of the basil (*tulasi*) plant and circumambulated it thrice. One day, when she was circumambulating, she slipped on a stone and fell down. Her right leg hurt very badly and she found it impossible to get up. She somehow dragged herself to a nearby mango tree, hoping to get up by holding on to the tree. She did manage to get up but as soon as she took a step or two, she fell down again and then she could not get up at all, however much she tried. She cried out for help but people in the house next door had gone away for the weekend. She continued calling out till she finally managed to attract the attention of a local youth who was passing that way.

The youth sprung to action. He got help from here and there, and rang for an ambulance. He got a lady acquaintance to pack a bag for her and got her house locked by the time the ambulance came. They took her to the Medical College Hospital. Though Devaki Amma was in some pain, she was conscious enough to talk and gave the young man her brother's phone number. Her brother reached the place in a few hours.

The medical team got moving. There was a fracture that needed surgery but they said they could not do it immediately. She was diabetic and they needed to have her diabetes brought under control before performing the surgery. Meanwhile, they put her in touch with the palliative care unit in the hospital for any help that she may need after the operation. They talked with her and told her she could contact them if and when she needed any help.

Eventually the operation was done and a few days later she was discharged. But the doctors had warned her that for whatever reasons, it may take quite some time for her leg to heal. When she was discharged, her brother took her to his home. They cared her for the three weeks after which the doctor had asked her to come for a review. When they went back to the doctor, what he said was what none of them wanted to hear – that it had not healed at all and it may take time to heal. The doctor explained several cases where it had taken months and years for the bone to heal but he ensured her that it would heal. Only that she needed to be very very patient.

Devaki Amma was taken back to her brother's home. She did not know what to do because she was already feeling guilty for having become a burden on her brother's family for more than a month by then. It was a busy family with both her brother and his wife working. The children were in their early teens and were busy with their karate classes, drum lessons, maths tutions, and the like. There was also the problem of space. She was occupying the room which her niece was using so that the girl had to shift her clothes and books to the drawing room and sleep on the drawing room divan. She did not want the family to put up with such inconvenience on her account.

She wracked her brain to find a solution for her problem. Then she suddenly remembered the palliative care team that she had met at the hospital. They had told her that the help they rendered was not restricted to nursing duties like giving injections or changing the catheter. They had specifically told her that she could discuss her problems, hopes, desires, goals, and preferences to a palliative team. Besides nurses, the team contained social workers and case managers who were ready to attend to the psychological needs of not just the patients but even their family members. They were trained in understanding which of the patient's needs were to be prioritized and the role those solutions could play in the overall healing process.

Devaki Amma was reasonably well-off. She had lived a frugal life and saved meticulously. All through her life, she was conscious of her lack of family and had braced herself for old age, when loneliness was bound to be more acute. Her parents had also left her some money which she had invested wisely. Then there was a small coconut grove that she and her brother jointly owned. Her brother took care of it and sold the coconuts periodically and sent her half the money. She saved that also. Overall, she was not too much worried about her finances.

That evening she gave a ring to the palliative team. She requested them to come the next day between 10 and 12:30 in the morning. She chose that time because that was the time when none of the family members would be there. At that time, only a part-time help that they had employed to attend to her would be at home. So she felt she could talk freely to them then.

Two volunteers from the palliative care unit came at the requested time. One of them was a social worker. Devaki Amma presented her problem to them in detail. She asked them in what way they could help her to solve her problem. She even expressed a ‘wish to die’ rather than being so dependent on others. Palliative care people understood her problem very well. They realised that she would be persistently unhappy unless she was freed of the guilt feeling of being a burden on her brother and family. From what she said, they also realized that her brother’s family life was also under some tension because of the changes they had to cope with. They asked her a lot of questions, got an assessment of her financial position, and promised to come back with some suggestion.

Hers was a unique case so the social workers in the team needed some time to discuss and find a solution for her problem. At any rate, they felt that they should not recommend her moving back to her own house and living alone. After a few days they got back to her at around the same time they had visited her first and suggested a proposal. They did this after consulting the doctor who had treated her. The doctor told them that her healing process could take quite some time – even up to two years. He said that delayed healing happened in many cases but also that she was sure to heal if she took complete rest.

They suggested that if she had the finances for it, she should build an additional room to her brother’s house and move to that room. That would at least resolve the space problem in the family. And if finances allowed, she should employ a full-time home nurse and that would completely free her of the feeling of dependence on her brother and his family. It would also give her some privacy. They also said that they would help in renting out her house to augment her income. Above all, if she wanted them to discuss all this with her brother and convince him, they were ready to do that also. The last statement gave a lot of relief to Devaki Amma, because, as they were talking, she was wondering how to present all that to her brother. Though she herself found the idea all right, her brother was a bit short-tempered and discussing things with him was an unpalatable idea for her.

Her brother did not instantly agree to the idea but the counsellors in the palliative care team discussed it in detail with him. They made him understand that he would not be inconvenienced in any way by the change and that he did not stand to lose any money or physical comfort as a result. Finally he agreed to it.

Patients generally communicate with palliative care workers in two ways – some of them convey their needs and wishes through their primary caregivers while others prefer to talk directly to palliative care service providers. The case discussed above is one in which the patient very much chooses to communicate directly. Devaki Amma is a person who most of her life didn’t have anyone close enough to freely discuss her problems with. For such people, it is a great relief to talk to people who understand the root of their problem. A strong will to live is seen comparatively less in lonely people, and palliative care workers can do a lot to instil in them an interest towards life.

The palliative care workers did not stop at convincing Devaki Amma's brother. They helped him all throughout in supervising the construction of the room and took care to design the room as a very patient-friendly one. By the time the room became ready, they had found not one but two tenants for Devaki Amma's house. The main house, which was the lower story of the house, was given on rent to a family. Then there was a single upstairs room that Devaki Amma rarely used and that was given in rent to a single individual who worked in a bank nearby. This new income plus what she already owned became sufficient for Devaki Amma to pay the wages of a home nurse. She soon shifted to the new room in her brother's house.

Under the new arrangement, both she and her brother's family had the privacy that each needed. Her home nurse took care of all her needs and her brother and wife came and sat with her every day for a little while and saw to it that her medicines and toiletries were regularly replenished. She had no special treatment regimens that required medical attention from the palliative care unit but they visited her regularly once in every week. However, some of the palliative care team members felt that even with all the protection she received, she was not having a consistent positive outlook on like. Often they felt that she was struggling with depression and failing to find any meaning in her totally aimless life. They felt that they had to do something to buoy up her spirits and improve her quality of life.

Once, during a conversation, Devaki Amma spoke about her life as a teacher and her skills as a raconteur. Then one of the palliative care workers asked her:

“Why don’t you continue teaching children?”

“How can I? I am retired. I no longer have students to teach”

“But you can teach children here, in this room. Just two or three of them. After all, you can sit up comfortably, can’t you? It is only your legs that you cannot move. Legs are not required for storytelling.”

“But where are the children?”

“Let us see if some family requires help. Because your nurse will be in the room full time, she can control the children if they are up to some mischief. You can probably help them with their homework or regale them with your stories.”

“Oh, I can still do that. Only if any parent is ready to send a child to an invalid for learning.”

Palliative care workers spread the information in the locality. They did it mainly through the other homes where they went to deliver palliative care. Quite interestingly, one of these homes had a six-year-old named Nitu whom her parents were finding it difficult to control. Even otherwise, it was not easy to make her sit down to do her homework. Now, with a patient (Nitu’s grandfather) at home to care for, they were finding it extremely difficult to manage the child and make her sit down for her homework. So, they said that they did not mind having a teacher who could control Nitu and get her homework done.

Thus Devaki Amma had her first student after she became disabled. She was still quite good at her job that very soon Nitu became enthusiastic to attend her classes and became up-to-date with her homework every day. And with Nitu away at Devaki Amma's place for nearly two hours a day, the parents got more time to focus on the patient and other important household matters. Soon some other family also sent their child to Devaki Amma so that she had two students. Devaki Amma refused to take any more because there was no space in a single room for more than two students. Both the children did well under her control.

It took nearly two years for Devaki Amma to heal fully. During the entire period of convalescence, the palliative care team and her home nurse were her main crutches. In-between, she had bouts of depression but the palliative team did a stupendous job pulling her out of it. She was not a terminally ill patient and anyway all terminally ill patients are not depressed. Her underlying reason for unhappiness was an emotional loneliness which she might have felt at that age even if she had not fallen sick. But the palliative team easily identified it and combated it by providing physical company through their own visits, through making her use her skills on the two children, and by making the nurse expose her to the latest news, movies, and similar things.

In this case, we see that in the course of improving the quality of life of a patient, a palliative team analyses in full the personal, clinical, and psycho-social factors associated with that person. Each patient's response to his or her situation arises not just out of the illness they are going through, its intensity, and its ultimate outcome. It is also based on the social settings and family life of the patient, and also on the unspoken dimensions of his or her life experiences that the patient may not realize in full because of its subconscious nature. But at least some people in the palliative care team may manage to get a glimpse of it. And they use it as the basis for finding solutions to the patient's problems. Each interaction with the patient in this case was like a session of psychotherapy. In fact this is an example of community welfarism through psychotherapy and by helping with human resources.

In Devaki Amma's case, she finally healed after 2 years. After that she did not need a home nurse and she no longer qualified for visits from the palliative team. So she became single and alone once again. She did have some difficulty in adjusting to this new normal. How she mentally coped with the new life is beyond the pale of this discussion but the excellent raconteur that she is, she often spoke in detail about her various experiences with the palliative care team. She regaled others by adding a tinge of humour to it.

## Summary

For successful palliative care, a caring attitude is considered essential. It may be insufficient focusing correct physical diagnosis and suitable treatment. There are many other aspects of suffering. It is difficult to teach the caring attitude. It is natural the caring individuals drawn to the practice of palliative care. Each patient may have unique problem. Considering everyone's problems similar may be of no use in solving individual confusions and desperate conditions.

Cultural differences among the patients should be given prime importance if they are influenced by their ethnic, racial and religious affiliations. Socio-economic situations also may be different for each individual. Some of them may be economically poor, some others may lack family support, and social interactions of many of them may be interrupted. Palliative care is availed by each of them to find a relief from the problems they are suffering in connection with their disabled condition.

Palliative care team's services ease the stressful experiences of chronically ill or disabled patients and their families. The team consisting of specially trained health professionals and volunteers approach each patient to fulfill the aim of providing their service as required by the patient and the family. Patients who became distressed and desperate become confident and hopeful in their life after the proper involvement of the whole team of palliative care. Case of Muhammed is the best example of the support beyond assisting the bodily disablement provided by the palliative care team members. Through offering a homely environment even in the institutional premises, Palliative care energized the desperate mind of Muhammed and his wife. And also his social interactions enhanced by the support given by the team properly.

Communication with the patient and family is also vital to get the exact problems that exist with each individual patient. Assuming the problems of the patient and family without proper communication may distort the actual purpose of the service. Some basic rules are there to follow when communicating with the patient. Giving required time, ensuring privacy, being truthful, being sympathetic etc. are some of them. Through open and proper communication, the patient or the family may be able to explain their actual concerns and the team will be able to identify the real problem that is to be eradicated and offer the required care to that particular patient and family. Case 3 of Devaki Amma is an example of the service by the team as a result of proper communication with the patient. Devaki Amma also was able to avail the service of the agency in maintaining her economic stability by renting out her parental house to generate finance for the new infrastructural facility for her at brother's house.

Palliative care volunteers are different from other volunteers as they are ready for providing the patients and their family whatever they require. Most of the volunteers are experts in observing and understanding the situations of each patient and family even the matters which are not addressed by them. Such an incident is clearly explained in the case of Santha who never expected palliative care members will be there to help in maintaining their domestic affairs during her disabled condition. Santha is also thankful to the team for refreshing her inner aspiration even in the disadvantaged condition.

The co-ordination of care by the whole team members in palliative care make their service valuable to the beneficiaries. The care receivers of palliative care are actually get elevated from their poor physical, economic, social and psychological status created by their disabled condition. Palliative care make them equipped to face the life challenging experiences through the excellent and timely intervention by the team.

The cases analysed in this research sufficiently explain the efforts put on by the palliative care agency for the holistic welfare of the beneficiaries of the programme. Hence the analyses support the postulate with which the study was started. The revelations amply indicate the contributions of the programme to the maintenance of the body, mind, and socio-economic relations of the individuals who are in a debilitated condition. Needless to say, at the macro level, the agency's efforts are to be seen as oriented to the building up of a welfare state.

# CHAPTER 10

# CONCLUSION

Interest in palliative care has been intensifying recently among health care professionals, financiers and policymakers, motivated by the welfares to patients, the necessity to engross patients earlier in the course of their illnesses, and the effective reduction in cost by reducing hospitalizations, repeated admissions and casuality visits.

Palliative Care is proposed to get rid of and preclude suffering for patients with terminal illness or disability. For such patients, Care which includes, medical, nursing, psychological, socio-cultural and spiritual aspects is required. Principles of Palliative Care include caring attitude, commitment, consideration to individuality, cultural considerations, consent of patient and choice of site of care. Communication among health care professionals and with patient and family also become the indispensable aspect of Palliative Care. Palliative Care principles insist comprehensive and multidisciplinary care with excellence and co-ordination. It should also be assured that the care is having continuity and it supports the care givers also.

The study was an attempt to analyse the individual physical, psychological, social and economic struggles of the patients who are either terminally ill or chronically disabled, the perceptions of the patients on the sufferings of their care givers and the extent of support and care provided by the Palliative Care agency to its beneficiaries.

## 10.1 Objectives

The major objectives of the study are:

1 To portray the functions of Palliative care in Kerala.

2 To analyze the socio-economic, physical and psychological conditions of the clientele community.

3 To assess the contributions of the palliative care initiative to easing the responsibilities of the caretaker/family of the respondents.

4 To analyze the effect of the non-medical services on managing pain and mental agony of the beneficiaries.

5 To study the support given to the poor who are unable to approach the corporatized health care industry.

6 To study the type of social solidarity brought about by the palliative care movement.

## 10.2 Hypotheses

The primary hypothesis of the study is that the Palliative care by its method of functioning contributes to maintaining the dignity of the individual and welfare of the clientele community and by thus increases the integration of the society.

**The subsidiary hypotheses are:**

1 Palliative Care Service helps the beneficiaries in managing their bodily discomforts which in turn helps maintain the physical fitness of the clientele community.

2 Palliative Care reduces the mental agony of the beneficiaries and by thus contributes to the maintenance of a healthy psychic condition of the community.

3 Palliative Care agency supports the clientele community in alleviating the non-medical problems and their holistic approach keeps the community in good stead economically, socially and psychologically.

4 Palliative Care Agency, by offering, in addition to health care services, those which are necessary to tide over the crisis situation of the individual and his/her care givers contributes to the welfare needs of the clientele community.

5 The services of the Palliative Care are primarily oriented to the poor sections of the society and by thus the agency is helping to improve the welfare of the subaltern section of the clientele community.

6 The new initiative in the field of health care which opens an arena for philanthropic common people to join with medical professionals and serve the needy gives the poor people a sense of security and comfort.

7 Easy accessibility to the Palliative team creates confidence in the beneficiaries about merit of the programme and their ability to help tide over the situation.

8 The 'familism' shown by the Palliative Care Agency by itself is capable of reducing the mental and physical agonies of the beneficiaries.

### 10.3 Methodology in brief

The method of study resorted to in this research is a combination of qualitative and quantitative approaches. Interviews of 300 beneficiaries of the palliative Care programme of the State of Kerala were the source of primary data for the quantitative part of the study. Case analyses, inputs from the discussions with Palliative Care authorities, Care takers of the disabled individual and personal observations of the researcher were the sources of data for the qualitative part.

The samples for the quantitative part were selected from three geographical zones of the State, the southern, central and northern. These zones are respectively represented by the districts of the State, namely, Thiruvananthapuram, Thrissur and Kozhikode. From each district four palliative care units were randomly selected and from the selected units 25 each beneficiaries were selected using random selection method. Hence the total samples, (3 x 4 x 25 = 300).

For the case analyses three representative cases were selected. The selection was carried out on the advice of the Palliative Care authorities and the discretion of the researcher.

The 300 respondents were interviewed using a semi-structured interview schedule prepared on the basis of the objectives and hypotheses formulated. For collecting information for the case analyses the cases chosen were interviewed with an interview guide very elaborately.

The quantitative data were analysed using computer software. For testing the association between variables chi-square statistic was used.

### 10.4 Problems attended to by the Palliative Care Service

From the analyses of chapters five to seven, it is found that palliative care beneficiaries are undergoing various bodily, mental and socio-economic problems associated with their age or chronic disabilities. The results of the analyses of each of these problems are discussed below.

#### 10.4.1 Bodily Discomforts of the Disabled

According to the WHO International Classification of Impairment, Disabilities and Handicap (ICIDH: 1980 – replaced by ICF in 2001), impairment relates to bodily functions, disability to activities, and handicap to social roles. The three are distinct but interrelated. The absence or abnormality of a body feature that may be biological, physiological or psychological, such as a missing limb or a psychiatric illness diagnosed, is a disability. An impairment is an inability or diminished capacity, such as being unable to walk, to perform an activity within the normal human range. A handicap is a restriction resulting from illness or disability that limits the social status of a person, such as being unable to function anywhere due to limited access. (healthknowledge.org.uk).

Analyses from **5.1.1** to **5.1.7** in chapter 5 discuss the physical impairments related to the illness or disability. Analysis **5.1.1** discusses the bodily changes of the respondents caused by the impairment. 83.33% of the respondents are facing severe bodily changes due to the chronic illness they have or the disabled condition they are passing through. In the case of physical pain (Analysis **5.1.2**) 51% of the respondents express their depraved experience during severe body pain while 49% of them are experiencing moderate pain.

Analysis **5.1.3** reveals that majority (54%) of the respondents have the opinion that routine activities are seriously affected due to their illness or disability. They are agonized about the status of dependence for fulfilling the day to day activities. Even to move from one place to another inside the home, most of them require assistance of their family members. Analysis **5.1.4** reveals that the respondents who always need such assistance and those who sometimes need are almost equal portions (43.67% and 47.33% respectively).

Majority (65%) of the respondents opine that their sleep is very much affected due to their terminal illness or physical disability. Only a negligible portion (2.33%) says their sleep is not at all affected by their illness or disability (Analysis **5.1.6**). Even in healthy people, consistent sleep deprivation can lead to hypertension, heart problems, impaired memory, and lowering of general quality of life. When it happens to people who are already ill, it can speed up their deterioration. It will also affect the health of caregivers because sleep-deprived people will have the tendency to call out to the nurse or ask for help frequently at night. This will make the caregiver also sleep-deprived and unable to do his or her duties properly. Sometimes, patients who are sleep-deprived may sleep during daytime but the caregivers may not be able to do that.

More than 50% of the respondents included in the study is continuing as disabled and dependent for more than 5 years (Analysis **5.1.7**). Managing the sufferings of illness or disability and the social life are becoming tedious for the patients as the disability and dependence are lasting for long duration. Such a situation leads to hopelessness. Hopelessness is perhaps the most damaging emotion not just for invalids but even for normal human beings because hope is what sustains people even in very bad situations. Hope is the driving force in our lives and when there is no hope there will be no willpower to sustain oneself.

There is a contrary viewpoint that hopelessness is a removal of illusion and bringing people face to face with reality when things have reached a stage beyond solution. There is an element of truth in this viewpoint because it is necessary to be honest with the patient to prepare himself/herself for the inevitable. However, when a patient turns utterly hopeless, he would become uncooperative and this would increase the nursing problems of palliative care workers and caregivers.

An individual in need of palliative care can have multiple physical issues, such as backache, headache, nausea, trouble breathing, bowel movement problems, scratching, incoherence, etc. The palliative care team's primary duty is to prevent or at least minimise these agonies and make the remaining life of the patient pain-free. Palliative care doctors can work with other medical professionals to treat the patient to this end. But the palliative care doctor focuses strongly on removing the patient's bodily pain and less on battling the illness, unlike the medical specialist.

### 10.4.2 Psychological Problems of the Impaired

Individuals with chronic illness or disability usually experience a decline in quality of life. As a consequence of physical disability, for instance, everyday tasks are adversely affected. And physical disability often increase the psychological problems of patients, making them more emotional and easily offended. They have difficulty voicing concerns and grievances, which in turn leads to feeling frustrated and not being noticed. (Sydney et. al., 2016).

Psychological miseries associated with the desperate situation of the respondents are analysed using different background variables like gender, age, religion, education, marital status, family size, family income and nature of disability. It is clearly understood that certain variables have significant association with various aspects of psychological wellness.

Analysis **5.2.1.1** revealed the association between marital status of the respondents and their life satisfaction amidst the disability. While 69.15% of married respondents feel some sort of satisfaction in their life, 50% of the unmarried patients and 52.94% among the ‘Separated/ Divorced’ feel no satisfaction in their personal life. 44.07% among ‘widow/widower’ also expresses the dissatisfaction in their personal life.

It is generally accepted that people who are happier and more satisfied with their lives generally tend to be healthier. This is applicable even when people are patients. When a person is able to look back upon his life and feel contended, he may not be very desperate and irritable as a patient. Here it is seen that married people are by and large more satisfied with life and this could be reflected in their attitude as patients also.

While asked about their interest in prolonged life (Analysis **5.2.2.1**), majority (75%) of the unmarried respondents and majority (74.14%) of the ‘widow/widower’ undoubtedly replied that they are not interested to be a burden for others for a long duration. This is a very positive attitude in anyone, because it is only proper on the part of any human being not to burden others. However, in the case of patients, this lack of interest in life may delay the healing process. Palliative care workers can make them understand that they are not taking advantage of the caregivers and that they have fallen sick not because of any fault on their part. Understanding this may reduce their guilt feelings on being a burden on others.

There is a gender wise difference in feeling strong mentally even in the tragic life situation (Analysis **5.2.3.1**). Male gender is comparatively higher portion (80.15%) when compared to female counterparts (68.90%) in feeling mentally strong and capable in facing the strenuous situations created by the terminal illness or disability. Though it is highly disputed whether men are really emotionally stronger than women or not, men are from childhood trained not to be very expressive and vocal about their fears and emotions and we can see this attitude when they are sick also.

Analysis **5.2.4.1** reveals that the feeling of isolation is persistent in majority (64%) of the respondents though there is an association between the family income and feeling of isolated existence. This is because financial security does give some emotional security to most people. It is also revealed that only 55.67% of the respondents opines that they are happy even though they are passing through a stressful period in their life (Analysis **5.2.5.1**). This is not a very high percentage but it appears quite gratifying that more than half the patients are able to maintain their cheer despite their rather unpleasant situation. We have already seen that significant percentages of males, married people etc. are either satisfied with life despite their problems, or are emotionally strong. As such, we can expect a reasonable number who are able to remain happy despite their complex situation.

The study indicates that multiple physical and mental impairments are encountered by patients having prolonged illness or disablement. The key goal of palliative care programmes is to support patients who are having these issues and their families take care of them. It must be inferred that in the context of Kerala, palliative care is necessary to provide physical care and mental consolation for those who do not need medical agency care because their services are not applicable for patients who fall under this category.

### 10.4.3 Reduction in Social Interactions among the Impaired

The problem of social interaction of the impaired can be secondary to changes in personality that often accompany chronic diseases or disabilities. Care professionals for the chronically ill need to be alert to social isolation and social disability concerns. Initially, families frequently react to extreme illness by being over-protective and encouraging dependency and a sense of diminished competence in the sick person. As the illness persists, because of the pressures of new responsibilities, exhausted resources, and other facets of a changing lifestyle, families also feel fatigue. In the network, feelings of frustration, shame, and helplessness arise, often leading to withdrawal of support; particularly as the capacity of the sick person to reciprocate support is impaired. Nursing interventions in circumstances of social isolation focus on reducing isolation by encouraging social interaction as appropriate, and by directly or indirectly activating or expanding the social network (Tilden and Weinert, 1987).

Chapter 6 analyses the interest for social interactions among the respondents. It is found that majority (76.33%) among them are interested in visiting their friends and relatives to overcome the loneliness of being bedridden at their home (Analysis **6.1.1.1**). Analysis **6.1.1.3** revealed a significant association between marital status of the respondents and their interest in visiting friends. Majority of the respondents among married (79.79%) and widow/widower category (81.36%) show somewhat interest in visiting friends. Unmarried respondents (61.11 %) and separated/divorced respondents (52.94%) at the same time constitute a lower portion when compared to the other categories.

As Aristotle said, “Man is by nature a social animal” and anyone who either cannot mingle with others or is so “self-sufficient as not to need to, and therefore does not partake of society, is either a beast or a god”. The vast popularity of social media networks underscores this. The fact that 76.33% of even sick people are interested in maintaining at least a semblance of social life points to the fact that illness need not necessarily change innate human nature. Even among unmarried and separated/divorced respondents who might have led comparatively lonelier lives, there are reasonably high percentages who maintain a keenness to retain their social contacts.

Analysis **6.1.2.1** reveals that majority (69.67%) of the respondents entertain the visitors come to their home while a negligible portion (6.67%) never entertain such visits enquiring their desperate conditions. The study also enquired about the interest of the respondents in taking part in various family functions was another part of the analysis. 77.97 % of the respondents expressed their interest in attending family functions and 20.34% of them opined that they are not at all interested in attending family functions (Analysis **6.1.4.1**).

Extroverts generally tend to welcome visitors while introverts do not. This innate nature could be a decisive factor in influencing the percentage of sick people who prefer to entertain visitors. But it is seen here that only 6.67% of palliative care recipients totally disliked being seen by visitors. This could be indicative of the fact that when people fall sick, more of them prefer to have visitors coming to enquire about them. People’s original introvert-extrovert ratio could be changing slightly when they fall sick.

While 70.33% of the respondents opines that their social acquaintances are losing to some extent due to their withdrawal from normal social activities, 24.33% of them expressed that they feel all of their social acquaintances are lost as a consequence of their absence in social activities (Analysis **6.1.6.1**). Social contacts would naturally decrease when a person becomes bed-ridden or otherwise incapacitated. Still, only 24.33% of them feel that their social contacts are completely lost. This indicates that those who had maintained good social contacts before they fell sick are able to maintain something of it even when they lose their ability to remain actively in touch. Their acquaintances also must be ensuring that they are not left out of the social circle of which they were a part. The all-pervasive digital media of the present day could also be helping them in retaining their acquaintances.

Palliative care recipients (52.67%) reported high perceived levels of support and accessibility from Palliative Care team members, and many (66.67%) expressed satisfaction in receiving additional assistance from team members. Notably, the team was considered to be available either at home or at the clinic according to the convenience of the participants.

### 10.4.4 Economic Struggles of the Disabled

Chronic illness and disability can have destructive, even disastrous, socioeconomic consequences on patients and their households particularly if the patient is the bread winner. Economic stability of the families of the patients is seriously affected due to their disability and withdrawal from their personal, familial, social and economic roles. Analyses in Chapter 6 also discuss the economic problems of the impaired.

A large portion (85.67%) of the respondents perceive their family economy became instable (Analysis **6.2.1.1**). Family income is a significant variable which has an impact on the respondent's perception about the stability of their family economy. From analysis **6.2.1.3**, it is obvious that the respondents from 'Low income' family may constitute the majority (94.09%) among those who opined about the instability of the family economy. Only 13.33% of the 'High income' family opines that their family economy is not stable. Since high-income families generally have reserves or other resources to fall back upon in case of emergencies, they would obviously not be unduly worried about the depleted income. Those who feel insecure despite the high income could be businessmen or professionals whose high income is dependent on the sick individual's skills. In such a situation, it is only natural that they would feel that the family's financial situation is unstable.

The majority (92.67%) of the respondents has the opinion that their family income is not sufficient to maintain the economic balance in the precarious situation created by their chronic illness or disability and related expenses (Analysis **6.2.2.1**). This is only natural because treatment options for some of the diseases like cancer, kidney failure, Alzheimer's disease etc. are very expensive. Analysis **6.2.3.1** reveals that 72.33% of the respondents perceive that their families deteriorated economically consequent on their prolonged illness.

For a kidney patient, hemodialysis is done through a surgically created vascular access. The surgery itself, through which a surgeon places an arteriovenous fistula in the patient's forearm, is an expensive procedure, especially if it is done in a private hospital. Even after the surgery, it may take about eight weeks for the fistula to become mature and usable, and till then the patient may have to rely on a venous catheter inserted into a vein in the neck, which would be another expense. Besides these, there is the cost of the thrice-weekly dialysis plus the cost of transporting the patient to a hospital every alternate day. When a person has to bear such an expense for all the remainder of his life, it is definitely not going to be economically easy and the family would obviously suffer especially if the patient was an earning member.

Likewise, in a disease like Alzheimer's, nursing options can be very expensive even if medicines are not. Specially turned nurses are required to handle Alzheimer's patients and they should be physically strong enough to restrain the patient. The very family atmosphere will deteriorate when such a patient is at home besides the financial strain the family is put to because of that. Sometimes care-giving may be so complicated that one of the family members might have to stop working to care for the patient. That would put the family into further financial strain. That could be one reason why all except 25% of the respondents feel that their family has deteriorated economically because of their disability and treatment expenses.

Principles of palliative care oblige them to provide the type of care as the beneficiary requires. Active total care envisioned by the agency may be fulfilled only if the actual type of care required by the beneficiaries is revealed. Palliative Care is availed by majority (57.67%) of the beneficiaries to reduce their economic burdens and to get social support. And it is revealed that the beneficiaries are getting enough financial support in various forms from the agency.

### 10.5 Perceptions of the Care Recipients on the Sufferings of Family Care givers

While family members have always provided care to seriously ill relatives, the care that family members are expected to provide in today's health-care environment is more complex than it was even a decade ago. Palliative Care team members can make a major contribution to family caregivers by educating and reassuring them in the caring process. Supporting family members may be possible by the team to an extent. But another complex concern is the agony of the patients in the struggles of family care givers. Chapter 7 discussed the perceptions of the care receivers on the stress of their family care givers.

Analysis **7.1.1.1** reveals that a large portion (74.33%) of the respondents feel that their family care givers are sacrificing their personal and social pleasures for caring their disabled or chronically ill family member. Marital status and Family size seem important in making an impact on the perceptions on the sufferings of care givers.

No one wants others to suffer on their account and this is amply proven by the fact that 74.33% of the respondents are worried about what their family members have to forego by being forced to care for them. However, people who have made enough contributions to the family's welfare and security when they were fit enough to do so, may feel less guilty about the adjustments the family has to make. That is why marital status has an influence on this. Likewise, in large families, care-giving is shared between family members so that each person's level of sacrifice may not be very high. That is why family size is also influencing this aspect of the problem.

Another agony of the patients is about their care givers' physical strain in caring them. 69% of them are conscious about the physical strain caused to their care givers. Only 6.67% has the opinion that they don't feel that they create additional physical strain for their care givers (Analysis **7.1.2.1**). Here also marital status and family size of the respondents have significant association with the perception of respondents.

Analysis **7.1.3.1** reveals that 98.79% among those who have children are very much anxious about their future. A sick individual would naturally be worried about the future of his/her children who are not yet settled in life. The 11.12% who do not appear to be worried about their children might have made the children's future financially secure and could be having a family member who has the full ability to take care of the children. As we can see, this is a very small percentage. This is because many people, even those who have done enough to ensure the financial and emotional security of their children, prefer to oversee things themselves.

Analysis **7.1.4.1** revealed that the percentage of respondents who always being concerned about the mental peace of their care givers is low (20 %), a considerable portion (57.67 %) of them are really worried about the disturbed mental peace of care givers. While 19 % of the respondents are often worried about the disturbance they create to the mental peace of their care givers, only 3.33% of them are not at all worried about the same.

Most of the respondents expressed their grief because of the burden created by them to their family care givers. While 61.33% of them are somewhat worried about the burden to their family, a considerable portion (24.67%) is very much worried that they are becoming a burden to their family members (Analysis **7.1.6.1**).

In total, the patients are very much distressed not only because of their disabled condition but also by the sufferings faced by their family care givers. Most of them are very much concerned about the same and perhaps they wish to reduce the strain of their care givers rather than their own pain and struggles. It is also found that their physical and mental agonies double according to the increase in the care givers' burden. Thus to assist the family in caring the disabled should be one of the prime aims of the palliative care agency.

Palliative care decreases the burden and pressure of family care givers through the multiple forms of care delivery assistance. To manage the expenses generated in connection with the patient's disabled status, some of the families do not have economic stability. Palliative care provides them with economic support. In certain other situations, where families are economically secure, nursing assistance might be needed. Palliative care is a solution there too. When one of the patients is in psychological distress, the family may need counselors to provide their family member with emotional support. The well-coordinated palliative care team is always prepared to give the beneficiaries each and every necessity.

## 10.6 Support from Palliative Care Agency to the Beneficiaries

Effective palliative care needs exposure to all facets of the pain of a patient. Established palliative care services work as a multidisciplinary team. They include a range of individuals from various disciplines and specialties who meet on a regular basis to discuss patient care and develop a unified plan of management for each patient. Palliative care service may sometimes have to be customized to suit the personal requirements and nature of the disease of particular patients. Since most palliative teams consist of healthcare professionals as well as volunteers with experience in various fields, the teams generally manage these adjustments without much difficulty.

Chapter 8 discusses the perception of the beneficiaries on the various support getting from the palliative care agency to reduce their bodily, mental and socio-economic problems, to reduce the stress of their family care givers and their satisfaction with the services provided by the agency.

According to the Palliative Care beneficiaries, Palliative Care Agency is the only solution to their struggles to some extent. Analysis **8.1** reveals that reasons to avail Palliative Care are different for different individuals as their requirements are different. 57.67% of the respondents decided to avail Palliative Care to reduce their economic burden associated with the disease or disability and the expenses incurred. At the same time, 27.33% of them requires mainly the nursing assistance rather than economic support. Only a negligible portion (2.33%) focuses the psychological support from Palliative Care Agency. There is 12.67% who requires economic support, nursing assistance and psychological support equally from the agency. The reason for the large portion requiring economic support may be because of their low economic status. As majority of the respondents are from low income families, it is natural that they seek financial assistance from the agency.

Nursing assistance is generally required by patients whose caregivers cannot manage certain aspects of nursing. This may include making the patient sit up while eating, giving an enema, inserting and removing a urinary catheter, turning a bed-ridden patient over, bandaging a sore, or giving the patient a bath. Some palliative care recipients may not require such services at all but may require economic help. The latter is seen to be of higher percentage.

Analysis **8.8** revealed that 52.67% get the service of the agency almost all the time when they require. 34.33% revealed that they get the services immediately whenever they require the same. 63.67% of the respondents get free medicines from the agency, 15.67% get rice and provisions also and 20.67% avails items like waterbed, airbed, wheelchair etc. together with medicines and provisions.

It is highly gratifying to notice that at least a certain percentage of patients feel that palliative care workers deliver their services quite promptly. This is an area where there should be further focus especially now when the healthcare system is getting over-strained under the onslaught of the Covid-19 pandemic. Palliative care services will now have to be more restricted to homes than hospitals, and authorities and palliative care volunteers will have to design creative ways to provide as much palliative care as possible under the circumstances.

Majority (62%) of the respondents are satisfied with the Doctor's service (Analysis **8.9**), 64% is satisfied with the Nursing service (Analysis **8.10**) and 65% is satisfied with the service of Palliative Care volunteers (Analysis **8.13**). It is also found that 74.33% is satisfied with the medicines provided by the agency (Analysis **8.12**) and an equal portion (74.33%) expresses their satisfaction with the overall services of the agency to its beneficiaries (Analysis **8.15**).

A large portion (83.33%) is having the opinion that the Palliative Care team spend enough time with the patients and family during their each visit or whenever they interact with them (Analysis **8.14**). Majority (58.67%) among the respondents are availing both institution based care and home based care as they require (Analysis **8.2.1**). It is found in the analysis that the type of care availed by the patients is varying based on the nature of their disability and their awareness of the services provided. Even though considerable portion (28.67%) among them feel they are visited by the doctors rarely (Analysis **8.3.1**), they are satisfied with the regular visits by the Palliative Care nurses (Analysis **8.4.1**) and Psychological support received from the volunteers (Analysis **8.5.1**).

While analyzing the psychological support from the volunteers to the beneficiaries (Analysis **8.5.1**), it is found that the majority (66.67%) of the respondents are getting relief from their psychological stress by chatting with the volunteers. 21.33% require the volunteers listen to their sorrows rather than mere chatting and 12% of them hope sharing their concerns with the volunteers to get psychological relaxation.

Although the majority of end-of-life care is provided by family and qualified caregivers, volunteers take on various tasks, such as helping with recreational and social activities, visiting patients, carrying them out and offering companionship and assistance. Such tasks are recognised as the essential to the delivery of quality palliative care.

Analysis **8.6** discussed the financial support given by the agency to its beneficiaries. It is revealed that 63.67% of the respondents get financial support from the agency in the form of free medicines. 15.67% of them get rice and provisions also and 20.67% is assisted financially by the agency with waterbed, airbed, walker, wheel chair, crutches, diapers, oxygen equipment etc.

An individual may receive palliative care for many years, months, weeks or days, depending on their circumstances. It is available for every one regardless of age, culture, background, notions etc. For those with a serious life-constraining condition, palliative care can make it a more positive experience. It is found that 82% of the respondents has the opinion that the absence of Palliative Care Agency and its services makes their life despondent (Analysis **8.16.1**). They feel that only the services provided by the agency make their life possible in the midst of chronic physical disability, psychological distress, economic instability and social exclusion.

### In Brief

The analyses in chapter 5 discussed the bodily and mental discomforts of the respondents while chapter 6 analysed the socio-economic problems of the beneficiaries in detail. Analyses in chapter 7 discussed the perception of the beneficiaries on the stress and strain of their family care givers. From the quantitative analyses in chapter 8, it could be understood that the palliative care agency is offering various types of support to its beneficiaries and their families to reduce their bodily discomforts, mental agonies and also to ameliorate their socio-economic conditions. Chapter 9 which discussed the specific cases among the palliative care beneficiaries qualitatively also substantiate the findings of the preceding chapters. Altogether the findings of the quantitative and qualitative analyses support the primary hypothesis that “the Palliative care by its method of functioning contributes to maintaining the dignity of the individual and welfare of the clientele community and by thus increases the integration of the society”.

- Analyses 8.9, 8.10, 8.11, and 8.12 prove the first subsidiary hypothesis that “Palliative Care Service helps the beneficiaries in managing their bodily discomforts which in turn helps maintain the physical fitness of the clientele community".

- Analyses summarized under 8.5.1, 8.5.2, 8.13 and 8.14 validates the second subsidiary hypothesis that "Palliative Care reduces the mental agony of the beneficiaries and by thus contributes to the maintenance of a healthy psychic condition of the community".
- The results of analyses 8.1, 8.5.1, 8.5.2, 8.6, 8.13 and 8.14 implies that the statement contained in subsidiary hypothesis three that "Palliative Care agency supports the clientele community in alleviating the non-medical problems and their holistic approach keeps the community in good stead economically, socially and psychologically" sustains its validity.
- The analyses mentioned above also proves the fourth subsidiary hypothesis that "Palliative Care Agency, by offering, in addition to health care services, those which are necessary to tide over the crisis situation of the individual and his/her care givers contributes to the welfare needs of the clientele community".
- Analyses summarized under 8.1 and 8.6 clearly validates the fifth subsidiary hypothesis that "The services of the Palliative Care are primarily oriented to the poor sections of the society and by thus the agency is helping to improve the welfare of the subaltern section of the clientele community".
- Analysis 8.5.1, 8.5.2 and 8.13 substantiates the sixth subsidiary hypothesis that "The new initiative in the field of health care which opens an arena for philanthropic common people to join with medical professionals and serve the needy gives the poor people a sense of security and comfort".

- Analyses 8.4.1, 8.4.2 and 8.8 substantiate the seventh subsidiary hypothesis that "Easy accessibility to the Palliative team creates confidence in the beneficiaries about merit of the programme and their ability to help tide over the situation".
- Analyses 8.14 and 8.16.1 prove the eighth and the last subsidiary hypothesis that "The 'familism' shown by the Palliative Care Agency by itself is capable of reducing the mental and physical agonies of the beneficiaries".
- The case analyses sufficiently support the primary and subsidiary hypotheses of the study.

To summarize the study found out the functions of Palliative care in Kerala. The socio-economic, physical and psychological conditions of the clientele community are also revealed. The contributions of the palliative care initiative in easing the responsibilities of the caretaker/family of the respondents were also one of the important matter of analysis in the study. The non-medical services of the agency on managing pain and mental agony of the beneficiaries are discussed through various analyses in the study. The support given to the poor who are unable to approach the corporatized health care industry is also brought to the light. Overall the type of social solidarity brought about by the palliative care movement is well established through the analyses which discussed the support by the agency to its beneficiaries. Cross analyses based on the background variables revealed that the perceptions of the respondents on their problems, the stress of family care givers and the services provided by the agency are influenced by their gender, age, religion, education, marital status, family size, family income and nature of disability.

Medical help is not seen by palliative care workers as the only solution to the problems of the patients. Due to the knowledge that this solace could give a new meaning to the life of the patient, they give a lot of importance to providing emotional support to an individual and his family. Even in a situation where his days are numbered, this will alter the outlook and understanding of the patient.

It is gratifying to see that a good majority of respondents are satisfied with the doctors, nurses, and medical care in general that palliative care teams provide. However, population is steadily increasing across the world, especially in countries like India. The demographic transition and the increasing life expectancy created a considerable percentage of aged people in the country who may be in need of palliative care. When more and more people are starting to avail palliative care help, the existing units may turn out to be insufficient to cater to the needs of all. The onus will then be on the society to increase the number of units.

Palliative care needs are immense and will continue to grow. Even though the number of Palliative Care services has increased dramatically in recent years, it is estimated that only a relatively small proportion of patients with chronic illness or disability are being accommodated. The solution to this problem requires both the further development of services and the education of all health care professionals in the essentials of Palliative Care.

### Suggestions

- There are various services (medical and non-medical) provided by the agency to support the needy.  Awareness campaigns on the types of services offered by palliative care agencies can assist those in need to opt the services they actually require.

- Since the agency offer economic support as free medicines, wheel chair, waterbed, airbed, rice and provisions for the needy, adequate financing by the State or voluntary sponsors should reinforce the funding of the agency. A mandatory item in the budgetary allocation of Panchayathiraj bodies should be Palliative Care.
- As the contributions of volunteers in the team are revealed to be important in the non-medical services like social and psychological support, more philanthropic individuals should come forward to improve the agency's services.
- SIPC (Students Initiative in Palliative Care) is a new programme to enhance the volunteer support. Palliative Care students and unemployed volunteers should be motivated by grace marks, weightage points, etc. at the time of admission for higher studies and even for job recruitment.
- Since the numbers of the chronically ill and aged are increasing day by day, existing units of palliative care may be insufficient. It would be more successful if Palliative Care could be considered essential by the Private Health Care institutions and officials also.
- As the joint family system is disappearing from our society, the caring of a disabled member is also becoming difficult to manage by the family itself. Though there will be external support from agencies like palliative care, the young family members should be trained physically and mentally for the same.
- There may be financially stable patients who are living without family or in need of 24 hours nursing care and able to pay for the nursing service. In such cases, it would be better to provide a palliative care nursing staff for round the clock service which will be more effective than frequent visits.

# BIBLIOGRAPHY

Abram, H. S. (1980). The Psychology of Chronic Illness. The ANNALS of the American Academy of Political and Social Science, 447(1), 5–10. https://doi.org/10.1177/000271628044700103

Adler, E. D., & Wettersten, N. (2017). Mending the Soul When the Heart Is Broken. *Journal of the American College of Cardiology*, *70*(3), 342–343. https://doi.org/10.1016/j.jacc.2017.05.058

Ahmadi, F. (2006). *Culture, religion and spirituality in coping: The example of cancer patients in Sweden*. Uppsala, Sweden: Uppsala University, Acta

Aiswarya, P.V. & Moli, G.K. (2012). Childlessness among Women in India, *Health and Population - Perspectives and Issues 35(3), 114-131.*

Akazawa, T., Akechi, T., Morita, T., Miyashita, M., Sato, K., Tsuneto, S., Shima, Y., & Furukawa, T. A. (2010). Self-perceived burden in terminally ill cancer patients: a categorization of care strategies based on bereaved family members' perspectives. *Journal of pain and symptom management*, *40*(2), 224–234. https://doi.org/10.1016/ j.jpainsymman.2009.12.015

Akpenpuun, J.R. (2014). Influence of Religious Beliefs on Health Care, *International Journal of Education and Research* Vol. 2 No. 4 April 2014,

Al-Mahrezi, A., & Al-Mandhari, Z. (2016). Palliative Care: Time for Action. *Oman Medical Journal*, *31*(3), 161–163. https://doi.org/10.5001/ omj.2016.32

Albert, I.W. (1996). *Social and Behavioral Aspects of Pharmaceutical Care,* CRC Press.

Alfredsson, G., & Eide, A. (1999). *The Universal Declaration of Human Rights: A common standard of achievement*. The Hague: Martinus Nijhoff Publishers.

Amy S. Kelley, Diane E. Meier (2014) *Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Care Reform*, Springer.

Ancoli-Israel, S., & Ayalon, L. (2006). Diagnosis and treatment of sleep disorders in older adults. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry*, *14*(2), 95–103. https://doi.org/10.1097/01.JGP.0000196627.12010.d1

Anderson, R. and Bury, M. (eds.) (1988). *Living with Chronic Illness: The Experiences of Patients and Their Families*. London: Unwin Hyman.

Anderson, R. E., & Grant, L. (2017). What is the value of palliative care provision in low-resource settings?. *BMJ global health*, *2*(1), e000139. https://doi.org/10.1136/bmjgh-2016-000139

Andrews, F. M. & Withey, S.B. (1976), *Social Indicators of Well-Being*. New York: Plenum Press.

Anooja, C. (2017). *Palliative Care Movement in Kerala: A Historic Overview*, Zamorin'sGuruvayurappanCollege, Kozhikode, Kerala, India 21 November 2017

Bhyan P, Al-Dhahir MA, Pesce MB, & Shrestha U [Updated 2020 Aug 16]. In: StatPearls Treasure Island (FL): https://www.ncbi.nlm.nih.gov/books/NBK470545/

Bickel, K., & Ozanne, E. (2017). Importance of Costs and Cost Effectiveness of Palliative Care. *Journal of oncology practice*, *13*(5), 287–289. https://doi.org/10.1200/JOP.2016.019943.

*Black, J. A., & Champion, D. J. (1976).* Methods and issues in social research. *New York: Wiley.*

Blieszner, R., Ogletree, A. M., & Adams, R. G. (2019). Friendship in Later Life: A Research Agenda. *Innovation in aging*, *3*(1), igz005. https://doi.org/10.1093/geroni/igz005

Bollini, P., Venkateswaran, C., & Sureshkumar, K. (2004). Palliative care in Kerala, India: a model for resource-poor settings. *Onkologie*, *27*(2), 138– 142. https://doi.org/10.1159/000076902

Brink H. I. (1993). Validity and reliability in qualitative research. *Curationis*, *16*(2), 35–38. https://doi.org/10.4102/curationis.v16i2.1396

Brumley, R. D., Enguidanos, S., & Cherin, D. A. (2003). Effectiveness of a home- based palliative care program for end-of-life. *Journal of palliative medicine*, *6*(5), 715–724. https://doi.org/10.1089/109662103322515220

Bury M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, *4*(2), 167–182. https://doi.org/10.1111/1467-9566.ep11339939

Buss, David & Goetz, Cari & Duntley, Joshua & Asao, Kelly & Conroy-Beam, Daniel. (2017). The mate switching hypothesis. Personality and Individual Differences. 104. 143-149. 10.1016/j.paid.2016.07.022.

Buss, M. K., Rock, L. K., & McCarthy, E. P. (2017). Understanding Palliative Care and Hospice: A Review for Primary Care Providers. *Mayo Clinic proceedings*, *92*(2), 280–286. https://doi.org/10.1016/j.mayocp.2016.11.007

Butchart, A., Kerr, E. A., Heisler, M., Piette, J. D., & Krein, S. L. (2009). Experience and management of chronic pain among patients with other complex chronic conditions. *The Clinical journal of pain*, *25*(4), 293– 298. https://doi.org/10.1097/AJP.0b013e31818bf574

Byrne, A. & Carr, D. (2005). Caught in the Cultural Lag: The Stigma of Singlehood. Psychological Inquiry. 16. 10.1207/s15327965pli162&3_02.

Cantarero-Prieto, D., Pascual-Sáez, M., & Blázquez-Fernández, C. (2018). Social isolation and multiple chronic diseases after age 50: A European macro-regional analysis. *PloS one*, *13*(10), e0205062. https://doi.org/10.1371/journal.pone.0205062

Chaturvedi, S. K., Loiselle, C. G., & Chandra, P. S. (2009). Communication with relatives and collusion in palliative care: a cross-cultural perspective. *Indian journal of palliative care*, *15*(1), 2–9. https://doi.org/10.4103/0973-1075.53485

Cheatle, M. D., Foster, S., Pinkett, A., Lesneski, M., Qu, D., & Dhingra, L. (2016). Assessing and Managing Sleep Disturbance in Patients with Chronic Pain. *Anesthesiology clinics*, *34*(2), 379–393. https://doi.org/10.1016/j.anclin.2016.01.007

Cibangu, S. (2012). "Qualitative Research: The Toolkit of Theories in the Social Sciences," Chapters, in: Asuncion Lopez-Varela Azcarate (ed.),*Theoretical and Methodological Approaches to Social Sciences and Knowledge Management*, IntechOpen.

Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, (Eds.) Families Caring for an Aging America. Washington (DC): National Academies Press (US); 2016 Nov 8. 3, Family Caregiving Roles and Impacts. Available from: https://www.ncbi.nlm.nih.gov/books/NBK396398/

Conger, R., Ge, X., Elder, G., Lorenz, F., & Simons, R. (1994). Economic Stress, Coercive Family Process, and Developmental Problems of Adolescents. *Child Development, 65*(2), 541-561. doi:10.2307/1131401

Coombs, R. (1991). Marital Status and Personal Well-Being: A Literature Review. *Family Relations, 40*(1), 97-102. doi:10.2307/585665

Coulehan J. (2009). Compassionate solidarity: suffering, poetry, and medicine. *Perspectives in biology and medicine*, *52*(4), 585–603. https://doi.org/10.1353/pbm.0.0130

Cousineau, Natalie & Mcdowell, Ian & Hotz, Steve & Hébert, Paul. (2003). Measuring chronic patients' feelings of being a burden to their caregivers: development and preliminary validation of a scale. Medical care. 41. 110-8. 10.1097/01.MLR.0000039832.32412.7D.

Crawley L.M., Marshall, P.A., Lo, B., Koening, B.A., & End-of-Life Care Consensus Panel (2002). Strategies for Culturally Effective End-of-Life Care. *Annalls of Internal Medicine, 136*(9), 673–679.

Creswell, John. (2009). Research Design: Qualitative, Quantitative, and Mixed-Method Approaches. SAGE.

Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, et al. (2019) Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLoS Med 16(4): e1002782. https://doi.org/10.1371/journal.pmed.1002782

DePaulo, B. M., & Morris, W. L. (2005). Singles in Society and in Science. *Psychological Inquiry, 16*(2-3), 57–83. https://doi.org/10.1207/s15327965pli162&3_01

Devi P. S. (2011). A timely referral to palliative care team improves quality of life. *Indian journal of palliative care*, 17(Suppl), S14–S16. https://doi.org/10.4103/0973-1075.76233

Durkheim, E. (2001).The Elementary Forms of Religious Life, Oxford University Press.

Durkhiem, E. (1893). *The Division of Labour in Society*, Doctoral Dissertation,

Durstine, John & Gordon, Benjamin & Wang, Zhengzhen & Luo, Xijuan. (2013). Chronic disease and the link to physical activity. Journal of Sport and Health Science. 2. 3–11. 10.1016/j.jshs.2012.07.009

Dzingina, M. D., & Higginson, I. J. (2015). Public health and palliative care in 2015. *Clinics in geriatric medicine*, *31*(2), 253–263. https://doi.org/10.1016/j.cger.2015.01.002

Erdek M. (2015). Pain medicine and palliative care as an alternative to euthanasia in end-of-life cancer care. *The Linacre quarterly*, 82(2), 128–134. https://doi.org/10.1179/2050854915Y.0000000003

Essue, B. M., Laba, M. .., Knaul, F., Chu, A., Minh, H. V., Nguyen, T., & Jan, S. (2017). Economic Burden of Chronic Ill Health and Injuries for Households in Low- and Middle-Income Countries. In D. T. Jamison (Eds.) et. al., *Disease Control Priorities: Improving Health and Reducing Poverty*. (3rd ed.). The International Bank for Reconstruction and Development / The World Bank.

Ferrell, B. R., Dow, K. H., Leigh, S., Ly, J., & Gulasekaram, P. (1995). Quality of life in long-term cancer survivors. *Oncology nursing forum*, *22*(6), 915–922.

Fitzpatrick, S. J., Kerridge, I. H., Jordens, C., Zoloth, L., Tollefsen, C., Tsomo, K. L., Jensen, M. P., Sachedina, A., & Sarma, D. (2016). Religious Perspectives on Human Suffering: Implications for Medicine and Bioethics. *Journal of religion and health*, *55*(1), 159–173. https://doi.org/ 10.1007/s10943-015-0014-9

Forbat L, Johnston N & Mitchell I (2020) Defining 'specialist palliative care': findings from a Delphi study of clinicians. *Australian Health Review*, 44 (2), pp. 313-321. https://doi.org/10.1071/ah18198

Fountain, P., Bush, R., Feener, M. (2015). (Eds.). *Religion and the Politics of Development,* Plgrave Macmillan

Gaertner, J., Siemens, W., Antes, G.et al (2015). Specialist palliative care services for adults with advanced, incurable illness in hospital, hospice, or community settings—protocol for a systematic review. *Syst Rev* 4,123. https://doi.org/10.1186/s13643-015-0121-4

Gaertner, J & Daun, M. & Wolf, Jürgen & von Bergwelt, Michael & Hallek, Michael. (2019). Early Palliative Care: Pro, but Please Be Precise!. Oncology Research and Treatment. 42. 10.1159/000496184.

Gaille, M., & Horn, R. (2016). The role of 'accompagnement' in the end-of-life debate in France: from solidarity to autonomy. *Theoretical medicine and bioethics*, *37*(6), 473–487. https://doi.org/10.1007/s11017-016-9389-1

Galik E. (2013) Institutional Care. In: Gellman M.D., Turner J.R. (eds) Encyclopedia of Behavioral Medicine. Springer, New York, NY. https://doi.org/10.1007/978-1-4419-1005-9_1424

Genet, N., Boerma, W., Kroneman, M., Hutchinson, A. & Saltman, R.B (2012) (Eds.). *Home Care Across Europe: Current Structure and Future Challenges*. Copenhagen: World Health Organization.

Gibson R. (2001). Palliative care for the poor and disenfranchised: a view from the Robert Wood Johnson Foundation. *Journal of the Royal Society of Medicine*, *94*(9), 486–489. https://doi.org/10.1177/014107680109400921

Gill A, Laporte A, Coyte PC. Predictors of home death in palliative care patients: a critical literature review. *Journal of Palliative Care* 2013; 29(2): 113-118

Givler, A., Bhatt, H., & Maani-Fogelman, P. A. (2020). The Importance Of Cultural Competence in Pain and Palliative Care. In *StatPearls*. StatPearls Publishing.

Goel, S. L. (2001). *Health care system and management*. New Delhi: Deep & Deep Publications

Goering S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current reviews in musculoskeletal medicine*, *8*(2), 134– 138. https://doi.org/10.1007/s12178-015-9273-z

Goh, M. L., Ang, E., Chan, Y. H., He, H. G., & Vehviläinen-Julkunen, K. (2018). Patient Satisfaction Is Linked to Nursing Workload in a Singapore Hospital. *Clinical nursing research*, *27*(6), 692–713. https://doi.org/10.1177/1054773817708933

Golics, C. J., Basra, M. K., Finlay, A. Y., & Salek, S. (2013). The impact of disease on family members: a critical aspect of medical care. *Journal of the Royal Society of Medicine*, *106*(10), 399–407. https://doi.org/10.1177/0141076812472616

Gopalakrishnan, P. K. (1994). Keralathinte samskarika charitram. Thiruvananthapuram: The State Institute of Languages.

Gossman W, Al-Dhahir MA, Pesce MB, Goyal A (2019) Palliative Sedation. In: StatPearls. StatPearls Publishing, Treasure Island (FL)

Grimmer, M., Riener, R., Walsh, C. J., & Seyfarth, A. (2019). Mobility related physical and functional losses due to aging and disease - a motivation for lower limb exoskeletons. *Journal of neuroengineering and rehabilitation*, *16*(1), 2. https://doi.org/10.1186/s12984-018-0458-8

Gurukkal, R., Varier, M. R. R. (1999). (Eds.). *Cultural history of Kerala*, Volume 1. Thiruvananthapuram: Department of Cultural Publications, Government of Kerala.

Hansson, R. O. & Carpenter, B. N. (1994). *Relationships in old age: Coping with the challenge of transition*. New York, NY: Guilford Press.

Harris D. (2007). Forget me not: palliative care for people with dementia. *Postgraduate medical journal, 83*(980), 362–366. https://doi.org/10.1136/pgmj.2006.052936

Have, H. & Jose, W. V. M. (2014). Palliative Sedation Versus Euthanasia: An Ethical Assessment, *Journal of Pain and Symptom Management,* Volume 47, Issue 1, January 2014.

Hawley P. (2017). Barriers to Access to Palliative Care. *Palliative care*, *10*, 1178224216688887. https://doi.org/10.1177/1178224216688887

Heijmans, M., Foets, M., Rijken, M., Schreurs, K., de Ridder, D., & Bensing, J. (2001). Stress in chronic disease: do the perceptions of patients and their general practitioners match?. *British journal of health psychology*, *6*(Pt 3), 229–242. https://doi.org/10.1348/135910701169179

Heins, M., Hofstede, J., Rijken, M., Korevaar, J., Donker, G., & Francke, A. (2018). Palliative care for patients with cancer: do patients receive the care they consider important? A survey study. *BMC palliative care*, *17*(1), 61. https://doi.org/10.1186/s12904-018-0315-3

Higginson, I. J., & Koffman, J. (2005). Public health and palliative care. *Clinics in geriatricmedicine*,*21* (1),45viii.https://doi.org/10.1016/j.cger.2004.08.003

Hjalmarsson, S., & Mood, C. (2015). Do poorer youth have fewer friends? The role of household and child economic resources in adolescent school-class friendships. *Children and Youth Services Review, 57*, 201–211. https://doi.org/10.1016/j.childyouth.2015.08.013

http://archive.mu.ac.in/myweb_test/TYBA%20study%20material/Gender %20& %20Soc..pdf

http://spb.kerala.gov.in/EconomicReview2016/web/ chapter01_02.php#:~:text=The%20urban%20populace%20of %20Kerala,47.72%20per%20cent%20in%202011.

http://spb.kerala.gov.in/ER2018/index.php

http://spb.kerala.gov.in/index.php/district-profile-kozhikode.html

http://whqlibdoc.who.int/publications/1980/9241541261_eng.pdf

http://www.censusindia.gov.in/2011census/PCA/PCA_Highlights/ pca_highlights_file/kerala/Exeutive_Summary.pdf

https://courses.lumenlearning.com/boundless-psychology/chapter/behaviors-that-impact-physical-and-mental-health/

https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/ Northern-Officers-Group-defining-impairment-and-disability.pdf

https://docplayer.net/12068996-Strategies-for- palliative-care-in-india.html

https://docplayer.net/12068996-Strategies-for-palliative-care-in-india.html

https://doi.org10.7326/0003-4819-136-9-200205070-00010

https://kozhikode.nic.in/about-district/history/

https://kozhikode.nic.in/health/

https://population.un.org/wpp/Publications/Files/WPP2019_Highlights.pdf

https://uk.sagepub.com/sites/default/files/upm-assets/76539_book_item_76539.pdf

https://www.facs.org/about-acs/statements/50-palliative-care

https://www.healthknowledge.org.uk/public-health-textbook/medical-sociology- policy-economics/4a-concepts-health-illness/section4

https://www.hzu.edu.in/bed/Basics-in-Education%20(NCERT).pdf

https://www.instituteofpalliativemedicine.org/

https://www.instituteofpalliativemedicine.org/

https://www.oecd.org/about/secretary-general/addressing-the-hidden-dimensions-of-poverty-paris-may-2019.

https://www.webmd.com/palliative-care/managing-pain-beyond-drugs

https://www.who.int/ageing/publications/global_health.pdf

https://www.who.int/bulletin/archives/79%2811%291047.pdf

https://www.who.int/bulletin/volumes/91/8/12-113985/en/

https://www.who.int/cancer/publications/nccp2002/en/

https://www.who.int/classifications/drafticfpracticalmanual.pdf https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response

https://www.who.int/news-room/fact-sheets/detail/palliative-care

*Hu, S.X., Lei, W.I., Chao, K.K., Hall, B., & Chung, S.F. (2016). Common chronic health problems and life satisfaction among Macau elderly people. International Journal of Nursing Sciences, 3, 367-370.*

Hudson, P., & Payne, S. (2011). Family caregivers and palliative care: current status and agenda for the future. *Journal of palliative medicine*, *14*(7), 864–869. https://doi.org/10.1089/jpm.2010.0413

Hung, W. W., Ross, J. S., Boockvar, K. S., & Siu, A. L. (2012). Association of chronic diseases and impairments with disability in older adults: a decade of change?. *Medical care*, *50*(6), 501–507. https://doi.org/10.1097/ MLR.0b013e318245a0e0

Inglehart, R. (1990) *Culture shift in advanced industrial society*, Princeton, US: Princeton University Press.

Institute of Medicine (US) Committee on Pain, Disability, and Chronic Illness Behavior, Osterweis, M., Kleinman, A., & Mechanic, D. (Eds.). (1987). *Pain and Disability: Clinical, Behavioral, and Public Policy Perspectives*. National Academies Press (US).

Iyalomhe G. B. (2009). Medical ethics and ethical dilemmas. *Nigerian journal of medicine : journal of the National Association of Resident Doctors of Nigeria*, *18*(1), 8–16.

Jennifer S. T., Joseph A. G., Alona M., Emily, R. G., Sonal, A., Vicki, A.,...Thomas J. L. (2010). ‘Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer’, *The New England Journal of Medicine*, 2010;363:733-42

Jerant, A. F., Azari, R. S., Nesbitt, T. S., & Meyers, F. J. (2004). The TLC model of palliative care in the elderly: preliminary application in the assisted living setting. *Annals of family medicine*, *2*(1), 54–60. https://doi.org/10.1370/afm.29

Jessee, V., & Adamsons, K. (2018). Father Involvement and Father-Child Relationship Quality: An Intergenerational Perspective. *Parenting, science and practice*, *18*(1), 28–44. https://doi.org/10.1080/15295192.2018.1405700

Joseph W. Shega, Amy Levin, Gavin W. Hougham, Deon Cox-Hayley, Daniel Luchins, Patricia Hanrahan, Carol Stocking, and Greg A Sachs (2003). Journal of Palliative Medicine. Volume 6, Number 2, 2003, 315-320. http://doi.org/10.1089/109662103764978641

Kesselring, A., Dodd, M. J., Lindsey, A. M., & Strauss, A. L. (1986). Attitude of patients living in Switzerland about cancer and its treatment. *Cancer nursing*, *9*(2), 77–85.

Keyes, C. L., Dhingra, S. S., & Simoes, E. J. (2010). Change in level of positive mental health as a predictor of future risk of mental illness. *American journal of public health*, *100*(12), 2366–2371. https://doi.org/10.2105/ AJPH.2010.192245

Khosla, D., Patel, F. D., & Sharma, S. C. (2012). Palliative care in India: current progress and future needs. *Indian journal of palliative care*, *18*(3), 149– 154. Doi:10.4103/0973-1075.105683.

Kliszcz J, Hebanowski M, Rembowski J. Emotional and cognitive empathy in medical schools. Acad Med. 1998;73:541. Retrieved November 11, 2019, from http://journals.lww.com/academicmedicine/ Abstract/1998/05000/Emotional_and_cognitive_empathy _in_medical_schools.25.aspx.

Koshy C. (2009). The palliative care movement in India: another freedom struggle or a silent revolution?. *Indian journal of palliative care, 15*(1), 10–13. https://doi.org/10.4103/0973-1075.53495

Kumar, S. (2012). Community-based Palliative Care in Kerala- Interview with Krishnadas, N. ehospice, 22 November 2012.

Kuppuswamy, B. (1972). *Social change in India.* Delhi: Konark.

Lang, Raymond. (2001). The Development and Critique of the Social Model of Disability

Lawton J. (2003). Lay experiences of health and illness: past research and future agendas. *Sociology of health & illness*, *25*, 23–40. https://doi.org/10.1111/1467-9566.00338

Lazarus, R. S., & Folkman, S. (1984). *Stress appraisal and coping*. New York:Springer.

Lewis, J. M., DiGiacomo, M., Currow, D. C., & Davidson, P. M. (2011). Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. *Journal of pain and symptom management*,*42*(1),105–118. https://doi.org/10.1016/j.jpainsymman.2010.10.265

Lewis, M. E., Lin, F. C., Nanavati, P., Mehta, N., Mounsey, L., Nwosu, A., Pursell, I., Chung, E. H., Mounsey, J. P., & Simpson, R. J., Jr (2016). Estimated incidence and risk factors of sudden unexpected death. *Open heart*, *3*(1), e000321. https://doi.org/10.1136/openhrt-2015-000321

Leys, R. (2010). Surveying the Emotions. *Emotion Review*, 2(2), 109–110. https://doi.org/10.1177/1754073909356003

Loscalzo. M. & Zabora. J. (1998), Care of the cancer patient:response of family and staff In E. Bruera and R. Portenoy(eds) *Topics in Palliative Care*, vol.2. Newyork: Oxford university press.

Mahadevan, K. & Sumangala, M. (1987). *Social development, cultural change, and fertility decline : a study of fertility change in India*. New Delhi ; Newbury Park, Calif : Sage

Manna, A. (2016). Difficulties in providing palliative care in rural India (West Bengal) – experience of an NGO, *Annals of Oncology*, Volume 27, Issue suppl_9, December 2016.

Manoj, R. (2020, March 15). Palliative Care in Kerala: A Success Story, *The Hindu*

Manstead A. (2018). The psychology of social class: How socioeconomic status impacts thought, feelings, and behaviour. *The British journal of social psychology*, *57*(2), 267–291. https://doi.org/10.1111/bjso.12251

McParland C, Johnston BM. Palliative and end of life care in prisons: a mixed-methods rapid review of the literature from 2014–2018. BMJ Open 2019;9:e033905. doi:10.1136/ bmjopen-2019-033905

Mechanic, D. (1978). Sex, illness, illness behavior and the use of health services. S*ocial Science and Medicine*, 12B:207-214, 1978

Meier, D. E., & Brawley, O. W. (2011). Palliative care and the quality of life. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, *29*(20), 2750–2752. https://doi.org/10.1200/JCO.2011.35.9729

Menard, L. A. (2014). Educational attainment and financial satisfaction: The changing economic value of a college degree. Paper presented at the Annual Meeting of the Mid-South Educational Research Association (Knoxville, TN, Nov 5-7, 2014).

Merkouris, A. & Andreadou, A. & Evdokia, Athini & Hatzimbalasi, M. & Rovithis, Michael & Papastavrou, Evridiki. (2013). Assessment of patient satisfaction in public hospitals in Cyprus: A descriptive study. *Health Science Journal*. 7. 28-40.

Merlins, J. S., Tucker, R. O., Saag, M. S., & Selwyn, P. A. (2013). The role of palliative care in the current HIV treatment era in developed countries. *Topics in antiviral medicine*, *21*(1), 20–26.

Meulen, Ruud & Wright, Katharine. (2005). The Role of Family Solidarity: Ethical and Social Issues. CESifo DICE Report. 8. 13-17.

Milberg, A., & Friedrichsen, M. (2017). Attachment figures when death is approaching: a study applying attachment theory to adult patients' and family members' experiences during palliative home care. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, *25*(7), 2267–2274. https://doi.org/10.1007/s00520-017-3634-7

Ministry of Health and Family Welfare (2012). Strategies for Palliative Care in India. Retrieved from https://docplayer.net/12068996-Strategies-for-palliative-care-in-india.html#

Murray, C. J. L., & Lopex, A. D. (1996). *The global burden of disease: a comprehensive assessment of mortality and disability from diseases. injuries and risk factors in 1990 and projected to 2020.* Cambridge: Harvard University Press.

Nambootiripad, E. M. S. (1967). *Kerala-Yesterday, Today, Tomorrow.* Calcutta: National Book Agency.

Narayanan, M. G. S. (1971). *Kerala Charithrathinte Adisthana Silakal.* Kozhikode: Lipi.

National Academies of Sciences, Engineering, and Medicine (2016). Families caring for an aging America. Washington, DC: The National Academies Press. Doi: 10.17226/23606.

National Research Council (US) Panel on Understanding Divergent Trends in Longevity in High-Income Countries; Crimmins, E.M., Preston, S.H. & Cohen, B., (2010). (Eds.). *International Differences in Mortality at Older Ages: Dimensions and Sources*. Washington (DC): National Academies Press (US); 2010. Available from: https://www.ncbi.nlm.nih.gov/books/NBK62592/ doi: 10.17226/12945

Ohls, C. (2015). Robert Walker (2014), The Shame of Poverty. Oxford, Oxford University Press. £25.00, pp. 248, hbk. *Journal of Social Policy, 44*(3), 643-644. doi:10.1017/S0047279415000112

Okediji, P. T., Salako, O., & Fatiregun, O.O. (2017). Pattern and Predictors of Unmet Supportive Care Needs in Cancer Patients. *Cureus*, *9*(5), e1234. https://doi.org/10.7759/cureus.1234

Oliver, M. (2013). The social model of disability: thirty years on https://doi.org/10.1080/09687599.2013.818773

Osella, F. & Osella, C. (2000). *Social mobility in Kerala: modernity and identity in conflict.* London: Pluto

Osmani, S.R.. (2009). TheSen System of Social Evaluation. Arguments for a Better World: Essays in Honor of Amartya Sen. 1. 10.1093/acprof:oso/9780199239115.003.0003.

Paleri, A.K. (2008). Showing the way forward: Pain and Palliative Care Policy of the Government of Kerala. *Indian Journal of Palliative Care* 2008;14:51-4

Parsons, T. (1951) *The Social System*. London: Routledge.

Payne, S., & Haines, R. (2002). The contribution of psychologists to specialist palliative care. *International journal of palliative nursing*, *8*(8), 401–406. https://doi.org/10.12968/ijpn.2002.8.8.10684

Pesut, B., Bottorff, J. L., & Robinson, C. A. (2011). Be known, be available, be mutual: a qualitative ethical analysis of social values in rural palliative care. *BMC medical ethics*, *12*, 19. https://doi.org/10.1186/1472-6939-12-19

Pesut, B., Hooper, B., Sawatzky, R., Robinson, C. A., Bottorff, J. L., & Dalhuisen, M. (2013). Program assessment framework for a rural palliative supportive service. *Palliative care*, *7*, 7–17. https://doi.org/10.4137/PCRT.S11908

Petitte, T., Mallow, J., Barnes, E., Petrone, A., Barr, T., & Theeke, L. (2015). A Systematic Review of Loneliness and Common Chronic Physical Conditions in Adults. *The open psychology journal*, *8*(Suppl 2), 113–132. https://doi.org/10.2174/1874350101508010113

Pettus, Katherine (2016), *Patient solidarity and the saving grace of palliative care*, Ehospice, International Edition.

Philip R.R, Philip, S, Tripathy, J.P, Manima, A & Venables, E. (2018). Twenty years of home-based palliative care in Malappuram, Kerala, India: a descriptive study of patients and their care-givers. *BMC Palliative Care*. 2018;17:26.

Pillai, N. (1983). *Social welfare services*. Thiruvananthapuram: University of kerala.

Pinquart, M., & Teubert, D. (2012). Academic, physical, and social functioning of children and adolescents with chronic physical illness: a meta-analysis. *Journal of pediatric psychology*, *37*(4), 376–389. https://doi.org/10.1093/jpepsy/jsr106

Placa, Vincent. (2007). Katz, I., Corlyon, J., La Placa, V. and Hunter, S. (2007). Review Paper: The Relationship Between Parenting and Poverty. York: Joseph Rowntree Foundation.. 10.13140/RG.2.1.4360.6161.

Priya, A. (2017). From Joint to Nuclear: Some Observations on the Changing Pattern of Family as a Social Institution *IOSR Journal Of Humanities And Social Science (IOSR-JHSS)* Volume 22, Issue 6, Ver. 3 (June. 2017) PP 28-31

Quill, T. E., & Abernethy, A. P. (2013). Generalist plus specialist palliative care-- creating a more sustainable model. *The New England journal of medicine*, *368*(13), 1173–1175. https://doi.org/10.1056/NEJMp1215620

R, Santhosh. (2015). Islamic Activism and Palliative Care: An Analysis from Kerala, India. 10.1057/9781137438577_5.

*Ragan, S.L., Wittenberg-Lyles, E., Goldsmith, J., & Sanchez-Reilly, S. (2008). Communication as Comfort : Multiple Voices in Palliative Care.*

Ragesh G, Zacharias L, Thomas PT (2017). Palliative care social work in India: Current status and future directions. Indian Journal of Palliative Care 2017;23:93-9

Rajan S. I. (1989). *Aging in Kerala: one more population problem?*. Asia-Pacific population journal, 4*(2), 19–48.*

Rajan, S. I. (2002). *Home away from home : a survey of oldage homes and inmates in Kerala. Thiruvananthapuram: Centre for Development Studies.*

Rajan, S. I., Zachariah, K. C. (2019). *Emigration and remittances: New evidences from the Kerala Migration Survey 2018* (Working Paper No. 12989)

Rak, A., Raina, R., Suh, T. T., Krishnappa, V., Darusz, J., Sidoti, C. W., & Gupta, M. (2017). Palliative care for patients with end-stage renal disease: approach to treatment that aims to improve quality of life and relieve suffering for patients (and families) with chronic illnesses. *Clinical kidney journal*, *10*(1), 68–73. https://doi.org/10.1093/ckj/sfw105

Rao, M. S. A. (1953). Social Change in Kerala. *Sociological Bulletin*, *2*(2), 124– 134.

Rebolj, A. B. (2013). The case study as a type of qualitative research. *Journal of Contemporary Educational Studies*. 28–43.

Rechenauer, M. (2003). Philosophical and technical welfarism. Some important distinctions (unpublished paper manuscript), LMU Munich.

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting Family Caregivers in Providing Care. In R. G. Hughes (Ed.), *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Agency for Healthcare Research and Quality (US).

Reinhardt J. P. (1996). The importance of friendship and family support in adaptation to chronic vision impairment. *The journals of gerontology. Series B, Psychological sciences and social sciences*, *51*(5), P268–P278. https://doi.org/10.1093/geronb/51b.5.p268

Rendall, M. S., Weden, M. M., Favreault, M. M., & Waldron, H. (2011). The protective effect of marriage for survival: a review and update. *Demography*, *48*(2), 481–506. https://doi.org/10.1007/s13524-011-0032-5

Richmond C. (2005). Dame Cicely Saunders. *BMJ : British Medical Journal*, *331*(7510),238.

Riess H. (2017). The Science of Empathy. *Journal of patient experience*, *4*(2), 74–77. https://doi.org/10.1177/2374373517699267

Rome, R. B., Luminais, H. H., Bourgeois, D. A., &Blais, C. M. (2011). The role of palliative care at the end of life. *The Ochsner journal*, *11*(4), 348–352.

Ross, C. (1990). Religion and Psychological Distress. *Journal for the Scientific Study of Religion, 29*(2), 236-245. doi:10.2307/1387431

Russell, Bertrand (1956). Portraits from Memory and Other Essays. Read Books, 2007

S Nieuwmeyer & M Hosking (2006) Counselling the terminally ill—Can we prepare for death? *South African Family Practice,* 48:6, 20-22, DOI: 10.1080/20786204.2006.10873405

S. Kumar,M. Numpeli (2005). Neighborhood network in palliative care. *Indian journal of palliative care*, 11 (2005), pp. 6-9

Salins N. (2015). Specialist Palliative Medicine Training in India. *Indian journal of palliative care*, *21*(3), 257. https://doi.org/10.4103/0973-1075.164904

Santhosh, R (2016). Voluntarism and civil society in the neoliberal era: a study on the palliative care movement in Kerala. *Journal of Social and Economic Development* volume 18, 1–16 https://doi.org/10.1007/s40847-016-0024-9

Sarkar S. (2016). Palliative Care for Non-Cancer Patients in Tertiary Care Hospitals. *International Journal of Medicine and Public Health.* 2016;6(4):151-153.

Saunders C. (1996). A personal therapeutic journey. *BMJ (Clinical research ed.), 313*(7072), 1599–1601. https://doi.org/10.1136/bmj.313.7072.1599

Scott, J., Treas, J., & Richards, M. (Eds.). (2007). *The Blackwell Companion to the Sociology of Families.* USA: Blackwell.

Scott, Ros & Howlett, Steven & Doyle, Derek. (2009). Volunteers in Hospice and Palliative Care- A resource for volunteer service managers. 2nd Edition. 10.1093/acprof:oso/9780199545827.001.0001.

Scutti, S. (2018, February 28). More money can mean Scrooge-like pride, study says', *CNN.*

Seidman, S. (Ed.) (1994). *The postmodern turn: new perspectives on social theory*. New York: Cambridge University Press.

Sen, A. (1979). Utilitarianism and Welfarism. *The Journal of Philosophy, 76*(9), 463-489. doi:10.2307/2025934

Shashikant, U. (2017) ''How financially secure you feel depends on these 5 factors' Economic Times, Business News, August 2017.

Shirley, O.G (2019). Passion, Purpose, and Preparation: The Power of Palliative Social Work', Shiley Institute for Palliative Care, https://csupalliativecare.org/social-workers-2019/

Sholjakova, M., Durnev, V., Kartalov, A., & Kuzmanovska, B. (2018). Pain Relief as an Integral Part of the Palliative Care. *Open access Macedonian journal of medical sciences*, *6*(4), 739–741. https://doi.org/10.3889/oamjms.2018.163

Singh, Y. (1973). Modernization of Indian tradition: a systemic study of social change. Thomson Press.

Smart (Eds.). *The handbook of social theory*. London: Sage.

Smith, S., Brick, A., O'Hara, S., & Normand, C. (2014). Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliative medicine*, *28*(2), 130–150. https://doi.org/10.1177/0269216313493466

Snowdon, C., Brocklehurst, P., Tasker, R., Ward Platt, M., Harvey, S., & Elbourne, D. (2014). Death, bereavement and randomised controlled trials (BRACELET): a methodological study of policy and practice in neonatal and paediatric intensive care trials. *Health technology assessment (Winchester, England)*, *18*(42), 1–410. https://doi.org/10.3310/hta18420

Sousa, L., & Lyubomirsky, S. (2001). Life satisfaction. In J. Worell, (Ed.), Encylopedia of women and gender: Sex similarities and differences and, the impact of society on gender (Vol. 2, pp. 667-676). . San Diego, CA:, Academic Press.

Souza, P. N., Miranda, E. J., Cruz, R., & Forte, D. N. (2016). Palliative care for patients with HIV/AIDS admitted to intensive care units. Cuidados paliativos no paciente com HIV/AIDS internado na unidade de terapia intensiva. *Revista Brasileira de terapia intensiva*, *28*(3), 301–309. https://doi.org/10.5935/0103-507X.20160054

Sreedhara, M. A. (1987). A Concise Political History of Modern Kerala: 1885- 1957, S. Viswanathan.

Sreedhara, M. A. (1978). *Cultural Heritage of Kerala: An Introduction,* East-West Publications.

Sreedhara, M. A (2008). *A survey of Kerala history. Kottayam:* D.C.

Srinivas, M. N. (1956). *Social change in modern India.* New Delhi: Orient Longman.

Stienstra, D., & Chochinov, H. M. (2012). Palliative care for vulnerable populations. *Palliative & supportive care*, *10*(1), 37–42. https://doi.org/10.1017/S1478951511000563

Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007). The public health strategy for palliative care. *Journal of pain and symptom management*, *33*(5), 486–493. https://doi.org/10.1016/j.jpainsymman.2007.02.016

Sultana, M., Mahumud, R. A., & Sarker, A. R. (2017). Burden of chronic illness and associated disabilities in Bangladesh: Evidence from the Household Income and Expenditure Survey. *Chronic diseases and translational medicine*, *3*(2), 112–122. https://doi.org/10.1016/j.cdtm.2017.02.001

Ter Meulen R. (2016). Solidarity, justice, and recognition of the other. *Theoretical medicine and bioethics*, *37*(6), 517–529. https://doi.org/10.1007/s11017-016-9387-3

Thavody, J. S. (2017). *National Mental Health Survey of India, 2015-16: Kerala State Report,* Kozhikode: IMHANS.

Thayyil, J., & Cherumanalil, J. M. (2012). Assessment of status of patients receiving palliative home care and services provided in a rural area-kerala, India. *Indian journal of palliative care*, *18*(3), 213–218. https://doi.org/10.4103/0973-1075.105693

Tilden, V. P., & Weinert, C. (1987). Social support and the chronically ill individual. *The Nursing clinics of North America*, *22*(3), 613–620.

Umberson, D. (1987). Family Status and Health Behaviors: Social Control as a Dimension of Social Integration. *Journal of Health and Social Behavior, 28*(3), 306-319. Retrieved December 20, 2020, from http://www.jstor.org/stable/2136848

Vanderstichelen, S., Houttekier, D., Cohen, J., Van Wesemael, Y., Deliens, L., & Chambaere, K. (2018). Palliative care volunteerism across the healthcare system: A survey study. *Palliative medicine, 32*(7), 1233–1245. https://doi.org/10.1177/0269216318772263

Varghese, A.S. (2018, June 25). 'For Kerala's 13.6 lakh single women, every day is a battle for survival', T*he New Indian Express.*

Verma, S. K. & Satyanarayana, A. (2012). Patterns of intergenerational relations in Indian family, *Indian Journal of Gerontology,* 26 (3), pp. 367–385.

Vernooij-Dassen, M. J., Osse, B. H., Schadé, E., & Grol, R. P. (2005). Patient autonomy problems in palliative care: systematic development and evaluation of a questionnaire. *Journal of pain and symptom management*, *30*(3), 264–270. https://doi.org/10.1016/j.jpainsymman.2005.03.010

Wade, J. B., Hart, R. P., Wade, J. H., Bajaj, J. S., & Price, D. D. (2013). The Relationship between Marital Status and Psychological Resilience in Chronic Pain. *Pain research and treatment, 2013,* 928473. https://doi.org/10.1155/2013/928473

Watts, J.H. (2012). The place of volunteering in palliative care. In: Chang, E. & Johnson, A. (eds). *Contemporary and Innovative Practice in Palliative Care*. InTech, pp. 83–102.

Wentlandt, K., Seccareccia, D., Kevork, N., Workentin, K., Blacker, S., Grossman, D., & Zimmermann, C. (2016). Quality of Care and Satisfaction With Care on Palliative Care Units. *Journal of pain and symptom management*, *51*(2), 184–192. https://doi.org/10.1016/j.jpainsymman.2015.10.006

Whitman, S. (2007). Pain and Suffering as Viewed by the Hindu Religion. *The journal of pain : official journal of the American Pain Society.* 8. 607-13. 10.1016/j.jpain.2007.02.430.

WHO (2011). World Report on Disability 2011- Understanding disability.

*WHO (2017). Depression in India: Let's Talk*

Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitchell, S. L., Jackson, V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, 300(14), 1665–1673. https://doi.org/10.1001/jama.300.14.1665

Yadav, Amit, 'Because uneducated people do not have anything to lose', https://www.quora.com/

Zafirovski, M (2018). Calvinist Predestination and the Spirit of Capitalism: The Religious Argument of the Weber Thesis Reexamined. *Hum Stud* 41,565–602 (2018). https://doi.org/10.1007/s10746-018-9481-9

Zalonis, R., & Slota, M. (2014). The use of palliative care to promote autonomy in decision making. *Clinical journal of oncology nursing*, *18*(6), 707– 711. https://doi.org/10.1188/14.CJON.707-711

Zaman, S., Inbadas, H., Whitelaw, A., & Clark, D. (2017). Common or multiple futures for end of life care around the world? Ideas from the 'waiting room of history'. *Social science & medicine (1982), 172,* 72–79. https://doi.org/10.1016/j.socscimed.2016.11.012

Zavaleta, Diego & Samuel, Kim & Mills, China. (2017). Measures of Social Isolation. Social Indicators Research. 131. 10.1007/s11205-016-1252-2.

Zegelin A. (2008). 'Tied down'- the process of becoming bedridden through gradual local confinement. *Journal of clinical nursing*, *17*(17), 2294–2301. https://doi.org/10.1111/j.1365-2702.2007.02261.x

Ziegler, L., Bennett, M. I., Mulvey, M., Hamilton, T., & Blenkinsopp, A. (2018). Characterising the growth in palliative care prescribing 2011-2015: Analysis of national medical and non-medical activity. *Palliative medicine*, *32*(4), 767–774. https://doi.org/10.1177/0269216317739805

# Appendix I

## Welfarism of Palliative Care in Kerala

**(Interview schedule)Malika U Varma, CHMK Library**

**University of Calicut**

## I. Personal Data

| | |
|---|---|
| Name | : |
| Address | : |
| Sex | : Male / Female |
| Age | : 20-40 / 41-60 / 61-80 / 81-100 |
| Religion | : Hindu / Muslim / Christian |
| Education | : No formal Schooling/ Primary/ Secondary/ College/ Technical/ Professional |
| Marital Status | : Married / Unmarried / Separated / Divorced / Widow / Widower |
| Occupation (Past) | : Govt. / Private / Business / Agriculture / Professionals |
| Monthly Income | : |
| Place of Residence | : Rural / Urban / Suburban / Slum / No residence |

## Nature of disability

| Old Age | Disease | Both Aged and Diseased |
|---|---|---|
| | Cancer<br>Kidney Failure<br>Others | |

## II. The Family

| Sl. No | Name of member | Relationship with the beneficiary | Age | Education | Marital status | Occupation | Monthly Income |
|---|---|---|---|---|---|---|---|
| | | | | | | | |

## III. Physical Health

1) Please rate your general health

Very good / Good / Fair / Poor / Very Poor

2) If you are a diseased person, how long have you been experiencing it?

Less than 1 year / Less than 2 years /Less than 4 years / 5 years and above

3) Did you feel any bodily changes caused by the disease? Yes / No

4) Have you been experiencing severe pain? Yes / No

5) Are your routine activities affected by your disability?

Very much / Somewhat / Not Affected

6) Do you need any assistance to move because of your disability?

Always / Sometimes / No

7) How often do you become bed ridden?

Never / Occasionally / Usually / Permanently

8) How much does your pain interfere with your sleep?

Very much/ Moderately/ Not at al

## IV. Your Feelings

9) How much of the time have you been a happy person?

Always / Sometimes / Never

10) How far you are satisfied with your personal life?

Very much / Somewhat / Not at all

11) How often do you feel depressed? Never / Sometimes / Often

12) ow far you are loved by others? Very much / Somewhat / Not at all

13) Do you feel that you are mentally strong?
Very much / Somewhat / Not at all

14) Do you think that you have nothing to look forward to?Yes / No

15) Are you emotionally stable? Very much / Somewhat / Not at all

16) Do you feel like crying? Never /Sometimes / Often

17) Do you feel that you are a burden for others? Very much / Somewhat / Not at all

18) How often do you feel isolated from others?
Never / Sometimes / Often /Always

**V. Socio-economic Conditions**

19) Are you interested in visiting friends / relatives?
Very much / Somewhat / Not interested

20) Are you interested in attending family functions? Very much / Somewhat / Not interested

21) Do you visit religious places? Yes/ No

22) If No, state your reason:

23) How far you are interested in participating in social ceremonies?
Very much / Somewhat / Not interested

24) Do you enjoy when visitors come to you? Never / Sometimes / Often / Always

25) Does any of your family members keep away from you? Never / Sometimes / Often / Always

26) Have you any entertainment activity? Yes / No

27) Do religious leaders visit you? Never / Sometimes / Often / Always

28) If yes, do you feel comfort with their visit and talk? Yes / No

29) Do you prefer the presence of any particular person by your side?
Yes / No

30) If Yes, who is the preferred person ?(Please explain the reason)

31) Do you think that your social acquaintances are losing because of your health condition? Very much / Somewhat / No

32) Do you feel that your presence in the family adversely affects other members? Very much / Somewhat / No

33) What do you feel about the economic stability of your family?
Very much stable / Somewhat stable/ Not stable

34) Do you have special arrangements inside the home for your convenience? Yes/ No

35) On an average how much is the daily expenditure for medicines?

36) On an average how much is the daily expenditure for other matters?

37) Is your income sufficient for your maintenance? Yes / No

38) If No, how does your family meet the expenses?

39) Has the family incurred debt for your maintenance? Yes / No

40) If Yes, the extent of debt incurred:

41) Do you think your diseased condition make your family economically deteriorated? Yes / No

## VI. Family Stress Management

42) How long have you been depending on others? Less than 1 year / Less than 2 years /Less than 4 years / 4 years and above

43) Who all else take care of you? Other family members / Friends / Relatives / No other person

44) Do your children help maintain you? Physical help / Passing information about the outside world / Communicative interaction

45) Do you feel that others are making sacrifices for you? Yes / No

46) If Yes, what sorts of sacrifices are they making? Routine activities / Religious / Social / Professional

47) Is your physical strain beyond your withstanding limit?
Never / Sometimes / Often / Always

48) What is your perception on the physical strain of other members of the family on account of your presence? Very much / Somewhat / No strain

49) Have you been experiencing anxiety about your future? Never / Sometimes / Often / Always

50) Have you been experiencing anxiety about the future of your children Never / Sometimes / Often / Always

51) Do you feel that mental peace of others is affected by your presence Never / Sometimes / Often / Always

52) Are the children of your family facing disturbances due to your presence? Never / Sometimes / Often / Always

**VII. Support by Palliative Care**

53) How long have you been undergoing Palliative Care?
Less than 6 months / 6-12 months / 12-18 months / 18-24 months / 24 months and more

54) How did you come to know about Palliative Care? Volunteers / Hospital / Clinic/ Doctor / Nurse / Media / Friends / Relatives / Others

55) Please specify the type of care you get: Home based care / Institution based care / Both

56) What prompted you to avail yourself of palliative care support
To reduce economic burden / To get nursing assistance / To get psychological relief / Others (specify)

57) Do you avail of any other medical treatment other than palliative care
Yes / No

58) If yes, please give details:

59) Do you get the services of Palliative Care Agency whenever you request? Always / Often / Sometimes / Never

60) Does any doctor visit you?
Regularly / Frequently / Occasionally / Rarely / Not at all

61) If Yes, type of care provided by the doctor

Medicines / Exercise and aids / Touch and closeness/ Discussion between you and your family members / Others (specify)

62) Does any nurse visit you?

Regularly / Frequently / Occasionally / Rarely / Not at all

63) If yes, type of care provided by the nurse

Giving bath / Attending to bedsore / Changing cloths / Giving medicines / Dressing wounds / Training family members in simple nursing tasks / Others (specify)

64) Specify the periodicity of visit of the volunteers

Everyday / Once in a week / Every other days in a week / Once in a month / Whenever necessary

65) Type of Physical care provided by volunteers

Bathing / Attending to bedsore / Changing cloths / Giving medicines / Dressing wounds / Training family members in simple nursing tasks / Others (specify)

66) Type of Social care provided by volunteers

Supportive counseling to the patient / Companionship / Others (specify)

67) Type of Psychological care provided by volunteers

Chatting with the patients / Listening the sorrows and fears of patients /Listening the concerns of family members / Sharing the problems of patients /Family counseling / Others (specify)

68) What all financial support are receiving from the agency

Supply of medicine free of cost / Supply of rice and provisions for the family /Wheel chair / Water bed / Commodes etc at free of cost / Books /Cloths /School fees for the kids / Others

69) Do you feel consolation due to the service of the agency?

Very much / Somewhat / Don’t feel

70) Satisfaction with the services of the doctor Highly satisfied / Satisfied / Not satisfied / No opinion

71) Satisfaction with the nurse's services Highly satisfied / Satisfied / Not satisfied / No opinion

72) Satisfaction with the volunteers' services Highly satisfied / Satisfied / Not satisfied / No opinion

73) Satisfaction with the medical treatment under Palliative care Team Highly satisfied / Satisfied / Not satisfied / No opinion

74) Satisfaction with the medicines provided through the agency Highly satisfied / Satisfied / Not satisfied / No opinion

75) Satisfaction with the overall services by the palliative care agency Highly satisfied / Satisfied / Not satisfied / Dissatisfied / No opinion

76) Do you think that the services are to be improved? Yes / No

77) If yes, suggest improvement:(tick any number of responses) Service of the doctor / Service of the nurse / Service of volunteers /Medicines supplied /Frequency of doctor's visit / Frequency of nurse's visit / Frequency of volunteers' visit

78) Are you satisfied with the time spent by the team with you? Yes / No

79) Do you share personal matters other than disease with any of the members of the team? Yes / No

80) Do you need care other than the care provided by the unit? Yes / No

81) If yes, specify:

82) Will you become a volunteer of the agency if you get an opportunity Yes / No

83) Do you give any financial contribution to the agency? Yes / No

84) Do you think that in the absence of the agency's service, your life would have been very miserable? Yes/No

85) Other details if any:

# Appendix II

# Welfarism of Palliative Care in Kerala

## (Interview Guide)

**Malika U Varma, CHMK Library, University of Calicut**

1. Personal Details and Family Background
2. How do you explain about your Nature of Disability?
3. What are the Bodily conditions you feel in the disablement?
4. To what extent do you need assistance to move and do the routine activities?
5. How do you feel mentally during your disabled condition?
6. Do you feel isolation due to your disablement?
7. Do you think your social interactions are reduced due to your impairment?
8. Do you have interest in visiting your friends and relatives?
9. Do you feel loss of social acquaintances consequent to your impairment?
10. What do you think about the economic stability of your family?
11. Do you think that your family income is sufficient for maintaining the expenses of treatment?
12. Do you feel your family is economically deteriorated due to your impairment?
13. How do you perceive the stress of family care givers?
14. Do you think that the family care givers are sacrificing a lot for caring you?

15. Do you feel self as a burden?
16. What are the services provided by the Palliative Care Agency?
17. What prompted you to avail of palliative care?
18. How the agency support you and your family financially?
19. How the agency help to reduce the bodily discomforts?
20. Do you think the psychological support from the palliative care team helps to get rid of from the distress?
21. Is the social support from the agency enough to maintain a normal social life in the disabled condition?
22. Are you satisfied with the services provided by the agency?
23. Do you feel life as despondent in the absence of the services of the agency?
24. Do you think the services of the agency are to be improved?

# Appendix III

## THE CHARACTERISTICS OF THE SAMPLE

### Age wise Distribution

| Age(in years) | Frequency | Percentage |
|---|---|---|
| 20-40 | 19 | 6.33% |
| 40-60 | 106 | 35.33% |
| 60-80 | 145 | 48.33% |
| 80-100 | 30 | 10.00% |
| Total | 300 | 100% |

### Gender wise Distribution

| Gender | Frequency | Percentage |
|---|---|---|
| Male | 136 | 45.33% |
| Female | 164 | 54.67% |
| Total | 300 | 100% |

*Third Gender is not included in the study

### Religious Composition

| Religion | Frequency | Percentage |
|---|---|---|
| Hindu | 199 | 66.33% |
| Muslim | 63 | 21% |
| Christian | 38 | 12.67% |
| Total | 300 | 100% |

### Education wise Distribution

| Education | Frequency | Percentage |
|---|---|---|
| Iliterate | 129 | 43% |
| Primary | 118 | 39.33% |
| Secondary | 37 | 12.33% |
| College | 16 | 5.33% |
| Total | 300 | 100% |

### Marital Status wise Distribution

| Marital Status | Frequency | Percentage |
|---|---|---|
| Married | 188 | 62.67% |
| Unmarried | 36 | 12% |
| Separated/Divorced | 17 | 5.67% |
| Widow/Widower | 59 | 19.67% |
| Total | 300 | 100% |

### Family Size wise Distribution

| Family Size | Frequency | Percentage |
|---|---|---|
| Small (2-4) | 78 | 26% |
| Medium(5-7) | 139 | 46.33% |
| Large (More than 7) | 83 | 27.67% |
| Total | 300 | 100% |

### Family Income wise Distribution

| Family Income (Monthly in Rupees) | Frequency | Percentage |
|---|---|---|
| Low (Below 5000) | 237 | 79% |
| Middle (5000-10000) | 48 | 16% |
| High (10000 and above) | 15 | 5% |
| Total | 300 | 100% |

## Nature of Disability wise Distribution

| **Nature of Disability** | **Frequency** | **Percentage** |
|---|---|---|
| Old Age related | 17 | 5.67% |
| Disease related | 261 | 87% |
| Both Old Age and Disease related | 22 | 7.33% |
| Total | 300 | 100% |