COMMUNITY BASED PALLIATIVE CARE IN NORTHERN KERALA: QUALITY AND SUSTAINABILITY IN A RESOURCE POOR ENVIRONMENT

COMMUNITY BASED PALLIATIVE CARE IN NORTHERN KERALA: QUALITY AND SUSTAINABILITY IN A RESOURCE POOR ENVIRONMENT

Dissertation submitted in partial fulfillment of the requirements for the award of the degree of Master of Philosophy in Economics of the Jawaharlal Nehru University.

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M Phil Programme in Applied Economics

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CENTRE FOR DEVELOPMENT STUDIES
THIRUVANANTHAPURAM

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I hereby affirm that the work for this Thesis, ***"Community Based Palliative Care in Northern Kerala: Quality and Sustainability in a Resource Poor Environment"***, being submitted as part of the requirements for award of the degree of Master of Philosophy in Applied Economics of the Jawaharlal Nehru University, was carried out entirely by myself. I also affirm that it was not part of any other programme of study and has not been submitted to any other University for the award of any Degree.

28/06/2011

Thiruvananthapuram
June 2011

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Certified that this study is the bona fide work of **Shyno N K**, carried out under our supervision at the Centre for Development Studies.

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To My Beloved Father and Mother...

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Shyno N K

Abstract of the Dissertation

Community Based Palliative Care in Northern Kerala: Quality and Sustainability in a Resource Poor Environment

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Demographic and epidemiological transitions in developing countries have brought to forefront the need for high quality end of life care. The speed of the transitions is high in Kerala, one of the Indian states, with sound social development and health indicators. Kerala is the state with high health risk factor which adversely affects both elder and poor peoples' accessibility of health care and thereby poor quality of life. Many researchers have raised doubt about the quality of life of the people because of high prevalence of communicable and non- communicable diseases in the state. The success of community based palliative care in Northern Kerala has attained much attention from policy makers of both developed and developing countries. However, the replicability of the programme to other states of India is a major challenge. The factors behind the successful implementation of palliative care service need to be understood. Literature related to Community Based Palliative Care in Northern Kerala reveals that quality of the care and sustainability of the palliative care are the major challenges in a state like Kerala where resources devoted by the government for health care is insufficient. In this context the present study attempts to analyse the quality and sustainability of Community Based Palliative Care in Northern Kerala in terms of structure, process and outcome. Specifically, the study analyzes both demand side perception related to care and supply side soundness in providing continuous care to the patients. The study is based two primary surveys-institutional survey conducted in three Northern districts of Kerala, Wayanad, Kozhikode and Malappuram and patient survey conducted in Wayanad district.

The supply side analysis revealed that NGOs, religious organisation and social organisations have played key role in the development and determination of palliative care service in Northern Kerala. Even though all sample institutions are self-sufficient in community participation, they have been experiencing lot of constraints in the path of development in terms of financial sustainability, poor integration with other components of health sector, weak infrastructure facilities, lack of essential drugs in the institution etc. Due to these constraints, they are not able to provide good quality and continuous care to the patients. The study brought out that the supply side weakness is much severe in Wayand districts as compared to other two districts. The demand side analysis found that needs and requirements of patients are multiple. The socioeconomic profile of the patients showed that they are one of the vulnerable sections of our society .Most of them are affected by chronic and terminally ill, socially and economically deprived section and depend upon family members to meet their basic needs. It has been observed that all sample populations are the victims of catastrophic medical expenditure. The FAMCARE scale analysis found that respondents are highly satisfied with the coordination of the care with the community participation. However, the components related to infrastructure facilities of the institutions indicate less satisfaction. The study finds an urgent need to strengthen quality of the structure, process and outcome of Community Based Palliative Care for long run sustainability of the programme.

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Chapter I

Introduction

1.1 The Context

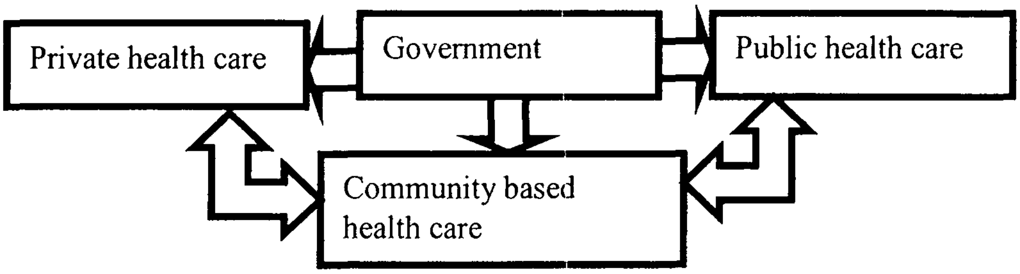
Tens of millions of people worldwide are affected by life threatening illnesses such as HIV/AIDS and cancer, which cause them and their families' great suffering and economic hardship. The majority of the cases occur in the developing world where quite often there is little accessibility to prompt and effective treatment for these diseases (Cecilia and Marlin, 2002). Of the 57 million people dying each year (WHO 2003), approximately 6 million deaths are from cancer and 3 million from HIV/AIDS with the majority occurring in developing countries. Around two thirds of patients with advanced cancer have pain (WHO) and patients with HIV/AIDS suffer similarly if not more. The incidence of cancer and HIV/AIDS in many developing countries is increasing (UNAIDS, 2006).For the majority of people dying in the developing world, cure or disease control in the form of surgery, chemotherapy and radiotherapy for cancer or anti-retroviral drugs for HIV is not available.

As child survival programs continue to achieve their goals of reducing infant and child mortality, the age structure and overall health status of the populations of most developing countries are changing. A decline in fertility in many parts of the world has resulted in a shift toward an older population. With an increasing proportion of the population falling into the adult and elderly age groups, the epidemiological profiles of developing countries increasingly reflect the diseases and health problems of adults rather than of children. In particular, chronic and degenerative diseases, and accidents and injuries, are becoming more important causes of death. In most countries, this process has been accelerated by a more rapid reduction in infant and child mortality rates than those of adults. This shift in demographic and disease profiles, often referred to as the epidemiological transition, is currently under way in most developing countries (James, Preston, 1993). The transition occurs at different paces in different places, depending on the rate of fertility changes, the distribution of risk factors that contribute to the incidence of disease, and the health system's ability to respond to the changing epidemiological profile.

The populations of developing countries are gradually shifting from environments with greater exposure to infectious diseases (poor water and food quality, unhygienic sanitation practices) to areas with a higher prevalence of risk factors for non-communicable diseases, such as motor vehicles, unsafe workplaces, and air pollution (Smith, 1990). Epidemiological studies indicate that smoking, hypertension, dietary fat, motor vehicles, occupational hazards, and poverty are among the leading risk factors for death from non-communicable diseases in developing and developed countries alike.

As a result of demographical and epidemiological transition the demand for health care in all over the world has been increasing rapidly. There are three kinds of health care are available in most of the countries; private, public and community based health care (figure 1.1).

Figure 1.1 Kinds of health care in developing countries



Source: Developed by the Author

As far as developing countries are concerned it is not easy to meet growing needs of health care of the people. Both public and private health care institutions have only a limited capacity to accommodate all the needy population with the available infrastructure facilities. Moreover they deliver the care up to a stage beyond that it is meaningless to extend the care in their perspective. The public and private health carers may not take much interest in giving treatment and care to the patients with incurable diseases after a stage of treatment. Who will care this population? Here lies the relevance of community based health care like palliative care which accommodates chronically and terminally ill patients and provides better quality of life in their last stage of life. Though both public and private health care institutions provide disease targeted care, Community based health care provides total care to the patients and their family.

To promote awareness of issues surrounding end-of-life care, the Lien Foundation commissioned the Economist Intelligence Unit to devise a "Quality of Death" Index. The Index ranks 40 countries (of which 30 are OECD nations) on their provision of end-of-life care. The Quality of Death Index scores 40 nations on 24 indicators in four categories[1]- Basic end-of-life healthcare environment, Availability of end-of-life care, Cost of end-of-life care, Quality of end-of-life.

Table 1.1 Quality of Death Index for selected countries (2010)

Categories	United kingdom	Australia	New Zealand	Ireland	United states	China	India
Basic end of life health care environment	29	19	28	17	9	36	39
Availability of end-of-life care	1	3	2	7	8	40	35
Cost of end-of-life care	18	1	3	9	31	37	39
Quality of end-of-life	1	2	3	5	7	35	37
Overall ranking	1	2	3	4	9	37	40

Source: Lien Foundation, 2010

It shows that developed countries like United Kingdom, Australia, New Zealand, Ireland and United States have better rank in the quality of death index. However India ranks last among the 40 countries indicate low quality of death in

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[1] *Basic end-of-life healthcare environment-The ten indicators in this category are : political instability risk, GDP per head, old age dependency ratio, life expectancy at birth, health care spending (% of GDP), number of hospital beds, doctors and nurses per 1000 non accidental death, social security expenditure on health, and national pension scheme coverage .Availability of end-of-life care-The four indicators in this category are: availability of hospices and palliative care services per million population aged 65 and over, availability of volunteer workers for end of life care support, percentage of death touched by the end of life care and the existence of a government-led national palliative care strategy. Cost of end-of-life care-The three indicators in this category are: availability of public funding for end of life care, financial burden to patients for available end of life care services, as well as average payment by patient for end of life care services per week. Quality of end-of-life--The seven indicators in this category are: public awareness of end of life care, training for end of life care in medical schools, availability of pain killers, accreditation for end of life care providers, doctors-patient transparency, government attitude towards end of life care and existence of a do not resuscitate(DNR) policy. Eleven of the indicators are quantitative, including factors such as life expectancy and healthcare spending as a percentage of GDP. Ten indicators are qualitative assessments, such as the level of public awareness of end-of-life care. Three are status indicators of aspects such as whether a country has a government-led end-of-life care strategy or is in the process of setting one up.*

terms of basic end of life health care environment, availability of end of life care, cost of end of life care and quality of end of care.

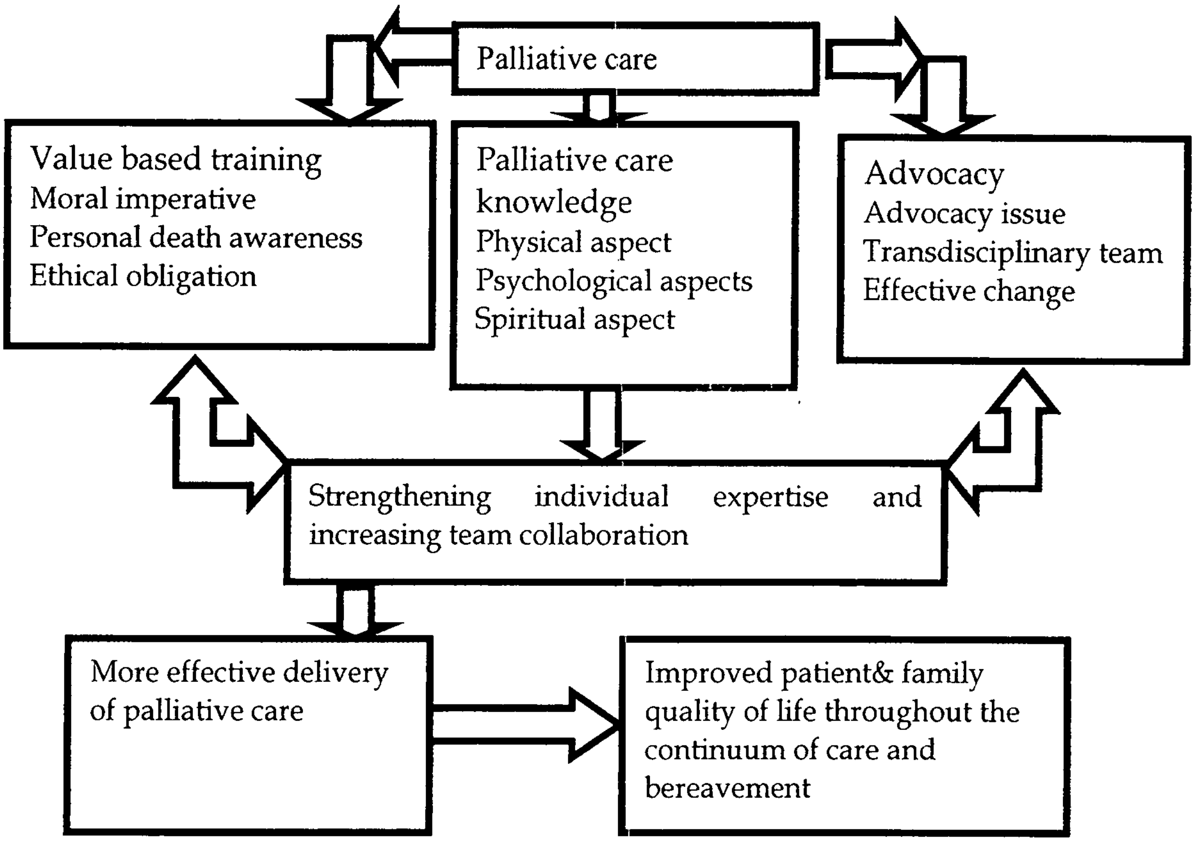
Countries with a national palliative care strategy tended to fare better in their care for the dying. "Highly developed or the rich countries of Asia do not necessarily rank highest in end-of-life care provision, but much depends on how palliative care services are organized and funded, and whether they are accessible to all those who need them (Cynthia, 2010. The report reveals that the top ranking countries where palliative care services are well integrated into their healthcare systems, have a national strategy to ensure quality care reaches the whole population. The report continues that in India except Kerala in all other states palliative care strategy is not functioning well.

It is estimated that around 2.5 million people suffer from cancer at any given time in India (Government of Kerala, 2008). Almost 80 % of patients reach hospitals in advanced stages of the disease. The majority needs palliative care, whereas only minority of the needy receives this input. The government of India suggested that palliative care be linked with cancer care in the final stage of the disease as part of supportive measures. Lately the explosion in HIV/AIDS cases in India has made the requirement for palliative forms of treatment even more acute. Among the Indian states Kerala has attained superior position in palliative care services. The relevance of palliative care in Kerala has been increasing over the years because of high prevalence of chronic diseases and due to the existence of high health risk factors. In its earlier stage of developments palliative care was mainly targeted to cancer patients. Now palliative care services are extended to all chronically ill patients. The aim of palliative care is to ensure better quality of life to patients and families by giving physical, social and economic care to them.

1.2 Palliative Care-A Conceptual Framework

Palliative care (from Latin palliare, to cloak) is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms, rather than striving to halt, delay, or reverse progression of the disease itself or provide a cure. The goal is to prevent and relieve suffering and to improve quality of life for people facing serious, complex illness. Non-hospice palliative care is not dependent on prognosis and is offered in conjunction with curative and all other appropriate forms of medical treatment. Figure 1.2 illustrates the conceptual frame work of palliative care.

Figure 1.2 conceptual illustration of palliative care



Source: Developed by the Author

Historically palliative care has been associated with the delivery of care by hospices to cancer patients. However from its early beginnings, promoters of the palliative care model have been at pains to emphasize that palliative care is a philosophy of care with no association with a particular setting, disease or type of caregiver (Clark and Seymour 1999, Seymour and Hanson 2001). Indeed, palliative care being recognized as an essential component in the care and treatment of all those who suffer from a life threatening or life limiting illness.

The aim of palliative care is to provide the best possible quality of life both for people approaching the end of life and for their families and carers. It is a holistic approach to care and support, and takes into account emotional, psychological and spiritual needs as well as physical needs. The goal of palliative care is achievement of the best quality of life for patients and families. Pain control is central to the concept of palliative care. Freedom from pain allows people to come to terms with their approaching death and enables them to make arrangements for the future of others who depend on them, as well as to live as fully as possible for as long as possible.

WHO (1990) defines palliative care as an approach that:

- Affirms life and regards death as a normal process.
- Does not hasten or postpone death.
- Provides relief from pain and other symptoms.
- Offers a support system to help patients live as actively as possible right up to their death.
- Integrates psychological and spiritual care.
- Provides a wider support to help the family cope during the patient's illness and their own bereavement after death.

The concept of palliative care is relatively new in India, but the requirement is beyond our imagination. With improved standard of living and adoption of western habits such as tobaconis and alcoholism, the number of cancer cases is increasing in India. Lately the explosion in HIV/AIDS cases in India has made the requirement for palliative forms of treatment even more acute.

1.3 Community Participation Approach

Community development approach aims to improve health by addressing socioeconomic and environmental causes of ill health within the community. The concept Community participation is defined as 'a process by which people are enabled to become actively and genuinely involved in the defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change' (WHO, 2002). Community recognizes the close relationship between individual health and its social and material contexts, which consequently become the target for change. In this approach individuals act collectively in order to change their environment rather than themselves.

Community participation in different programs is usually of two types depending on the perspectives. What most programs mean by community participation is only utilization of community resources (money, manpower.) to supplement what is otherwise available for the program. Volunteers in such programmes are asked to fill certain preset "slots.' They do not play any major role in planning, valuating, monitoring, or modifying the program. On the other hand, community participation can also be a tool for empowerment, enabling local communities to take responsibility for identifying and working together to solve their own health and developmental problems. Neighborhood Network in Palliative Care [2](NNPC) is an attempt at such a community development program in palliative care. This approach, in essence, sees participation as an end, where the community or group sets up a process to control its own development.

The community approach is the only realistic model for achieving significant coverage of care for two thirds of the world's terminally ill. Meaningful palliative care requires a combination of socio economic, cultural and medical solutions. Only by the active involvement of the community in addressing all three factors can palliative care reach all suffers in need of it. Community health care givers can easily identify those socially and economically deprived patients through volunteers.

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[2] *The Neighbourhood Network in Palliative care is an attempt to develop a sustainable community led service capable of offering comprehensive long term care and palliative care to the needy in developing world. The Neighbourhood Network in Palliative care programmes have been successful in all the district of kerala where they have launched. In this programme ,volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively with active support from a network of trained professionals. . The palliative care movement in Northern Kerala is an inimitable one because of its functioning through a Neighborhood Network. These Neighborhood groups are functioning in close cooperation with the decentralized state bodies, religious, social and political groups in the region. Trained volunteers from the community assist in providing care, and family members were empowered in order to ensure continuity of treatment. Besides empowering the local communities to identify the chronically ill, the Neighborhood Networks in Palliative Care also provide the patients with medical and non-medical rehabilitation services. Districts such as Malappuram, wayanad, Kozhikode and Trissur where the speed and coverage of NNPC were remarkable.*

Figure 1.3 Agents of community based palliative care

Source: Stjernsward, 2005

The figure1.3 gives an idea about the major agents of the community based palliative care which is proposed by Stjernsward 2005. Specialists have a definite but small role. Primary care physician in the periphery to be involved. Massive involvement from the local community is the basis of the proposed model.

1.4 Palliative Care in Kerala-Review of literature

The Community Based Palliative Care Network in Northern Kerala is one of the largest of its kind in the developing world. The palliative care movement in Northern Kerala is an inimitable one because of its functioning through a Neighborhood Network (Sajan Thomas, Aju Mathew and Prabhu Dass G ,2007). These Neighborhood Groups are functioning in close cooperation with the decentralized state bodies, religious, social and political groups in the region. Trained volunteers from the community assist in providing care, and family members were empowered in order to ensure continuity of treatment. Volunteers identify and address a variety of nonmedical issues, including financial problems, patients in need of care, organizing programs to create awareness in the community, and raising funds for Palliative care activities.

With only 3% of India's population, the tiny state provides two-thirds of India's palliative care services (Lien foundation, 2010). Moreover, the state has a formal palliative care policy in place (it is the only Indian state with such a policy) and its government provides funding for Community Based Care Programmes. It is also one of the first of India's states to relax narcotics regulations to permit use of morphine by palliative care providers. Kerala has also extended the definition of palliative care to include the long-term chronically ill and even the mentally incapacitated.

However the functioning of palliative care in Kerala is subject to severe financial constraints (Rajagopal, 2010). Its main source of revenue is the small donation from the public which is insufficient to meet even basic expenses. Yet, money is not the only answer to relieving suffering and improving quality of life for those in the last stages of their lives. Other important factors are government policy, support, community involvement and the awareness of doctors of not only pain control but also of what palliative care provides more generally.

Literatures shows that community based palliative care is very successful in Kerala (Kumar 2010,Anil Paleri 2010, Rajagopal 2010 ,Jan Stjernsward 2010,Libby Sallnow, Shabeer, 2010). Kerala's unique system proves the importance of these points, embodied in the Neighbourhood Network in Palliative Care (NNPC) project. Since 2001 this project, which grew from a more traditional, institutional based palliative care experiment, has employed an army of volunteers that deliver services to patients who largely remain in their own homes. The aim of NNPS is to improve both accessibility and quality of end-of-life care, and the principles of community involvement make this feasible on a large scale (Suresh Kumar, 2010). However, they are doubt about the reproducibility of the programme to other states of the country. The factors behind the success of palliative care in Kerala need to be explored. However, within Kerala the development of palliative care programme varies across districts.

As compared to Southern districts in Kerala Northern districts such as Malappuram, Wayanad, and Kozhikode have wide coverage both in terms of number of clinics and patients under treatment (Kumar, 2010). In a study done in Malappuram district of Kerala it was found that around 40% of those people who are dying would have benefited from applying the principles of palliative care and their management. In Kerala, with a population of 32 million and crude death rate of 6.3 (2001 census) around 80000 dying patients and families would be benefited each year (Government of Kerala Palliative, 2008). To this if add the number of people living for years with chronic conditions the total number will be much more.

The challenges before palliative care workers are to evolve a culturally and socio-economically appropriate and acceptable system for long-term care and palliative care that is accessible to most of those who need it. Patients with incurable diseases have medical and nursing problems, but these are only a part of a complex situation, which cannot be addressed solely by a doctor/palliative care centre. Issues associated with chronic ill are basically social problems with a medical component. The satisfaction of patient and family depend upon how care providers succeeded in managing those issues.

The existing health care facilities are more attuned to caring for acute health problems and they play only a limited role in the care of the chronically ill in the society (Anil Paleri 2010). Those who need continued supportive care spend their lives not in the hospital, but in the community among their family and neighbors. Hence the community has major role in the care of these individuals. The diseases and the cost of curative treatment often plunge the family into depth of poverty. Palliative Care Patients' Trust tries to help families especially when the sole earning member of the family is rendered physically helpless due to the illness. But the economic services of the programme are subjected to financial constraint. The major source of fund is the small contributions of people. Local governments also have been devoting some amount in their budget. But the increasing need for palliative care has raised the issue of financial sustainability of the programme (Kumar and Paleri, 2010).

In Northern Kerala the coverage of palliative care services has increased recently with community participation. It is important to ensure that coverage in palliative care does not involve an acceptable fall in quality (M. R. Rajagopal, and Gayatri Palat2002. In Kerala Palliative care is still not accessible to those most in need. Even though wayanad has wide coverage of palliative care, most of the incurable disease patients are not getting the community care (Rameshan, 2010).

Recently government of Kerala declared the pain and palliative care policy. However the few questions still unanswered. Will the new policy be sustainable in the long run, with funding coming from local communities only, with different institution and financial arrangements(Anil Paleri 2010,Jan sternward 2010)?The government of Kerala reacted very favorably to the new policy, but it was unable to provide substantial support due to shrinking resources in the public sector, affecting the whole India. It will be relevant to monitor whether the current level of political support will be sufficient to encourage funding from the community, or whether institutional financing mechanism will be necessary for the expansion and continuation of the initiatives.

In a state like Kerala where social security schemes are not sufficient to meet the medical expenditure of poor people, the caring of dying people is essential to provide better quality of life at the last stage of life (M. R. Rajagopal, and Gayatri Palat2002). The people's attitude and perception about the institutionalized palliative care can be different. The acceptability of palliative care approach depends up on the cultural and ethical issues. However most of patient getting treatment in the palliative care are economically depressed people. Study is required to identify the factors, which forced them to accept the care from palliative care institution.

The primary aim behind the palliative care is ensuring quality of life at the end of life. The experts working on palliative care are worrying about the sustainability and quality of palliative care programme since it has been facing lot of institutional constraints in meeting its aim. In the Kerala context there is no study so far conducted to study the community based palliative care and its sustainability. The study on quality aspect (structure, process and outcome) is essential both for policy purpose and for identifying the weakness of the system. The present study is an attempt to understand the quality and sustainability of Community based palliative care in Northern Kerala.

1.5 Objectives of the study

The specific objectives of the present study are:

1. To study the evolution, structure, process and persistent challenges of Community Based Palliative Care of Northern Kerala
2. To measure the quality of Palliative care in terms of satisfaction of family members
3. To study socio economic and health profile of the palliative care patients and implications

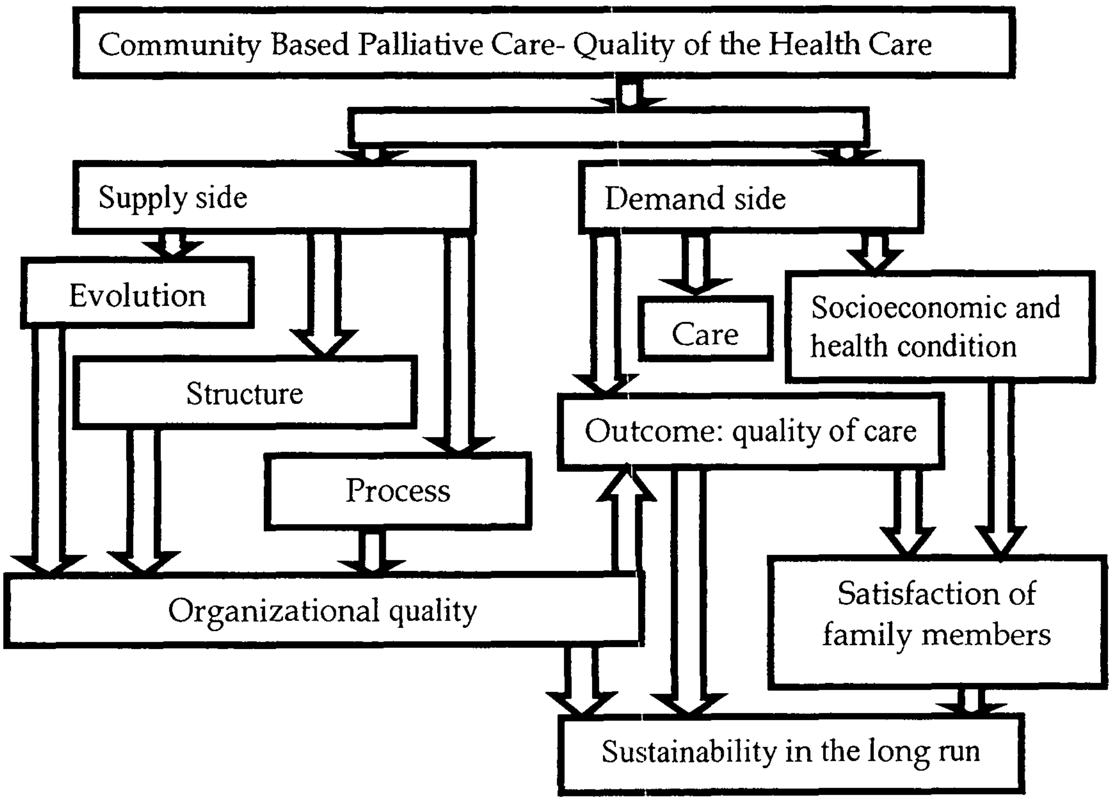
1.6 Analytical Framework

The quality of a health care system relates to how effective that system or organization is in achieving its aim. The quality of an organization can be represented and assessed using a three part model of structure, process, and outcome (Lucy Selman, Richard Harding 2010). The merits of the three types of measures have been debated since Donabedian (1966) conceptualized quality measures in the three broad categories of structure, process, and outcome. In recent years, outcome measures have been emphasized for evaluating health-care quality (Lohr and Schroeder 1990; Shortell and Hughes 1988; Rinke 1987; Luft and Hunt 1986; Institute of Medicine 1986; Kane and Kane 1988).

Each of the three aspects of quality assessment interact,ie, good structure increase the likelihood of good process and good process increase the likelihood of good outcome. As far as supply side of the health care is concerned evolution, structure and process of health care determines the quality of the organization and its long run sustainability. The structure of the organization can be analyzed through looking at the attributes of the settings including staff, equipments, money, infrastructure facilities, integration with other health sector, etc. The process of the care means the way of care delivery (both medical and non-medical), what is being done and how resources are used ie, home visit, clinics, diagnosis and treatment given.

The determinants of health owe much to the nature and pattern of health care provision, infrastructure, and the socio-economic status and the cultural aspiration of the people. The single most important factor influencing the individual or family health status is the quality of life, which would be determined by socio-economic and demographic factors. From a political economy view point, the demand for health care depends much on the nature and pattern of resource allocation in the health sector, the quantity and quality of medical care services and on distributional and equity patterns. The outcome of the care, change in the quality of the life, is an important determinant of demand for health care which ultimately determines sustainability of a health care programme. The outcome of the health care can be analyzed from two perspectives, patient perception related to care and satisfaction of family with the care. The present study measures the outcome in terms of satisfaction of family satisfaction. Satisfaction with care has been defined as the evaluation of distinct health care services received by both the patient and the family.

Figure 1.4 Analytical Framework of the Study



Source: Developed by the Author

Figure1.4 illustrates the analytical framework of the study. Both supply and demand side of the health care would be analyzed to understand the quality of palliative care. In the supply side we analyse the organizational quality in terms of evolution, structure and process. In demand side, initially we analyse the socio economic and health condition of the patients which in turn determines the quality of life of the people. The demand for health care of the people is determined by several factors including socio economic and health condition, quality of life etc. And what they get from the care institution determines the satisfaction of patients and family members and thereby the quality of care. Both demand and supply side quality aspects together give an insight into the long run sustainability of the programme.

1.7 Methodology

In order to study the first objective an institutional level survey has been conducted in palliative care institutions. The study has been conducted in the three districts of Northern Kerala namely, Wayanad, Kozhikode and Malappuram. These three districts are distinct in many socio economic and demographic contexts. In wayand, one of the backward districts in Kerala state, the density of tribal population is higher than other districts. Malappuram is the highly populated district in the state with higher proportion of Muslim population. These three districts have been selected for the study mainly because of successful experience of community based palliative care in these districts.
To analyse first objective 40 sample institutions were randomly selected from these three districts. Out of 40, 14 institutions are from Wayanad, 11 institutions are from Kozhikode and 15 institutions are from Malappuram. We have selected those institutions which provide all kinds of medical care (inpatient, outpatient and home patient care). The questionnaire has been prepared in such a way as to collect information from different aspects including evolution and agents of palliative care, structure, infrastructure facilities, community involvement, integration with health sector, medical and nonmedical care, financial aspect and role of government.

In order to study second and third objective the study area is restricted to wayanad; one of the districts where Community Based Palliative care is very active. However, in the chapter 3 we find that palliative care institutions in this district have been facing several organisational difficulties as compared to other two districts, Malappuram and Kozhikode. In order to analyse second and third objectives 100 samples were taken from three palliative care institutions in wayanad district. All sample population are including in the category of home based patients. Due to poor infrastructure facilities, Palliative caregivers prefer home based care which is considered as better substitute for inpatient care. Home based care is meaningful and most appropriate one in many contexts. One is that family members themselves can act as care givers, so that continuous care can provide to the patient. Secondly, patient can spend their last stage of life with family members.

Questions related to various aspects including socio economic and health condition, health expenditure, coverage of social security schemes, kind of care receives from palliative care institution, perception related to quality of care were asked to patients and their family members. Most of the patients were not able to response. Family members were helped to finish the questionnaire.

In order to measure the quality of care FAMCARE scale [3]were used. It actually measures the satisfaction of family members with the palliative care. It includes 20 items related to various aspect of life. The present study uses only 13 questions related to various aspect of health care such as physical care, general care, and medical care, availability of health care infrastructure, etc. simple descriptive statistics and factor analysis have been used to measure the satisfaction of family members. A detailed description of the methods and data sources used for the study will be discussed in the forthcoming chapters.

1.8 Organisation of the Thesis

The present study is divided into six chapters including the introduction. Chapter 2nd analyses the Relevance of Palliative Care in Kerala: Existence of high health risk factors and low public spending on health sector. This chapter is

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[3] *The FAMCARE scale was developed by Kristiansen LJ, Faculty of Nursing, and University of Manitoba, Canada. The FAMCARE was developed to measure the degree to which family members are satisfied with the health care received by both the patients and the family with respect to the following four components of care: information giving, availability of care, psychological care and physical patient care.*

based on the various NSSO round data and available secondary data. Chapter 3rd study the evolution, structure, process and persistent challenges of community based palliative care in Northern Kerala. Chapter four discusses the socioeconomic and health profile of the palliative care patients and its implication on the demand for palliative care. Chapter five measures the quality of palliative care: satisfaction of family members with the palliative care. Major findings, conclusions and policy suggestions are presented in the final chapter.

Chapter II

Relevance of Palliative Care in Kerala: Existence of High Health Risk Factors and Low Public Spending in Health Sector

2.1 Introduction

Kerala model of development has achieved wide consensus and attention among researchers and policy makers of developing countries mainly because of its sound social indicators despite slow economic development. Mortality indicators show that health status of Kerala is far advanced and higher than the all India average and is even comparable with developed countries. This outstanding progress of health status is achieved through widespread growth of the three systems of medicine in public, private, co-operative sectors combined with people's health awareness. At the same time, the nature of transition to modern neo-plastic diseases has been in tune with the morbidity profile elsewhere. Though Kerala has attained better health indicators, the people are now facing the problem of high morbidity[1] both from communicable and non-communicable diseases. Moreover, high prevalence of disability[2] and higher medical expenditure prevents poor people from acquiring better medical care. Literatures show that Kerala is the one of the states has been experiencing high health risk factors like smoking, hypertension, dietary fat, motor vehicles, occupational hazards, and poverty, high prevalence of diseases, high medical expenditure etc. The quality of health status of Kerala people is doubtful in the context of existence of high health risk factors even though we have sound health indicators.

This chapter analyses the relevance of palliative care in Kerala in the context of emergence of large number of Community Based Palliative Care institutions in Kerala. Here we analyses some of the important issues like aging, morbidity,

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[1] *NSSO definition of morbidity was "any deviation from the state of normal and mental well-being is considered as illness" the reference period is 30 days preceding the survey.*

[2] *A person with restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being was treated as having disability. It excluded illness/injury of recent origin (morbidity) resulting into temporary loss of ability to see, hear, speak or move.*

disability, government spending on health sector and higher medical expenditure on the basis of NSSO 60th round survey data, census data and through other available secondary data. This chapter contains 7 section including introduction. The section 2.2 examines the aging and need of health care for aged people in Kerala. The Section 2.3 analyses prevalence of morbidity and chronic diseases among different age groups in Kerala and its implication. The section2.4 discusses various disabilities in kerala and its implication on health care. The section 2.5 demonstrates the catastrophe health expenditure and its implication on poor people. The section 2.6 looks at the public investment on health care system in Kerala. The section 2.7 concludes the major findings of the chapter.

2.2 Demographic aging in Kerala

Old age is considered to be the last chapter of life. Though, a universal phenomenon, it is not a uniform experience among senior citizens. Some persons achieve a sense of fulfillment and satisfaction in their old-age while others turn bitter and lament the decline of their physical abilities and social significance. The specific health problems among the elderly are totally different from adult or young. Though there has been a shift in disease pattern from communicable to non-communicable diseases, they usually suffer multiple chronic diseases. That is, old age is generally accompanied by a number of problems that the aged have to face and adjust within varying degrees. These problems may range from ensured and sufficient income to support themselves and their dependents to sound health, creative use of free time, social security, love and recognition, social participation, dignity, and self-respect. Loss of economic independence and physical vigor and emergence of various types of generative diseases change an aged from an independent self supporting individual to one who needs help from their children, members of the family and society in general (Mohanachandran and Balasubramanyam, 2000).

Aging population is the one of the major population issues in India which has vast economic and social implications. This establishes a number of serious challenges that range from social security coverage to increasing needs for health care, changing consumer behavior, and possibly changes in productivity (Irudaya Rajan and C. Shanthi Johnson, 2010). In India the process of demographic transition occurring much faster in the South as compared to the Northern states (Irudaya Rajan, 2005). Among the south Indian states, Kerala is in the final stage of demographic transition with low fertility and low mortality. As a result the share of elderly population has been increasing in Kerala. With Kerala having undergone the demographic transition, however, the number of caregivers in the families has been on the decline (Irudaya Rajan, Sabu Aliyar 2007). A population with increasing share of elderly people requires special care to the elder people to ensure high quality of life in the final stage of life.

Table 2.1 Elderly population in India as per 2001census

Rank	India/ states	Share of 60+ population (%)	Share of 70+ population (%)	Share of 80+ population (%)
	INDIA	7.5	2.9	0.8
1	Kerala	10.5	4.4	1.2
2	Punjab	9	3.9	1.2
3	Himachal Pradesh	9	4.0	1.3
4	Tamil Nadu	8.9	3.4	0.9
5	Maharashtra	8.7	3.2	0.8
6	Goa	8.4	3.1	0.8
7	Pondicherry	8.3	3.3	0.8
8	Orissa	8.3	3.2	0.8
9	Uttaranchal	7.7	3.0	0.8
10	Karnataka	7.7	3.0	0.9
11	Andhra Pradesh	7.6	2.7	0.7
12	Haryana	7.5	3.1	0.9
13	Tripura	7.3	3.3	1.1
14	Chhattisgarh	7.2	2.6	0.7
15	West Bengal	7.1	2.8	0.8
16	Madhya Pradesh	7.1	2.7	0.7
17	Utter Pradesh	7	2.7	0.8
18	Gujarat	6.9	2.6	0.7
19	Rajasthan	6.8	2.6	0.7
20	Manipur	6.7	2.8	0.8

Source: Irudaya Rajan, 2005

According to 2001 census the share of elderly population in the total population in Kerala is 10.5% which is highest among the Indian states. Table 2.1 shows that Kerala state has highest proportion of aged people for all aged categories ie.60 above, 70 above and above 80. Two features of Kerala health status, high life expectancy and low mortality rate, prolongs the life span of the people. More over the process of demographic transition leads to shrinking of younger age group and expansion of the proportion of elderly population. This elder population requires special care and medical treatment for keeping good quality of life. Further high prevalence of morbidity and disability among elder people makes them more vulnerable group in the society. Both society and government have the responsibility to ensure better quality of life in their last stage of life. Government has been adopting different social security schemes for helping this kind of people. But it is well aware that current systems of social schemes are not sufficient to provide adequate funds to the beneficiaries. Moreover most of them are not covered by any of the schemes.

Table 2.2 Number of aged per 1000 persons for each sex and major states

Major states	No. of aged per 1000 persons (Rural)			Old age dependency ratio	No. Of aged per 1000 person (Urban)			Old age dependency ratio
	Male	Female	Person		Male	Female	Person	
Andhra Pradesh	73	77	75	110	53	64	58	83
Assam	53	43	48	76	54	50	52	76
Bihar	59	52	55	99	62	55	59	91
Chhattisgarh	53	77	65	103	43	57	50	71
Gujarat	67	68	68	128	54	69	61	86
Haryana	72	84	78	103	51	77	63	92
Himachal Pradesh	92	95	94	119	50	52	51	79
Jammu& Kashmir	73	54	64	134	60	50	55	75
Jharkhand	63	48	56	95	68	69	68	98
Karnataka	71	66	69	100	58	61	59	84
Kerala	106	123	115	155	103	109	106	139
Madhya Pradesh	63	68	65	107	54	64	59	88
Maharashtra	83	88	86	129	65	76	70	96

Source: NSSO, 2006

Table 2.2 shows that the number of aged per 1000 persons for each sex and major states. The NSSO 60th [3]round survey demonstrates that number of aged per 1000

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[3] *A survey on 'Morbidity and Health care' was undertaken by the NSSO during the NSS 60th round (January - June 2004) at the request of Ministry of Health and Family Welfare. This subject was taken up along with the subjects of household consumer expenditure and employment-unemployment. The enquiry covered the curative aspects of the general health care system in India, utilization of health care services provided by the public and private sector and the expenditure incurred by the households for availing these services. In addition, information on the condition and problems of the aged persons was also collected. In the Central sample, the actual numbers of households surveyed in the rural and urban areas were 47,302 and 26,566, respectively. In kerala the actual number of household surveyed in rural and urban were 1839 and 990 respectively.*

persons is higher in Kerala which is 115 in rural areas and 106 in urban areas. It is evident from the table that rural area standing first in terms of both number and old age dependency ratio where little accessibility and inadequate of health care facilities are the key issues. The proportion of female is higher than male in both rural and urban areas.

According to the 2001 census, Kerala had 33 lakh elderly persons representing around 10.5 per cent of the total population. In 1961 the share of elder population was only 5.1 and has been increasing over the years and likely to reach 39.6 in 2061 as per population projections done by Irudaya Rajan and Sabu Aliyar in 2007. Even though the growth rate of elder populations are declining, much attention is requires mainly because of increase of absolute number of elder population.

Table 2.3 Demographic profiles of elderly in Kerala, 1961-2061

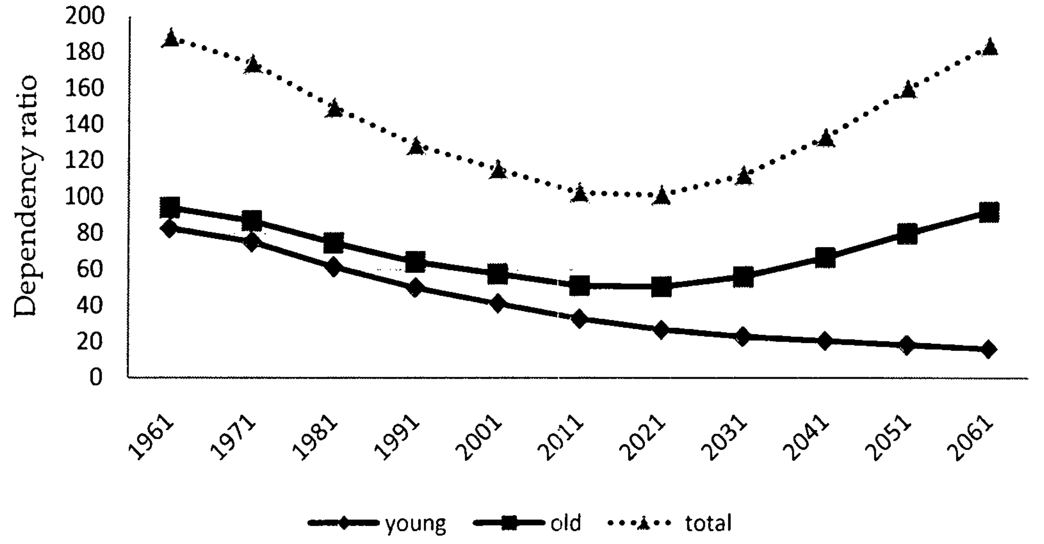
Year	Number of aged (millions)	Percentage of total population	Growth rate (per cent)
1961	0.99	5.1	
1971	1.33	6.2	3.47
1981	1.91	7.5	4.38
1991	2.57	8.9	3.48
2001	3.33	10.5	2.94
2011	4.2	12.2	2.61
2021	5.75	16	3.69
2031	7.78	21.3	3.53
2041	9.88	27.8	2.7
2051	11.48	34.4	1.62
2061	11.95	39.6	0.41

Source: Irudaya Rajan and Sabu Aliyar (2007).

The relatively faster increase in the elderly population will contribute to a higher dependency ratio of the population. The old age dependency ratio which was 11.3 in 1961 and increased to 16.5 in 2001 is likely to increase to 76.1 in 2061. Therefore, responsibilities for care elderly will fall either on young wage earners or on the Government. It is also interesting to see that young age dependency ratio is coming down while that of old age group is rising fastly. This phenomenon is happening mainly because of low fertility and higher life expectancy of the Kerala people. Low fertility and aging creates atmosphere for health care issues like absence of cares in the family to care elder people.

Furthermore, while the care of the child is the direct responsibility of the parents, the care of old persons is only a social obligation which does not carry with it any legal sanction.

Figure2.1 Dependency ratio for youg and old age population in Kerala



Source: Constructed by the author from various data sources

It is obvious from the figure 2.1 that the difference between the dependency ratio for young and old age population has been increasing over the years. For the society, this shift in the dependency structure would call for a substantial change in the pattern of public sector expenditure.

One of the consequences of aging is the economic dependence of elderly population on others. In this age they are forced to retrieve from the labour force and dependent on others for getting basic needs. So that quality of their life depends upon the mercy of family members. The 60th round NSSO survey (2006) shows that around 75 per cent of elder population in Kerala economically dependent, partially or fully, on others. As compared to other Indian states economic dependency of elder population is high in Kerala. The table 2.4 shows the distribution of aged person by the state of economic independence for major state of india.This age group without any strong economic status seems to be burden to the family members. Take up and give better quality of life to these people not seems to be an easy task.

Table 2.4 Per 1000 distribution of aged person by state of economic independence (NSSO 60th round survey, 2006)

States	Not dependent on others	Partially dependent on others	Fully dependent on others	n.r	Total	Partially or fully dependent (%)
Andhra Pradesh	331	108	551	10	1000	65.9
Arunachal Pradesh	222	382	202	194	1000	58.4
Assam	306	157	495	42	1000	65.2
Bihar	388	134	457	21	1000	59.1
Chhattisgarh	377	108	491	24	1000	59.9
Delhi	372	106	511	11	1000	61.7
Goa	421	181	397	0	1000	57.8
Gujarat	311	116	569	4	1000	68.5
Haryana	264	372	359	5	1000	73.1
Himachal Pradesh	382	162	431	24	1000	59.3
Jammu & Kashmir	423	113	448	15	1000	56.1
Karnataka	349	114	532	5	1000	64.6
Kerala	241	186	563	10	1000	74.9
Madhya Pradesh	372	109	494	25	1000	60.3
Maharashtra	334	142	518	6	1000	66.0
Orissa	274	163	538	25	1000	70.1
Punjab	291	158	539	11	1000	69.7
Rajasthan	288	131	578	3	1000	70.9
Sikkim	385	197	381	37	1000	57.9
Tamil Nadu	345	151	504	0	1000	65.5
Uttaranchal	491	52	424	33	1000	47.6
Uttar Pradesh	366	90	523	21	1000	61.3
West Bengal	314	119	543	24	1000	66.2

Source: NSSO, 2006

Aging is a serious issue to concern because of existence of multiple health risk factors in Kerala. While public health care has traditionally been strong in Kerala ,compared to other states ,the public sector has not kept up with the growing demand for health care in recent years (kumar,1993; Nabae,2003) and concerns have been expressed about its capacity to address the specific needs of the aging population (Suresh Kumar and Rajagopal ,1996;Bollani,2004).

Reduction in family size, large scale migration both internal and external, and a high work participation rate of women have contributed to an attenuation of resources for the care of elderly. At the same time, the increasing presence of older persons in the state is making people of all ages more aware that we live in a diverse and multigenerational society. It is no longer possible to ignore aging, regardless of whether one views it positively or negatively.

2.3 Morbidity, Chronic diseases and hospitalization in Kerala

Kerala has entered into the fourth stage of the epidemiological transition with rising tendency of life style related diseases (Navaneetham and Kabir 2006). Further, the patterns of age -sex morbidity for a given diseases also seem to have undergone changes in Kerala.

Challenge to ensuring the health and quality of life the aging population is the double burden of diseases and disability. Chronic morbidity and physical impairments in the old age adversely affects mobility and capacity to perform personal self-care can confine the elderly to their home or bed (Arber and Ginn, 1991). Kerala is the most advanced state in India in terms of demographic transition, with mortality levels close to those of developed nations for the last two decades. However, morbidity levels are comparatively higher than elsewhere in India in this highly literate, densely populated and rapidly aging population. The picture continues, with the two recent national level surveys showing reported morbidity in Kerala well above that in the other Indian States, in both rural and urban areas and across all age groups (National Sample Survey Organization [NSSO] 2006; Registrar General of India [RGI] 2007).

High morbidity is an emerging health issue that matters for human development since it raises issues regarding "quality and affordability of Health care" (CDS, 2006).The co-existence of high level of morbidity with low levels of mortality and high life expectancy in Kerala is one feature, which has attracted much attention. Human Development Report 2005 adduces increase in life expectancy as one of the reasons for high levels of morbidity in Kerala (Centre for Development Studies, 2006).

There is a clear age pattern in morbidity levels, with disease composition revealing the relatively higher prevalence of acute ailments in younger age groups and of chronic ailments in older ones (NSSO 1998; Dilip 2002; Navaneetham and Kabir 2006). Reported morbidity and the duration of life lived with a disease is higher in Kerala. Economic inequalities were found only in late-working ages and the elderly, primarily due to higher prevalence of life style associated chronic conditions in these two age groups.

Table 2.5 Number (per 1000) of persons reporting ailment (PAP) during last 15 days in India across various age group and region

	Rural			Urban			Rural + urban		
Broad age group	Male	Female	All	Male	Female	All	Male	Female	All
0-14	76	68	72	84	74	79	78	69	74
15-29	41	57	49	44	56	50	42	56	49
30-44	64	93	78	64	95	79	64	93	78
45-59	107	132	119	127	173	149	113	143	128
60 & above	285	282	283	352	383	368	301	307	304
All	83	93	88	91	108	99	85	97	91
NSSO 52nd round	(54)	(57)	(55)	(51)	(58)	(54)	(53)	(57)	(55)

Source: NSSO, 2006

Table 2.5 illustrates the Proportion of Ailing Persons [4](PAP), measured as the number of persons reporting ailment during a 15-day period per 1000 persons for some broad age-groups. The PAPs are found to be higher for children and much higher for the higher age groups. The elderly are more vulnerable to disease because of decreased physiological reserves and defense mechanisms. The lowest being the PAPs for the youth (age 15-29 years).The rural urban differentials are also significant among the aged. As compared to 52nd NSSO (2002) round result the prevalence of morbidity considerably increased in both rural and urban sectors.

As per NSSO 60th survey Kerala standing ahead in terms of number (per 1000) of persons reporting ailment (PAP) and number reporting Commencement of any ailment [5](PPC) during last 15 days. Table 2.6 reveals wide inter-state variations in PAP as well as PPC in both rural and urban areas. The level of morbidity in the rural areas of the major States, measured in terms of PAP, varied from 33 in Jharkhand to 255 in Kerala. The variation in PPC, on the other hand, ranged from 21 in Jharkhand to 103 in Kerala. Comparatively, inter-state variation in morbidity reporting in the urban areas was less pronounced, with PAP ranging

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[4] *PAP measured as the number of persons reporting ailment during a 15-day period per 1000 persons for some broad age-groups.*

[5] *PPC number per 1000) of persons reporting commencement(PPC) of any ailment during the reference period of 15 days preceding the date of survey,*

from 50 in Jharkhand to 240 in Kerala. It is, however, seen that the states with relatively high morbidity reporting in the rural areas also reported high morbidity in the urban areas. In fact, in both rural and urban areas, the states of Kerala, Punjab, West Bengal and Andhra Pradesh were at one extreme reporting high levels of morbidity, while at the other extreme were Jharkhand, Uttaranchal, Bihar and Rajasthan with low levels of morbidity reporting.

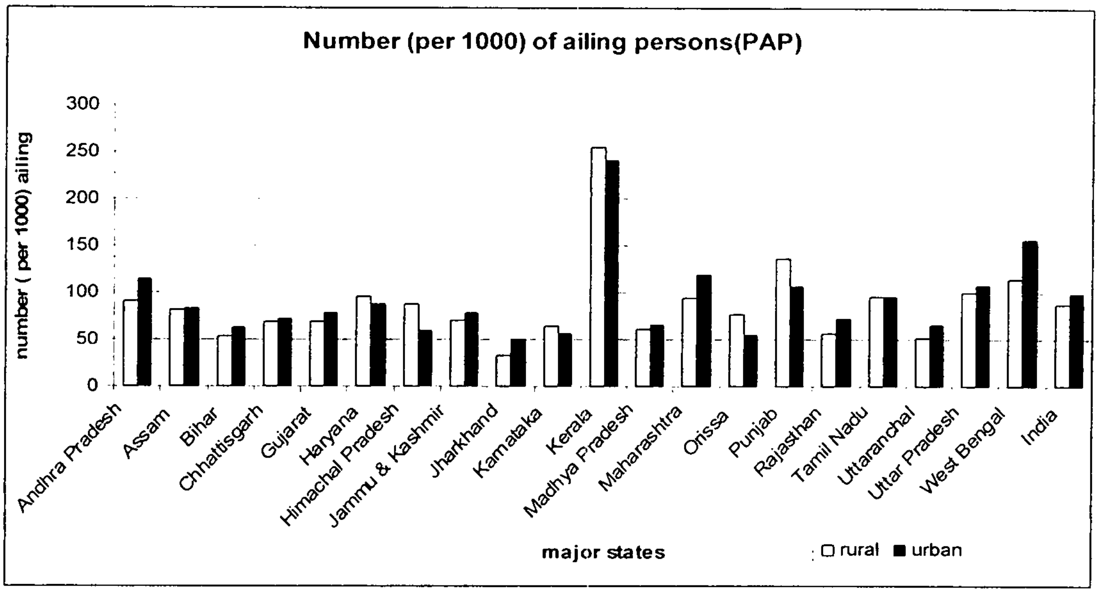
Table 2.6 Number (per 1000) of persons reporting ailment (PAP) and number reporting Commencement of any ailment (PPC) during last 15 days,

Major state	Rural		Urban	
	PAP	PPC	PAP	PPC
Andhra Pradesh	90	36	114	47
Assam	82	58	83	48
Bihar	53	32	63	30
Chhattisgarh	69	38	72	31
Delhi			16	7
Gujarat	69	29	78	29
Haryana	95	48	87	43
Himachal Pradesh	87	26	59	19
Jammu & Kashmir	70	30	78	34
Jharkhand	33	21	50	21
Karnataka	64	32	57	20
Kerala	255	103	240	100
Madhya Pradesh	61	32	65	36
Maharashtra	93	44	118	50
Orissa	77	49	54	30
Punjab	136	61	107	44
Rajasthan	57	23	72	27
Tamil Nadu	95	54	96	49
Uttaranchal	52	31	65	25
Uttar Pradesh	100	55	108	55
West Bengal	114	56	157	62
India	88	45	99	44
NSSO 52nd round	(55)	(31)	(54)	(30)

Source:NSSO,2006

Figure 2.2 shows the state wise reported number ailment per 1000 person. It is clear that Kerala is an outlier with high prevalence of ailments. As a result of high prevalence of ailment among the various age groups, the demand for health care has increased in the state. Even though prevalence of ailment is high among elder population, diseases among younger population also need special consideration because of emergence and spread of diseases like AIDS and other degenerative diseases.

Figure 2.2 state wise number of ailing person per 1000 (NSSO 60th round)



Source:NSSO,2006

It may be noted that Kerala besides having the lowest infant mortality rate, was also far ahead of other states in achievements in the field of health care, as reflected by other indicators like birth rate, proportion of institutional births, life expectancy, etc. But since the state had high proportion of aged people (60 years and above) with, as one might expect, high levels of morbidity, the overall morbidity levels of this state tend to be higher than those of other states. The proportion of the aged in Kerala (11.2 per cent) is found by the 60th round NSSO survey to be much higher than that of the country as a whole (6.9 per cent).

Table 2.7 Incidence of morbidity by gender and sector for different region (in %)

Gender	Northern Kerala	Southern Kerala	All Kerala			All India		
			Rural	Urban	Comb	Rural	Urban	Comb
Male	17.7	28.2	24.2	23.5	24	8.3	9.1	8.5
Female	17.6	31.9	26.6	24.5	26	9.3	10.8	9.6
Total	17.6	30.1	25.5	24	25.1	8.8	9.9	9.1

Source: NSSO, 2006

Incidence of morbidity [6]is higher in Kerala than India as a whole. For the population as a whole it is 25.11 per cent for Kerala as against 9.11 percent for All-India. For both men and women, it is higher, though marginally, in the rural

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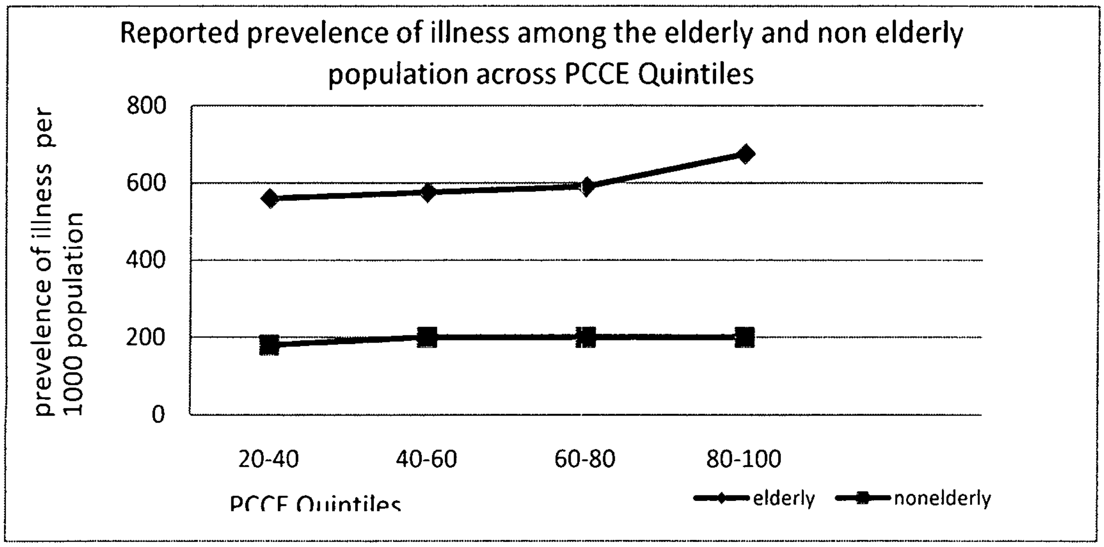
[6] the incidence rate measures the frequency of illnesses commencing during a reference period

sector than in the urban in Kerala and the reverse at the all-India level. It is uniformly and marginally higher for women than for men across sectors both in Kerala and in India as a whole. Within Kerala, it is higher for women only in the South; it is the same as/marginally less for women than for men in North Kerala. Within Kerala, the incidence is much higher (almost twice) in the South than that in the North.

Figure 2.3 reported prevalence of illness among the elderly and non elderly population in Kerala across PCCE Quintiles



It is very clear from the figure 2.3 that irrespective of economic status, the reported prevalence of illness is substantially higher for the elderly population compared to non elderly population. NSSO 60th round survey shows that in Kerala for every income group more than 50 per cent population has been reported any ailment during a 15 days period.

We find that morbidity is higher among the higher age groups as compared to young age group. Kerala aging survey [7]also demonstrates that aged people are the most vulnerable groups because of high prevalence of morbidity and chronic diseases in that groups. Kerala aging survey conducted in 2005 showed that joint

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[7] *Kerala aging survey (2005) has been completed with the funding support from the Indo Dutch program on alternatives in development of Indian Council for Social Science Research ,New Delhi ,Shatri Applied Research Project of the shastri lindo Canadian institute, New Delhi and the global health initiatives of the Canadian institutes of Health Rresearch ,Canada. The survey is coordinate by S Irudaya Rajan of centre for development studies. The household survey consists of two parts and the institutional survey had one questioannare.The survey has targeted several social, economic and health issues pertaining to the elderly in kerala.*

pains were the most often reported morbidity among elderly, with women reporting higher percentage compared to men. Other common morbidities among elderly people are loss of memory, having no energy, sleep problems and chest pains.

Table 2.8 Morbidity among elderly in Kerala, KSA 2005 (per cent)

	60-69		70-79		80+	
Kinds of morbidity	Male	Female	Male	Female	Male	Female
having no energy	16.3	23.1	28.4	34.9	39.8	44.4
forgetfulness	19.8	26.3	30.22	35.3	47.4	51.9
sleep problem	15.3	19.5	21.2	23.8	30.6	31.3
chewing/dental	8.7	10.9	14.6	16.4	19.7	20.3
chest pain	16.7	20.5	21.5	21.1	15.5	23
joint pains	37.6	51	43.4	57.2	48.4	52.4
immobility	3.2	6.4	6.9	7.7	10.2	15.8
incontinence	1.3	2.5	2.8	4.1	7.9	5.6
stomach problem	12.2	12.7	12.6	16.2	17.8	15.2

Source: Irudaya Rajan, 2005

Kerala aging survey also canvassed the prevalence of chronic diseases among elderly population in Kerala. Hypertension emerges as the single largest chronic diseases among the elderly in Kerala, followed by diabetes and arthritis. The 60th NSSO survey also shows that the major diseases among the elder population are Hypertension (121 per 1000 population), disorder of joint and bones (96), Diabetes (86) and heart diseases (55). It is very clear from the table 2.9 that as compared to male elderly population the prevalence of chronic diseases are high among the female population. Moreover as age increases the percentage of people with chronic diseases has been increasing.

Table 2.9 Chronic illness among elderly in Kerala, KSA 2005 (per cent)

	60-69		70-79		80+	
Chronic diseases	Male	Female	Male	Female	Male	Female
Arthritis	16.4	23.48	21.76	27.78	21.71	21.12
Asthma	12.07	10.03	16.03	11.14	17.76	10.43
Alzheimer's	3.16	4.35	4.58	5.74	7.24	5.35
Cancer	1.5	0.94	1.78	1.99	0.99	1.34
Diabetes	17.74	17.59	19.59	15.36	16.12	9.63
Heart problem	8.91	7.59	13.1	9.5	10.53	9.36
Hypertension	23.56	34.85	30.03	39.27	26.64	33.42
Osteoporosis	2.25	4.48	2.93	4.81	1.97	1.6

Source: Irudaya Rajan, 2005

As the morbidity rate is high in Kerala as compared to national level one would expect high rate of hospitalization which depend upon the availability of hospitalization facilities and intensity of the morbidity. Table 2.10 shows state wise proportion of persons hospitalized per 1000 in rural and urban areas.

Table 2.10 State wise Proportion (per 1000) of persons hospitalized in rural and urban areas (NSSO 60th round)

Major state	No. Per 1000 hospitalized	
	Rural	Urban
Andhra Pradesh	22	28
Assam	11	16
Bihar	10	10
Chhattisgarh	12	27
Gujarat	29	36
Haryana	32	31
Himachal Pradesh	32	31
Karnataka	23	26
Kerala	101	90
Madhya Pradesh	18	29
Maharashtra	30	36
Orissa	23	30
Punjab	30	30
Rajasthan	18	25
Tamil Nadu	37	37
Uttaranchal	17	19
Utter Pradesh	13	20
West Bengal	23	35
India	23	31

Source: NSSO, 2006

The estimates reveal wide inter-state variation in the proportion. In Kerala, the proportion, in both rural and urban areas, was much higher than in the rest of the major states. While for the country as a whole, out of every 1000 persons, 23 in the rural areas and 31 in the urban areas were hospitalized during a period of 365 days, the corresponding estimates for Kerala were as high as 101 and 90. Two kinds of implications can be possible. First, due to better health care facilities Kerala reported large number of hospitalized cases. Second, most of the patients are chronically ill patients they need immediate attention. The table 2.11 gives details of hospitalization by type of diseases in Kerala and India.

The table 2.11 shows the percentage of hospitalization during the past 365 days by type of diseases. Diarrhea, tuberculosis, asthma, fever of unknown origin, accident, heart diseases are the major hospitalized cases in India as well as

Kerala. In Northern Kerala the share of Diarrhea, fever of unknown origin, hypertension and cancer in the total hospitalized cases are very high as compared to southern Kerala and all India. Particularly, the cancer and other tumors account 4.1 per cent of total hospitalized cases in Northern Kerala and the corresponding percentage in Southern Kerala and all India are 1 and 2.67 respectively. Disease cancer is one of the most dangerous diseases in terms of pain and expense. It is not an age specific diseases in the sense that both younger and older age groups are victims of this catastrophic disease.

Table 2.11 Hospitalization (during the past 365 days) by type of diseases in Kerala and India (per cent)

Population sub group	Northern Kerala	Southern Kerala	All Kerala	All India
Diarrhea/ dysentery	4.52	3.53	3.78	6.47
Gastritis/ gastric or peptic ulcer	1.28	2.28	2.02	4.1
Hepatitis/Jaundice		1.98	1.47	2.16
Heart disease	5.48	7.7	7.15	7.29
Hypertension	10.15	2.64	4.58	3.25
ear/nose/throat ailments	1.77	10.48	8.23	
Tuberculosis	0.26	0.56	0.48	1.74
Bronchial asthma	5.46	5.53	5.51	3.05
Disorders of joints and bones	2.32	4.3	3.79	2.7
Diseases of kidney/urinary system	3.06	4.58	4.17	4.94
Gynecological disorders	4.86	4.67	4.72	5.25
Neurological disorders	2.03	1.04	1.3	3.02
Psychiatric disorders		0.21	0.15	0.59
Cataract	1.17	0.43	0.62	2.51
Diabetes mellitus	6.32	4.99	5.34	2.33
Malaria		0.15		3.8
Fever of unknown origin	17.56	15.04	15.69	6.97
Locomotor disability	0.74	0.07	0.24	0.9
Accidents/injuries/Burns/etc.	8.13	10.69	10.03	9.02
Cancer and other tumors	4.1	1	1.8	2.67

Source: NSSO, 2006

Table 2.12 shows that the number of cancer patients in Regional Cancer Centre Trivandrum. It gives the fact that the number of cancer patients has been increasing over the years. Number of new patients admitted in the centre during 2005-06 was 10310, which has been increased to 12123 during 2008-09. These patients are coming from the different parts of the kerala reveals the fact that immediate health care attention is required to give better care at their last stage of life.

Table 2.12 Number of cancer patients in Regional Cancer Centre Trivandrum (2005-2009)

	2005-06	2006-07	2007-08	2008-09
No. of new patients	10310	11173	11327	12123
Existing number of patients	118131	129974	139818	151714

Source: Economic Review 2009

Besides diseases, accident is another major hospitalization case in both Northern and Southern Kerala (NSSO, 2006). Table 2.11 shows that the percentage of hospitalization due to accident in Kerala is 10.03 which is higher than corresponding all India figure (9.02). Table 2.13 shows the district wise road accident in Kerala during 2005-06.Eventhough the growth rates of accident for most of the districts are negative still the absolute number of accident of each districts is a worrying factor. An accident would either lead to death or injury to the victim. A serious injured person is really a burden to the family because of immobility, medical and non medical expenditure etc. This kind of patients need long term and continuous care which may not be an easy task for family members because of financial constraints.

Table 2.13 District wise road accident in Kerala during 2005-09

Districts	2005-06	2006-07	2007-08	2008-09	Growth rate 2005-06 to 2008-09
Trivandrum	3472	2309	3311	3487	0.43
Pathanamthitta	1691	1171	2039	2121	25.43
Kollam	3645	2631	1062	1128	-69.05
Alappuzha	3127	2087	2178	2413	-22.83
Kottayam	1198	833	1871	1966	64.11
Idukki	6965	5013	782	821	-88.21
Ernakulum	4544	3313	4183	4538	-0.13
Trissur	2463	1651	363	3147	27.77
PalaKkad	2537	1909	1616	1624	-35.99
Malappuram	2247	2103	1964	1967	-12.46
Kozhikode	3286	2470	2108	2409	-26.69
Wayanad	625	432	458	445	-28.80
Kannur	1717	1269	1200	1288	-24.99
Kasargode	896	607	592	616	-31.25

Source: Economic review, 2005 and 2009

2.4 Disability

Besides an increased level of illness, the aging process leads to certain disabilities such as blindness resulting from cataracts and glaucoma, deafness resulting from nerve impairment, loss of mobility from arthritis and a general inability to care for one's self. A person with restrictions or lack of ability to perform an activity in the manner or within the range considered normal for a human being was considered disabled. The data collected in the National Sample Survey 58th Round [8]in 2002 concerning disabilities among the elderly reveal that 6.4% of the elder populations in rural and 5.5 per cent of the elderly population in urban area are suffered from disability. Approximately half of those affected were visually disabled. The remaining half were suffering from disabilities related to hearing, speech or locomotor functions.

Table 2.14 Percentage of disabled person for each age group

Age groups	Rural	Urban
0-4	0.523	0.487
5-9	1.167	1.015
10-14	1.549	1.317
15-19	1.748	1.337
20-24	1.627	1.242
25-29	1.487	1.00
30-34	1.448	1.054
35-39	1.444	1.138
40-44	1.594	1.309
45-49	1.907	1.476
50-54	2.283	1.855
55-59	3.025	2.571
60& above	6.401	5.511

Source: NSSO, 2002

In all age group disability is high among rural people than urban people. In rural area 52 per cent of disability is due to locomotor disability and 10 per cent of disabled persons have multiple diseases. On the other hand in urban area 55 per cent of disability due to locomotor and 12 per cent of disabled people are affected by multiple diseases.

The estimates of prevalence of disability (number of disabled persons per 1, 00,000 persons) are given in the table 2.15. The survey reveals that for every 1, 00,000 people in India, there were 1755 who were either mentally or physically

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[8] *National Sample Survey Organisation (NSSO) in its endeavour to provide information on the magnitude and other characteristics of the disabled persons conducted the third survey of disabled persons in the country during July 2002 to December 2002. The number of sample villages and urban blocks surveyed in Central sample was 4637 and 3354, respectively. In kerala the actual number of village surveyed in rural and urban were 160 and 102 respectively.*

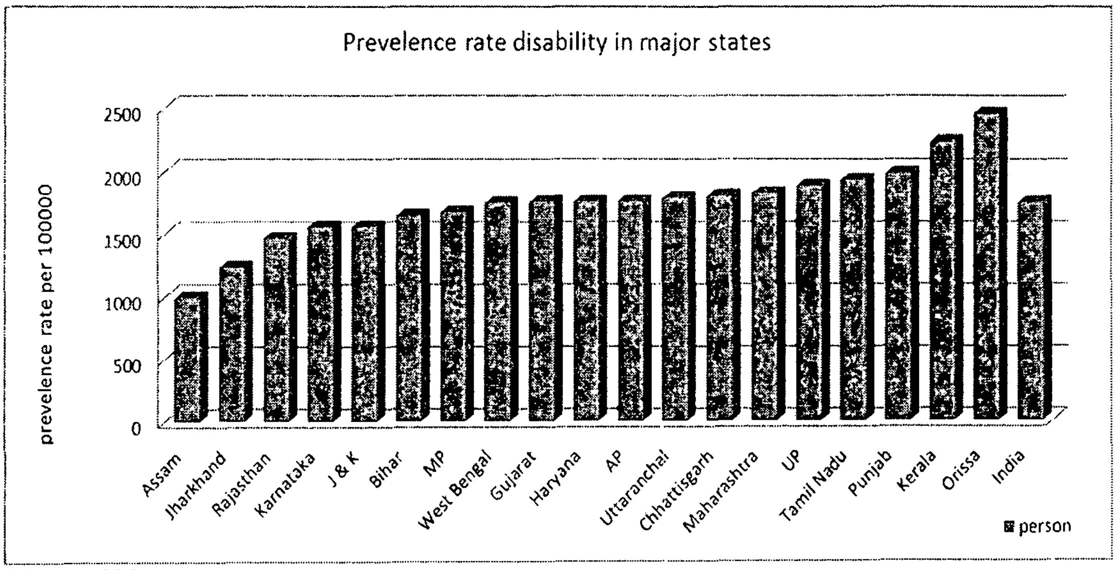
disabled. Kerala has reported second highest prevalence of disability which is 2235 per 100000 persons. Between the two sexes, the prevalence of disability was marginally higher among males than among females. It become more clear by looking at the prevalence rates of disability for major States and all- India in the figure 2.4.

Table 2.15 Number of disabled persons per 1, 00,000 persons for major states

States	Male	Female	Person
AP	1852	1675	1765
Assam	1072	900	993
Bihar	2056	1213	1652
Chhattisgarh	2006	1607	1810
Gujarat	2036	1471	1761
Haryana	2076	1421	1762
J & K	1966	1158	1562
Jharkhand	1563	893	1236
Karnataka	1754	1359	1558
Kerala	2475	2026	2235
MP	1909	1424	1680
Maharashtra	2067	1572	1827
Orissa	2586	2330	2459
Punjab	2255	1672	1987
Rajasthan	1768	1158	1468
Tamil Nadu	2112	1755	1934
Uttaranchal	1966	1596	1791
UP	2214	1523	1887
West Bengal	2028	1451	1754
India	2000	1493	1755

Source: NSSO, 2002

Figure 2.4 Prevalence rate of disability in major states (NSSO 52nd round)



Source:NSSO,2006

High proportion of aged population may be one of the reasons for the high prevalence of disability observed in Kerala, which have the highest proportion of aged population among the Indian states. The increasing proportion of ageing observed in the state will expect to raise the disability prevalence in Kerala.

2.5 Catastrophic Medical expenditure in Kerala and Its implication on poor people.

The Kerala model of health care is in a crisis. The main reasons attributed to this crisis are catastrophe health care expenditure (George 2006) and decline of public spending in health care due to fiscal crisis (Vohra 1999). The expansion of private sector and increasing health care expenditure in Kerala are adversely affecting the poor people's access to health care (Arun and Varatharajan 2005, Llavesque 2009).

Kunhikannan and Aravindan (1996) present descriptive account of the high levels of expenditure on health care in Kerala. Based on a survey of 31 households for the years 1991 to 1994 they find that the increase in the per capita total expenditure on medical care was twice that of the increase in general consumption expenditure. They also noted that the non drug items like doctor's fees, laboratory investigations etc have shown a far greater rate of increase. In a subsequent attempt kunhikannan and Aravindan (2000) based on a survey of around 500 individuals in the state found that medical expenditure per morbid person per episode increased from Rs 16.56 to 165.22 during the period 1987-1996, an increase of 898%.

Narayana (2004) based on a survey of 472 household spread over 21 panchayats in the Northern district of Kasaragode in Kerala during June 2002 to march 2003, addresses the issues relating to high health care costs and their means of financing. Also the study exposes the extent of inability to access health care owing to high expenditure. The bulk of those who had to find some sources of finance turned to pawning household items ,borrowing from friends, family ,banks etc or sale food stocks. Considering all the sources of finance together, it is observed that about 55 per cent of the households had resorted to soliciting aid of one kind or other in meeting health expenses.

Ghosh(2006) shows that during the period 1993-94 to 2004-05, the highest increase in poverty due to OOP (Out-of-Pocket Health Spending) payments was observed in Kerala (1.82 percent). Using data from the National Sample Survey on consumption expenditure undertaken in 1993-94 and 2004-05, he measures catastrophic payments and impoverishment due to out-of-pocket payments for health care. The analysis shows that the OOP payments for medical care increased over the study period. There are important differences in the incidence of catastrophic health payments across states. The incidence of catastrophic expenditure increased substantially in Kerala (15 percent).The findings indicate that 4.4 percent of the total population in India (up from 4 percent in 1993-94) fell below the poverty line because of OOP payments on health care. The poverty impact of OOP payments is significant in all the selected states, but it was the greatest in Uttar Pradesh (6.6 percent), Kerala (6.1 percent), Madhya Pradesh (5.5 percent) and West Bengal (5.0 percent) in 2004-05. While Andhra Pradesh, Bihar, Tamil Nadu, Karnataka, Punjab and Assam recorded a decline in the incidence of poverty because of OOP payments, this has increased in the other states surveyed.

The higher medical expenditure adversely affects the accessibility of health for poor people. It creates financial burden on both family and patient. NSSO 60th round survey reveals that financial problem is the one of the reasons for the no treatment of ailment. Table 2.16 demonstrates the percentage of distribution of untreated spells of ailments by reason for no treatment. The corresponding estimates for NSS 52nd round are also presented in the table. It is seen that, 60th round of survey as well as in the 52nd , the reason most often cited for no treatment was that the ailment was 'not serious'. This reason was reported by 32 per cent and 50 per cent of the cases of untreated ailments in the rural and urban areas, respectively. In the 52nd round, this reason accounted for about 50 to 60 percent of the cases of untreated ailment. The proportion is found to have come down considerably in the rural areas since 1995-96, pointing to an increase in health consciousness among rural households and emergence of chronic diseases which require immediate hospitalization. The 'financial problem' was next in importance as a reason for no treatment, accounting for 28 per cent and 20per cent of the untreated ailments in the rural and urban areas, respectively.

Table 2.16 Percentage distribution of untreated spells of ailments in India by reason for no treatment-India

Reason for no treatment	Rural		Urban	
	2004 *60th rd*	'95-96 *52nd rd*	2004 *60th rd*	*95-96-52nd*
No medical facility	12	9	1	1
Lack of faith	3	4	2	5
Long waiting	1	1	2	1
Financial problem	28	24	20	21
Ailment not considered serious	32	52	50	60
Others (incl. n. r.)	24	10	25	12
all (incl. n.r. cases)	100	100	100	100

Source: NSSO 60th round

As far as Kerala is concerned financial problem is the major reason for the no treatment of ailment for both elderly and non elderly. The percentage of poor people with no treatment of the diseases are 36.7 and 32.6 for elderly and non elderly respectively. It shows that financial problem is higher among rich elder people indicate that both rich and poor elder people are the victims of catastrophic medical expenditure.

Table 2.17 Percentage of distribution of reason for no treatment in Kerala

Reason for no treatment	Poor		Rich	
	Elderly	Non elderly	Elderly	Non elderly
No medical facility		1.6		
Lack of faith	6.5	1.6		2.9
Financial problem	36.7	32.6	52.8	0.7
Ailment not considered serious	37	54.7	19.1	81.6
Others (incl. n. r.)	19.8	9.4	28.1	14.8
all (incl. n.r. cases)	100	100		

Source :Mukherjee and Levesque,2010

The total per capita hospitalization cost is seen to be highest for Kerala. In Kerala the per capita hospitalization cost is RS.509, on the other hand the all India average hospitalization cost is RS. 187. Further it is revealed that the per capita hospitalization cost for elderly is around four times higher than that of the non elderly. In Kerala the per capita hospitalization cost for elderly people is RS.1505, on the other hand for non elderly it is RS.382. This phenomenon is happening mainly because of high rate of hospitalization and prevalence of morbidity among the elder population. Since most of the elder people have no source of earnings, the inflation in medicine would affect adversely especially among poor elder people.

Table 2.18 Cost of hospitalization per capita (in RS) for elderly and non elderly for major states (NSSO, 2006)

States	Elderly (per capita cost	Non elderly(per capita cost)	Total (per capita cost)
AP	492	163	186
Assam	181	47	54
Bihar	288	68	81
Goa	753	109	171
Gujarat	917	178	226
Haryana	615	350	372
Himachal Pradesh	545	263	288
J&K	327	86	102
Karnataka	643	125	160
Kerala	1505	382	509
MP	276	98	109
Maharashtra	925	216	272
Orissa	214	102	112
Punjab	1558	372	469
Rajasthan	590	139	167
Tamil Nadu	1108	224	298
UP	318	121	135
West Bengal	514	127	154
All India	623	154	187

Source: NSSO, 2006

Kerala is the state devote major share of their income for the consumption of medicine. Table 2.18 shows per capita monthly value of consumption on health expenditure for major States in India. Both institutional and non institutional expenditures are high in urban area than rural area. Kerala is most expensive in terms of both inpatient and non inpatient health care services in the country.

Table 2.19 Monthly per capita value of consumption (in rupees) on medical (institutional and non institutional) expenditure for rural urban areas for the 15 major states for India, 1999-2000)

State	Rural India		Urban India	
	institution(inpatient care)	medical non institutional(non inpatient	institution(inpatient care)	medical non institutional(non inpatient
AP	7.63	22.08	6.43	25.36
Assam	2.99	7.23	10.54	34.7
Bihar	2	4.57	2.46	17.84
Gujarat	10.35	17.62	12.29	28.19
Haryana	12.96	35.85	23.27	40.05
Karnataka	6.68	17.62	16.36	27.1
Kerala	21.56	39.27	27.37	41.08
MP	5.33	18.79	8.86	29.7
Maharashtra	11.04	26.54	19.72	35.27
Orissa	3.77	18.07	6.84	23.99
Punjab	15.5	40.38	13.88	40.11
Rajasthan	5.57	21.56	8	29.05
Tamil Nadu	7.8	22.18	13.9	29.36
UP	5.73	32.96	7.2	35.31
West Bengal	3.72	16.63	10.26	32.12
all India	6.66	22.92	12.33	30.95

Source :NSSO,2001

Kerala's government health-care system functions relatively well compared with other Indian States, but utilization levels are decreasing due to lack of essential facilities. (Varatharajan D, Thankappan R, Jayapalan S, 2004). The opportunity cost of seeking medical care from the government sector is high, even for the poor, with 60-70% of the poor seeking care from the private sector and spending disproportionately on health care (about 40% of income compared with 2.4% by the rich).

2.6 Public investment in health care

In India, there are formidable challenges in ensuring healthcare Services to the needy. Inadequate allocation of public resources and its Inequitable spread across different states have resulted in low access and poor quality of public health facilities. In addition, there are severe problems in delivery systems. The consequence of these has been to force the households to spend a significant proportion of their incomes on private healthcare facilities (M. Govinda Rao, Mita Choudhury, 2008).

It is well known that health expenditure in India is dominated by private spending. To a large extent this is a reflection of the inadequate public spending that has been a constant if unfortunate feature of Indian development in the past half century. This is particularly unfortunate because of the large positive externalities associated with health spending, which make health spending a clear merit good. The greater reliance on private delivery of health infrastructure and health services therefore means that overall these will be socially underprovided by private agents, and also deny adequate access to the poor. This in turn has adverse outcomes not only for the affected population but for society as a whole. It adversely affects current social welfare and labour productivity, and of course harms future growth and development prospects. (Economic Research Foundation, 2006).

It is widely agreed that public investment in the social sector has been declining in the post economic reform period and the central grants to the states have been consistently coming down after the introduction of the macro-economic structural adjustment programmes (Panchamukhi, 2000; Baru, 1989; Narayana, 2001). The socioeconomic factors, life style and diet related factors are significant non-medical determinants of the health seeking behavior in the contemporary world (Lang, 2001).

Medical technology revolution has been remarkable in improving health status of the population. However, the technology intensive and patient oriented health care services have increased health care expenditure. Physician acting as proxy for the patient liberally recommend diagnostic prescriptions which pulls up health care expenditure (Ashokan, 2007). Population health is determined/constrained by many factors in the social and economic environment outside the formal health care system. The share of health expenditure in gross state domestic product has been declining in major states in India followed by a marginal increase in government health expenditure both in real and per capita terms (Berman and Ahuja, 2008). Among the poor states, government health expenditure is much lower than the national average and it has become an issue of concern since health care problems of these states are directly linked to poverty and deprivation (Selvaraju, 2003, Duggal, 1995).

Table 2.20 Interstate difference in health expenditure

	Per capita expenditures (Rs)			Percent of GSDP		
State	1995-96	2000-01	2004-05	1995-96	2000-01	2004-05
Andhra Pradesh	117.33	229.03	282.09	1.06	1.24	1.1
Assam	128.58	208.09	259.29	1.63	1.74	1.69
Bihar	91.59	108.18	100.12	2.69	1.89	1.55
Gujarat	135.24	397.88	345.69	0.85	1.84	1.04
Haryana	171.42	297.16	418.42	1.06	1.13	1.14
Karnataka	149.13	263.7	284.1	1.3	1.32	1.06
Kerala	166.57	270.65	354.31	1.31	1.23	1.17
Madhya Pradesh	146.72	222.49	210.05	1.65	1.81	1.33
Maharashtra	141.78	252.5	316.33	0.78	1.02	0.87
Orissa	115.01	183.64	238.61	1.45	1.73	1.55
Punjab	159.22	324.32	344.68	0.91	1.19	1
Rajasthan	250.01	353.14	408.91	2.6	2.5	2.25
Tamil Nadu	166.07	299	447.51	1.25	1.31	1.53
Uttar Pradesh	87.88	99.59	156.58	1.21	0.95	1.19
West Bengal	101.38	236.36	206.9	1.02	1.35	0.84
Mean	131.37	224.29	262.24	1.23	1.37	1.18
CV	0.307	0.36	0.38	0.467	0.31	0.315

Source: Rao and Choudhury, 2008)

Table 2.17 shows that interstate disparity in terms of health expenditure has been increased over the years. Health expenditure as a percentage of GSDP has been declining for all states except few states. In Kerala the medical expenditure as a percentage of GSDP in 1995-96 is 1.31 which is decreased to 1.17 in 2004-05. The slow withdrawal of government from the health sector would adversely affect the poor people's accessibility of health care.

2.7 Conclusion

This chapter analyzed the importance of community based health care in Kerala in the context of aging, morbidity and disability, and catastrophe health expenditure and low level of public spending. It has been found that Kerala is a state with highest proportion of elderly population, most of them need special health care because prevalence of morbidity and disability are higher among these groups. Population ageing has emerged as the grand challenge of this century; for policymakers, care providers and society as a whole. As age advances, numerous physical and psychological changes in life style assume significance among the elderly. Furthermore, the situation is made worse by the fact that such health problems lead to major disabilities and restricts their movements, which makes their life miserable. Studies have shown that elderly people in India suffer a double-whammy effect; the combined burden of both communicable and non-communicable diseases. This is compounded by an impairment of special sensory functions like vision and hearing that decline with advancing age. Thus, elders have a considerable burden of both infectious diseases like tuberculosis and chronic illnesses such as diabetes mellitus, ischemic heart disease, and cancer.

In addition to high prevalence of chronic disease, Kerala has been experiencing high rate of accidents and other health risk factors. Moreover morbidity and other diseases among other age groups necessitate the need for community based health care. Kerala's sound health indicators are attractable to all policy makers. However the quality of life is doubtful in the context of high prevalence of morbidity and disability among various age groups. They need both physical and financial helps from the family members. As far as poor family is concerned the higher cost of medical expenditure is unbearable. In Kerala, there are large number of social security schemes and medical insurance are exists, however, the amount is not sufficient to meet the catastrophe health expenditure. Government hospitals have a limit to absorb all ill patients and to give total care to the diseased person. So it is the responsibility of both government and society to give better quality of life to these people.

Catastrophe health expenditure and low public investment in health sector are the serious issues in Kerala which affects adversely on poor people's accessibility of health care. In this context a mechanism or social organization to save poor from the hand of horrible health expenditure is necessary one. The experience of palliative care services in Kerala has been showing that this is the feasible mechanism to ensure better quality of life to the chronically ill patients.

Chapter III

Evolution, Structure, Process and Persistent Challenges of Community Based Palliative Care in Northern Kerala

3.1 Introduction

One of the objectives of this chapter is to analyze the institutional evolution, arrangement, process and the persistent challenges of the Community Based Palliative Care in Northern Kerala which gives an insight into the sustainability and quality of palliative health care. Palliative care services have altered dramatically since the first clinic started in 1993. The constant acquisition of new faces and collaborations with new organizations has meant the services are constantly evolving in time with, and determined by, the needs of the local community. The diversity of the groups involved reflects the diversity of the communities they serve. This provides a vast reservoir of appropriate skills and resources on which to draw from in order to meet new challenges. Many see this as the reason for the successes of palliative care services in Kerala. The richness afforded by the collaboration gives it a unique stability and resilience. This Community bases palliative care is very successful and active in three Northern districts such as Wayanad, Kozhikode and Malappuram.

This chapter comprises 4 sections including introduction. The section 3.2 discusses the evolution and development of community based palliative clinic in Northern Kerala. The section 3.3 analyses the structure, process and institutional arrangements and challenges of community based palliative clinics in Northern Kerala on the basis of sample survey conducted in three Northern districts of Kerala i.e. Wayanad, Kozhikode and Malappuram. The section 3.4 concludes the chapter.

3.2 Evolution and Development of Community Based Palliative Care

This section basically analyses the evolution and development of community based palliative clinic in Kerala especially in Northern Kerala on the basis of literature and sample study in three Northern districts of Kerala. This section helps to identify the factors or agents behind the evolution of community based palliative care Northern Kerala which gives an insight into the institutional soundness and the sustainability of the programme.

3.2.1 Early palliative clinic in Kerala

The Pain and Palliative Care Society (PPCS) a Non-Governmental Organization (NGO) began at Kozhikode in 1993 (Anil Paleri, Mathews Numpeli, 2010). An outpatient clinic was set up at the Kozhikode medical college. Subsequently, a memorandum of understanding was signed with the government of Kerala. The government gave permission to the NGO to work in the premises of the medical college and also agreed to provide a few nonmedical staff and medicines. Other needs, such as providing remaining staff and medicines and finding the remaining expenses to run the establishment had to be met by PPCS.

Since its inception, it was clear to the founders of PPCS that professionals alone would not be able to carry the entire weight of the task of looking after chronically ill people but would also need the support of the community (Anil Paleri, Mathews Numpeli, 2010). The clinic itself began with one volunteer and a part time doctor. Other volunteers were encouraged to join the initiative, and at that time they were seen as people to help with the nursing tasks. A volunteer could work in a clinic or a home care programme only during the hours in which these programme were run. Hence, almost all the volunteers worked in the clinics, which often were far from their place of residence, and they often worked in isolation as there were few other volunteers from their locality. So initially, the voluntary activities were clinic centered, and because of this, many who were employed elsewhere could not find a slot.

The first link centre of the PPCS was established in 1996 at Manjeri in the neighboring district of Malappuram (Libby sallnow, shabeer chenganakkattil, 2010). The method of setting up a new link centre was to train a doctor, or preferably a team of a doctor and a nurse, and to encourage them to set up a palliative care clinic in their area. These 'doctor initiated' clinics had many limitations (Anil Paleri, Mathews Numpeli, 2010). First and foremost, they depended in many instances on a few individuals and did not have wide representation in the community where they were set up. Others secondary problems included difficulty getting the volunteers and difficulty raising funds from the locality. But the numbers of link centers did increase steadily.

3.2.2. From Clinics to Neighborhood Networks in Palliative Care (NNPC)

During this period, it was noticed that the link centres at Nilambur in Malappuram district were more successful in coverage and fund raising (Kumar s 2004). It was also noted that volunteers took the responsibility of planning and organizing the services, raising funds, administering the day-to-day activities of the programme, attending to and organizing support for the social and financial needs of the patients, and organizing rehabilitation programmes. The professional's main role was attending to medical issues. It was also observed that persons coming from the same place as the patients were better at prioritizing the needs of the patients and individualizing the care that was provided.

These observations were discussed with the palliative care teams which already existed in the district and also with new groups interested in setting up palliative care services. Volunteers were trained and given the freedom and support to set up palliative care initiatives. Thus began the NNPC, which are now looking to develop into a sustainable community led service capable of offering comprehensive care to those needing palliative and long term care.

Initially, there was isolated resistance from dictating health care professionals who thought that volunteers were 'taking over' and terms' to them. The issues resolved as soon as it became evident that volunteers were not taking over but were supplementing the care given to the patients by attending to the non-medical issues.

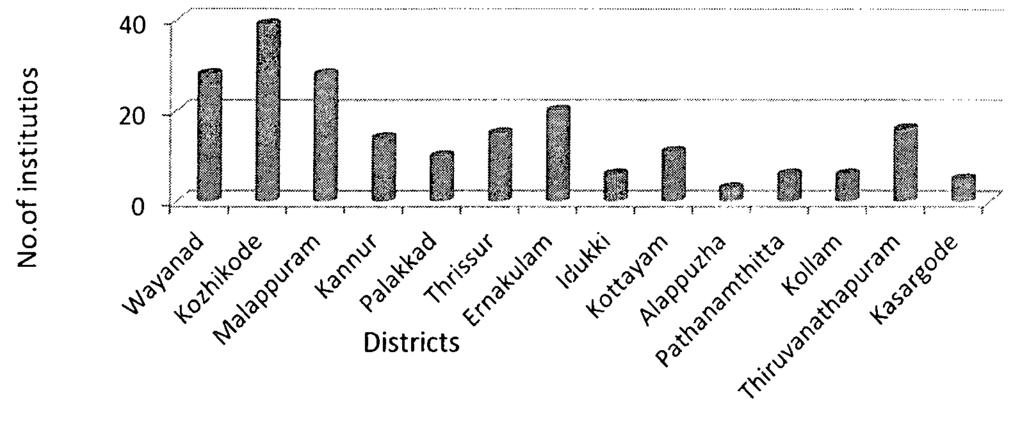
The Neighborhood Network in Palliative Care (NNPC) was started in 2001. It was an attempt to determine the reasons for the success of the two satellite centers at Manjeri and Nilambur, and to actively replicate the phenomenon in other districts (Libby sallnow, shabeer chenganakkattil, 2010). A crucial aspect of the project was to try to mobilize people from the local community. After a period of training, they would be supported in setting up centers providing palliative care and to go on to develop the services as dictated by their local community. In the first stage, local groups providing similar services, such as basic healthcare and social projects were approached and became involved in the NNPC. Other, larger groups working in other areas such as literacy and education were subsequently involved.

Neighborhood Network in Palliative Care (NNPC) is an attempt to develop a sustainable community led service capable of offering comprehensive Long Term Care (LTC) and Palliative Care (PC) to the needy in the developing world (Suresh Kumar,mathews Numpeli 2010). In this programme, volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively with active support from a network of trained professionals. Essentially, NNPC aims at empowering local communities to look after the chronically ill and dying patients in that community. It is inspired by the concept of primary health care described by the World Health Organization at the declaration of Alma-Ata.

3.2.3. Present Scenario

At present there are around 207 palliative care units in Kerala. Majority of them are organized and supported by Community-Based Organization and the rest are based on government and private hospitals. They are self-sustainable in terms of manpower, money and other amenities. In some districts however, palliative care services are in rudimentary stage. Palliative care services in Kerala dependent on trained volunteers for organizing the services and psychosocial support to the patient and family. Majority of units are supported by local self-governments institutions and are able to provide home visits, outpatient services and free drug for the poor. They provide physical as well as emotional support to both patients and family members.

Figure 3.1 District wise number of palliative clinics in Kerala



As compared to southern districts in Kerala Northern districts such as Malappuram, Wayanad, and Kozhikode have wide coverage both in terms of number of clinics and patients under treatment (Suresh Kumar,mathews Numpeli 2010 ,Anil Paleri, Mathews Numpeli, 2010). In a study done in Malappuram district of Kerala it was found that around 40% of those people who are dying would have benefited from applying the principles of palliative care and their management (Government of Kerala, 2008). In Kerala, with a population of 32 million and crude death rate of 6.3 (2001 census) around 80000 dying patients and families would be benefited each year (Government of Kerala, 2008). To this if add the number of people living for years with chronic conditions the total number will be much more.

One of the founding principles of the NNPC is that issues faced by people with terminal and chronic illnesses are social problems with medical components, rather than the converse, commonly held view (Libby sallnow, shabeer chenganakkattil, 2010). Palliative care cannot be separated from its broader social, political, religious and cultural ties and indeed satisfactory services will optimize the utilization of these resources. When this is achieved, the rewards are comprehensive and wide ranging and involve the patients, volunteers and the community as a whole.

Today at many centers the volunteers take the key roles in administration and fund raising, perform nursing tasks like bed sore management and wound care, counsel patients and family, organize social support, and organize awareness programmes in the community (Anil Paleri, Mathews Numpeli, 2010). Many of the volunteers are people who are already involved in other social and political activities. They often have much better administrative and organizational skills than the average health care professional. Even though they may be new to the concept of palliative care, most have already been involved in organizing support for people from the local area. The palliative care training makes them improves their skills in caring for the chronically ill.

After the initial training, the volunteers are encouraged to form a local group and to start a home care programme. Unlike clinic centered services, the volunteers can work at any time that is convenient to them and the patient. Since they are from the same locality, they can work in groups and share and plan their work together. Starting with a home care programme also has other advantages. It helps to make people aware of the programme and it helps to generate support. Patients are seen in an atmosphere that is most comfortable to them, it gives the volunteers an idea of the living conditions of the patients, it helps prioritize the needs of the patients and family, and it is an opportunity for recognition and continued learning for the volunteers who join the programme.

A management plan for each patient is set in consultation with the medical team, and professionals look after the medical needs of each individual patient. Psychological and emotional problems are often addressed jointly. The community volunteers try to address the social and spiritual issues. Problems such as the lack of food, poor housing, and children's education are better addressed by people from the same locality than by doctors or nurses.

Such work is quite different from traditional volunteering in palliative care where volunteers are given preset tasks to supplement the existing resources - tasks like front office managing, office work, minor nursing tasks, gardening, etc. They usually do not have any role to play in planning and administering the programme and they often work in isolation. Although in a sense this is also community participation, the community may never know what these volunteers are doing. On the other hand, in NNPC, the community through the volunteers is identifying and prioritizing the health issues of its own members and then organizing programmes to address them. Some home care programmes go on to develop outpatient clinics. Wherever the network is active, the continuity of care is maintained, the coverage is improved, patients have easy access to the health care system, and the professionals, the local government and other organizations are supportive.

The community based palliative care Network in Northern Kerala is one of the largest of its kind in the developing world. The palliative care movement in Northern Kerala is an inimitable one because of its functioning through a Neighborhood Network. These Neighborhood groups are functioning in close cooperation with the decentralized state bodies, religious, social and political groups in the region. Trained volunteers from the community assist in providing care, and family members were empowered in order to ensure continuity of treatment. Besides empowering the local communities to identify the chronically ill, the Neighborhood Networks in Palliative Care also provide the patients with medical and non-medical rehabilitation services.

Literatures show that 'doctor initiated' palliative care was targeted to cancer patients. In the initial stage of development doctors and nurses were the major agents of palliative care service and they provided only limited care to the patients. Later the doctor led care transformed to community based palliative care with wide public participation in all aspects. In this model both manpower and money is collected from public for common good. However, whether resources from community alone are enough to meet its growing needs remain to be seen.

3.3 Institutional Survey- structure and process of palliative care programme

Micro level study is required to identify structure, process and evolution of palliative care which is essential to understand the sustainability and challenges of community based palliative clinics in Northern Kerala. An institutional level survey has been conducted in three districts of Northern Kerala namely Wayanad, Kozhikode and Malappuram. These three districts are distinct in many socio economic and demographic contexts. These three districts have been selected for the study mainly because of successful experience of community based palliative care in these districts. Total 40 sample institutions were selected from these three districts. Among this, 14 institutions are from Wayanad, 11 from Kozhikode and 15 institutions are from Malappuram. We have selected those institutions which have been providing both home based and outpatient care. The questionnaire (see appendix 3.1) has been prepared in such a way as to collect information from different aspects including evolution and agents of palliative care, infrastructure facilities, community involvement, integration with health sector, medical and nonmedical care, financial aspect and role of government. The questionnaires were filled by the coordinators/volunteers of respective institutions. Table 3.1 shows involvement sample institutions with religious, political and social organisations.

Table: 3.1 Details of Sample Institutions

Districts	Sample size	Number of institutions involved with religious ,political and social organization				
		Religious organization			Political parties/leaders	Kudumbasree units
		Hindu	Christian	Muslim		
Wayanad	14	8	6	-	14	2
Kozhikode	11	4	7		11	2
Malappuram	15	-	-	15	15	12

Source: Field survey

The speed at which the movement of palliative care spread to different parts of the Kerala is different. However, in Northern Kerala its effect spread very fastly especially in Wayanad, Kozhikode and Malappuram. In Malappuram 15 institution's mean year of starting is 1998, whereas it is 1999 in Kozhikode for 11 institutions and 2001 in Wayanad for 14 institutions (sample survey). It means that the initial development of community based palliative care services in Malappuram easily spread to the neighboring districts and they replicated the programme very successfully in their districts.

Religious groups are an important and integral part of the NNPC, having been involved from the outset. In Malappuram Muslim organizations have evolved with the establishment of palliative care clinics in different parts of the districts. The 15 sample institutions selected from the district have been closely working with the Muslim organization. They help with fundraising and encouraging new volunteers. The first clinic in Wayanad district was initiated by Hindu organization. In a short time, the Catholic Church showed an interest in the projects. Out of 14 sample institution from this district 8 and 6 institutions have been working with Hindu and Christian religious organizations respectively. In Kozhikode church act as an input at different levels. There are many church based groups run palliative care clinics with input from other groups. 7 institutions out of 11 from Kozhikode are strongly connected with the Christian religious organization. And rest is work with Hindu organizations. In these three districts strong religious roots and support from religious organization helps to successful experience of Palliative Care movement in Northern Kerala.

The study finds that local units of political parties and their leaders are actively indulge in the day to day functioning of the programmes of all sample institutions. They use their organizational skill to manage the programme and collect funds from public and from government. Recently a new phenomenon in its operation is the intervention of Kudumbasree Units in the care of chronically ill people and helps to raise resources for the programme. Today a large number of the volunteers in NNPC come from Kudumbasree and indeed they are now fully responsible for running a number of palliative care units. The sample study shows that they are very active in Malappuram as compared to other districts. The study find that 80 per cent of sample institutions from the Malappuram districts have getting benefits from Kudumbasree units either in the form of supply of volunteers or in the form of donation or both. On the other hand involvement of Kudumbasree units in the other two districts is in the rudimentary stage.

Many other groups like local libraries, sports and arts clubs and merchants association are also involved in the activities at different levels. Their involvement ranges from supporting the existing groups in different areas like fundraising, awareness and rehabilitation to organizing palliative care units in different areas. The volunteers coming to the NNPC from other social, political or religious organizations often joined them for reasons such as: a wish to influence social change; to care for the sick in society; to fight against poverty; to develop a sense of self identity or a sense of community identity. All these are valid motives for joining voluntary groups *per se* and certainly the NNPC. It provides real opportunities for volunteers to realize these personal goals whilst performing a valuable role in providing both palliative care and health care for the local community.

Table 3.2 Region wise reasons for the emergence of palliative care service in the selected districts (in percentage)

Reasons	Wayanad	Kozhikode	Malappuram	Total
High prevalence of chronic diseases and	28.6	27.3	60	40.0
Lack of government mechanism	21.42	27.27	13.33	20
Higher medical expenditure	21.4	9.1	6.7	12.5
All the above	28.57	45.45	20	27.5
Total	100	100	100	100.0

Source: Field survey

We find that NGOs, religious organizations and other political and social organizations are key agents played in the initiation of Community Based Palliative Care in Northern districts. However, the reasons for the emergence of palliative care in those districts are related to the high prevalence of communicable and non-communicable diseases and lack of government mechanism to absorb the chronically and terminally ill patients. These lead to poor quality of life at the last stage of life. The caregivers' response shows that 40 per cent of institutions emerged mainly because of high prevalence of chronic diseases and disability among various age groups. The region wise data shows that in Malappuram 60 per cent of the institutions launched its operation primarily due to high prevalence of chronic diseases and disability. This figure is significant as compared to corresponding figures of Wayanad (28.6) and Kozhikode (27.3). Lack of government mechanism to care chronically and terminally ill people and higher medical expenditure have demanded the need for institutional care to those people. 20 per cent of the institutions began to operate for the reason that lack of government mechanism and 12.5 per cent of institutions emerged basically for saving poor patients from the catastrophe of higher medical expenditure. Among these all reasons high prevalence of chronic diseases and disability and lack of government mechanism are significant and need special consideration in the future. Nevertheless, the basic purpose of palliative care is to give relief from pain and ensure better quality of life to the patients.

3.3.1. Patients in the Institutions

These 40 institutions accommodate around 5473 patients of whom 66.87 per cent are outpatients, 2.46 per cent are inpatients and 30.65 per cent are home care patients. The district wise sample data shows that average number of patients per institution is higher in Malappuram (162.4), next Kozhikode (141) and last wayanad (84.71). It is interesting to see that the number of inpatients is higher in Malappuram. This may be due to two reasons. One reason is that clinics or centre with better infrastructure facilities can accommodate more inpatients. Second reason may be better integration of institution with the private and government hospitals, they can accommodate more inpatients.

Table: 3.3

District wise Number of patients in palliative care institutions (current status)

		Number of Out patient	Number of inpatients	Home based patients	Total
Wayanad	Mean	48.5	1.92	34.28	84.71
	Sum	679	27	480	1186
Kozhikode	Mean	92.63	2	46.36	141
	Sum	1019	22	510	1551
Malappuram	Mean	110.8	5.73	45.86	162.4
	Sum	1662	86	688	2436
Total	Mean	91.5	3.375	41.95	136.82
	Sum	3660(66.87)	135(2.46)	1678(30.65)	5473

Source: Field survey

It is evident from the table 3.4 that around 53.85 per cent of the patients in the palliative care are suffering from the disease cancer. Besides this palliative care patients are the victims of asthma (6.79 %), tuberculosis (2.79%), AIDS (3.88%), heart diseases (4.24%), accidental cases (1.21%). This picture reveals that patients are the victims of incurable diseases and chronic disease diseases. Remaining 27.21 per cent have other kinds of diseases and disabilities. District wise data also shows more or less same pattern. In Wayanad and Malappuram around 55 per cent of patients are cancer patients, while in Kozhikode it is 50 per cent. However, majority are cancer patients in all districts.

Table: 3.4 Percentage of Patients with various diseases for three sample districts

Diseases	Wayanad	Kozhikode	Malappuram	Total
Cancer	55.89	49.91	55.13	53.85
Tuberculosis	3.34	2.85	2.40	2.79
Asthma	10.08	7.72	4.15	6.79
AIDS	3.14	4.68	3.83	3.88
Heart diseases	4.12	6.20	3.05	4.24
Accidental cases	0.92	1.58	1.22	1.24
Others	22.51	27.07	30.21	27.21
Total	100.00	100.00	100.00	100.00

Source: Field survey

3.3.2 Infrastructure Facility

Infrastructure facilities like ambulance, building, medical store, beds, etc are essential and basic necessities for a health care institution. The data shows that all institutions have their own medical stores. However, only 6 institutions have ambulance which is essential for the home based care and for speeding up non-medical help to the patients. Most of the institutions do not have their own building to operate. Only the 17.5 per cent of the sample institutions have own building. The institutions without own building operate in private building by giving rent to the owner of the building. It is very clear from the table 3.5 that infrastructure facilities are very weak in wayanad as compared to the other two districts.92.9 percent of the palliative care institutions in wayanad do not have their own building whereas the corresponding figures for Kozhikode and Malappuram are 81.8 and 73.3 per cent respectively.

Table 3.5 Availability of basic infrastructure facilities in sample palliative care institutions (in percentage)

	Wayanad	Kozhikode	Malappuram	Total
Ambulance	7.1(1)	18.2(2)	20(3)	15(6)
Medical store	100	100	100	100(40)
Own building	7.1(1)	18.2(2)	26.6(4)	17.5(7)

Source: Field survey

On an average 3.5 beds are available in each institution. However, the availability of beds varies across the districts. The average number of bed available in wayanad is 2.07, in Kozhikode it is 3.81 and in Malappuram equivalent figure is 4.73. The study shows that 0.0255 beds are available for each patient. The ratio is lower in wayanad (0.024). All patients in the palliative care institutions not require hospitalized treatment. So that the ratio of beds to inpatients make more sensible which is 1.05 means that 1.05 beds are available for each inpatient. In Malappuram the figure is less than 1 reveals that some patients getting inpatient treatment from the private or government hospital.

Table 3.6 Availability of beds in palliative care institutions

	Wayanad	Kozhikode	Malappuram	Total
No. of beds	29	42	71	142
Average bed	2.07	3.81	4.73	3.55
Bed per patients	0.024	0.027	0.0291	0.0255
Bed per inpatients	1.07	1.9	0.82	1.05

Source: Field survey

There are 5393 caregivers in these 40 institutions; it comprises volunteers, doctors and nurses. The people participation in the form of volunteers are plenty, they consist more than 95 per cent total care givers. All three districts are self-sufficient in terms of community participation. The ratio of caregivers to patients (figure in the bracket of table 3.7) is 0 .98 reveals that for each patient around one caregiver is available. The availability of caregivers per patients is slightly higher in Wayanad (1.44) as compared to other districts.

Table 3.7Manpower in sample institutions (in number)

	Wayanad	Kozhikode	Malappuram	Total
Volunteers	1664	1529	2063	5256(0.9603)
Nurses	30	27	38	95(0.0173)
Doctors	15	11	16	42(0.007)
Total	1709(1.44)	1567(1.01)	2117(0.86)	5393(0.98)

Source: Field survey, figure in the bracket are the ratios of caregivers to patients

Most of the indispensable drugs listed by government of Kerala in palliative care policy of 2008 are not accessible in certain institutions. Only 37.7 percent of the total institutions have all necessary medicines in their stores. The main reasons behind the no stock of essential medicines are the non-availability of drugs and non-affordability of the higher price of the medicine. There are district wise variations in the availability of indispensible medicine. The study shows that only 21.4 per cent of the sample institutions of wayanad possess the essential drugs. However the corresponding figures for the neighboring districts are 36.4 and 53.3 respectively.

Table 3.8Drug availability in sample institutions (in percentage)

	Wayanad	Kozhikode	Malappuram	Total
Essential medicine are available	21.4	36.4	53.3	37.5
Not available	78.6	63.6	46.7	62.5
Total	100	100	100	100.0

Source: Field survey

The study discovers that all sample institutions are dissatisfied with the present level of infrastructure facilities. The basic infrastructure facilities in the sample palliative care institutions are very weak. The institutions are either dissatisfied with the lack of basic facilities or with the lack of modern facilities or both. The study reveals that 57.5 per cent of the total sample institutions are dissatisfied because of poor basic facilities like building, beds, etc. the study finds that all sample institutions do not have modern facilities to care the patients. However, only 15 per cent of the institutions reveal their dissatisfaction with the lack of modern facilities. According to them giving modern treatment to the patients is beyond their capacity.

Table 3.9 Reasons for dissatisfaction with the present infrastructure (percentage of institutions)

	Wayanad	Kozhikode	Malappuram	Total
Lack of basic facilities	57.14	63.64	53.33	57.5
Lack of modern facilities	14.29	18.18	13.33	15.0
Both 1 and 2	28.57	18.18	33.33	27.5
Total	100.00	100.00	100.00	100.0

Source: Field survey

3.3.3 Identification of patients

Since palliative care is a community based approach, it has not been difficult to identify patients from the community. The volunteers are responsible for identify patients from different socioeconomic background.

Palliative care givers have been adopting some criteria while selecting patients. Table 3.10 shows that various criteria of institutions follow to select patients.95

per cent of sample institutions have been considering economic status of the patients and all institutions giving special preference to the patients on the basis of diseases. Their main target is to give better care to the chronically and terminally ill patients. Interestingly, the study shows that 75 per cent of the institutions give special preference to aged people. Most of the patients in the palliative care are old people with different diseases and disabilities.

Table: 3.10

Criteria follow to select patients in sample institutions (in percentage)

Criteria	Wayanad	Kozhikode	Malappuram	total
Economic	92.9	90.9	100.0	38 (95)
Disease	100.0	100.0	100.0	40 (100)
Age	71.42	81.81	73.33	30(75)
Accessibility	50.0	36.4	80.0	23 (57.5)
Social Condition	7.1	27.3	26.7	8 (20)

Source: Field survey

District wise sample data also shows that economic background, type diseases and diseases are the major consideration. In Wayanad 92.9 per cent of the institutions follow economic condition of patients and their family, in Kozhikode it is 90.9 and in Malappuram all institutions give special considerations to the patients coming from the poor financial background. It is clear from the data that the nature of the diseases has major impact on the patient's selection. Generally, palliative care is mainly for the chronically and terminally ill patients. Most of the patients in the palliative care are struggling with diseases like cancer, tuberculosis, asthma, AIDS, heart diseases, accidental cases etc. It has found that accessibility of health facilities also significant criteria. 57.5 of the institutions consider ability to access the health care facilities of beneficiaries. However a social condition of the patients has not that much influence on the selection criteria. Only 20 per cent of the sample institutions consider the social background of the patients.

3.3.4 Integration with health sector

The sustainability of the health care institutions like palliative care depends upon its integration with the existing health sector components. Most of the institutions are in the rudimentary stage of integration. As far as community based palliative care is concerned integration with the other components of health sector is difficult task. The possible components of health sector for integration are private hospital, government hospital, primary health centre, medical college.

The study shows that 60 per cent of the institutions are integrated either with government hospital or private hospital or both and 40 per cent of the institutions are not integrated. The sample study show that the percentage of institutions integrates with other health sector is very less in wayanad (50 per cent) and high in Malappuram (73.4 %). The table 3.11 shows integration of palliative care institutions with other health sectors for three sample districts.

Table: 3.11Percentage of institutions Integrates with the health sector components for three districts

Health sector components	Wayanad	Kozhikode	Malappuram	Total
Government hospital	14.3		6.7	7.5
Private hospital	28.6	18.2	26.7	25.0
Govt. hospital and private hospital	7.1	36.4	40	27.5
Not integrated	50	45.5	26.7	40.0
Total	100	100	100	100.0

Source: Field survey

Integrations are in terms of consultation, inpatient treatment and supply of medicine. 7.5 per cent of the sample institutions get only consultation to its patients because of this integration with the private and government hospitals. 37.5 per cent of the institutions get both consultation and inpatient treatment to its patients and 15 per cent of institutions gets all services such as consultation, inpatient treatment and supply of medicine to its patients. The table 3.12 also reveals that the terms of integration varies across the district with Malappuram standing ahead in terms of integration.

Table: 3.12 The Terms of Integration (in percentage)

Integration in terms of	Wayanad	Kozhikode	Malappuram	Total
Consultation	7.1	9.1		7.5
Inpatient treatment and consultation	14.3	36.4	60	37.5
Inpatient treatment, consultation and supply of medicine	28.6	9.1	13.3	15.0
Not integrated	50	45.5	26.7	40
Total	100	100	100	100.0

Source: Field survey

Around 92.5 per cent of the institutions or care givers are not satisfied with the present level of integration because it is not sufficient to give good quality of care to the patients. Palliative care patients require high technical treatment which is not available in all sample institution. A government supportive integration is necessary to provide continuous life care to the chronically and terminally ill patients. The current level of integration between palliative care institution and hospitals do not ensure sustainable integration because for most of institutions it is only an informal integration developed mainly developed through the mutual understanding between the care givers and hospitals.

3.3.5. Financial Aspect

All the Neighborhood groups under the programme have managed to raise the money needed for the delivery of the care locally through small contributions and support from the local government. This economic independence of the programme helps the local communities to be in full charge of the initiatives. In situations, where external funding is needed, NNPC initiatives need it only for initiation. Funds from the local community are raised mainly through small donations from lower middle class and poor families and shopkeepers, donations from students in various campuses, regular donations from manual labourer, etc.

In NNPC programmes, support from external sources is used only for initiation and not for continued running. If not managed well, external support can lead to reduced local support and prevent the local people from taking full charge of the programme.

The community is willing to support these initiatives because the principal beneficiary is the community itself. People know where the money goes and who in the community benefits. These transactions happen right in the community under its watchful eyes, and any financial aberrations would be picked up immediately. Other methods of donations include distributing envelopes for collecting money to the public which are later collected by the palliative care team and selling souvenirs. Such ventures also provide an opportunity to spread the word about palliative care. Support does not only come in the form of money.

Many people donate provisions. Volunteers avoid publicity when taking these provisions to the needy families because poverty is not a thing to be celebrated.

Table: 3.13 Sources of finance for palliative care institutions (in number)

Sources of finance	Wayanad	Kozhikode	Malappuram	Total
Donation from public	14(100)	11(100)	15(100)	40(100)
Grants from government	12(85.71)	11(100)	15(100)	38(95)
Its own revenue source	-	-	-	0
External source	--	-	4(26.66)	4(10)

Source: Field survey, figure in the bracket are percentages of institutions

The sample survey also shows that the major sources of finances are donations from public, grants from the government and external sources. Among these donations from the public is the major source of revenue for all the institutions. Annual grants from the Local Self Governments also a source of revenue to the palliative care centres. The sample study shows that 95 per cent institutions get the grants from the local self government and 2 institutions from Wayanad are not obtaining any financial help from the LSGs. They manage their expenses by collecting small amounts and donations from the public. However the amount deliver from the local self governments to palliative care institution depends on the availability of fund to the Panchayat. It is the fact that the grants from the governments are not sufficient to meet its expenses. 10 per cent of the institutions have external source of finance and all these institutions are functioning in Malappuram districts. But the care givers are not wish to depend much on the external source because of interference of those organisation and groups in the internal affairs of the palliative care institution.

Table: 3.14 Percentage of revenue mobilize from public for the sample institutions

Percentage of revenue from public	Wayanad	Kozhikode	Malappuram	Total
80	21.4	9.1	26.7	20
85	28.6	18.2	40	30
90	50	72.7	33.3	50

Source: Field survey

The study finds that donations from the public are foremost source of revenue to the all palliative care institutions. On an average more than 85 per cent of the revenue is come from the donations of public. For 50 per cent of the institutions 90 per cent of the revenue gets from the public.

Table: 3.15 Major sources of donations for the sample institutions

Major Source of donation	Frequency	Percent
Box collection	16	40
Donations of business men	24	60
Social organization	0	0
Student and professionals	0	0

Source: Field survey

Donations from public consists box collection, donations of business men, social organisation and student and professional organisation. For 40 per cent of the institutions box collection is the major source of donation. Donations of business men are the key source of donation for 60 per cent of the institution. Contributions of business men are not only to the financial basket but also they provide lot of non medical help to the patients like food items, clothing etc.

95 per cent of the sample institutions have regularly been getting financial help from the LSGs. The amount is varies across the districts. Around 80 per cent of the institutions get the amount between 50000 to 75000 ranges.

Table: 3.16 Number of institutions getting grants from LSGs across different amount category

Grant from LSGs	Wayanad	Kozhikode	Malappuram	Total
25000-50000	1(7.14)			1(2.5)
50000-75000	11(78.57)	8(72.72)	13(86.66)	32(80)
75000-100000		3(27.27)	1(6.66)	4(10)
100000-1.5 lakh			1(6.66)	1(2.5)
	12(85.71)	11(100)	15(100)	38(95)

Source: Field surveys, figures in the bracket are the percentage of institution

However grants from the Local Self Government and donation of public are not sufficient to meet it multiple needs. The survey finds that 57.7 per cent of the institutions run in deficit and 40 per cent of institutions experience balanced budget. The problem of deficit is high among in Kozhikode as compared to other districts. The study shows that around 90 per cent of the institutions in Kozhikode have been experiencing deficit budget. The corresponding figure for

Wayanad and Malappuram are 57.1 and 33.3 per cent respectively. Deficit budget prevents them to give continuous and long term care to the patients. In Malappuram 66 per cent of the institutions are running in balanced budget. Balanced budget is attained mainly because of low spending in non medical care. An outlier institution has been experiencing surplus budget which is from Malappuram districts.

Table 3.17 Budget position of sample institutions (in number)

	Wayanad	Kozhikode	Malappuram	Total
Deficit	8(57.1)	10(90.9)	5(33.3)	23(57.7)
Surplus			1(6.66)	
Balanced	6(42.9)	1(9.1)	9(66)	16(40)

Source: Field survey, figure in the bracket are the percentage

Patients in the palliative care require continuous care, so that it is not possible to postpone the need of the patients. Care givers manage the deficit situation by borrowing money from money lenders or from other sources or by installing stalls in the festival areas to collect money for managing palliative Care services. As we found earlier 57.5 per cent of the sample institutions run in deficit, among this 27.5 per cent of the institutions solve this shortage by carrying out special collection and 25 per cent use both borrowing and special collection strategies to finance deficit.

Table: 3.18 Way of deficit financing (in %)

Way of financing deficit	Wayanad	Kozhikode	Malappuram	Total
Borrowing	14.3			5
Special collection	21.4	36.4	26.7	27.5
Both	21.4	54.5	6.7	25
Total	57.1	90.9	66.7	57.5

Source: Field survey

We find that donations from the public are the key source of revenue to the community based palliative care. However we find that most of the institutions have been experiencing financial shortage in the path of its development. Most of the patients require multiple care (both medical and nonmedical) and continuous care. In this context the financial sustainability of the programme in the long run is an emerging issue.

3.3.6 Medical and Non -Medical care Delivery

The target of the care givers is to give total care to the victims of chronically and terminally ill people. It contains the element of the both medical and nonmedical needs of the patients and the family. All the sample institutions give both medical and nonmedical care to the patients and their family at free of cost. Institution bears the cost of care by collecting money from the public. The kinds of medical care deliver to the patients are basic care which includes medicine, inpatient care, nursing and consultation. All institutions from the three districts provide all kinds of medical care to the patients except inpatient care. The sample study shows that only 64 per cent of the institutions provide inpatient care to the patient. However, technological treatments are not available from the institutions. No sample institution does have modern high tech facilities like radiation, surgery, dialysis etc.

Table: 3.19 Kinds of medical care providing (% of institutions)

Kinds of medical c are	Wayanad	Kozhikode	Malappuram	Total
Free medicine	100	100	100	100
Inpatient care	64.3	72.7	60	64
Free nursing	100	100	100	100
Free consultation	100	100	100	100
High tech treatment-radiation ,surgery, chemotherapy,	0	0	0	0

Source: Field survey,

In the initial stage of its development, medical care was the primary intention of the palliative care. Later it expanded the operation in all areas including nonmedical care of the patients and their family. The nonmedical care includes financial help, transportation charge, rehabilitation cost, food and clothing, children's education and job training. The study shows that the provision of nonmedical cares are not unique in all institution. It depends upon the availability funds and the infrastructure facilities of respective institutions.

Most of the institution would not like to give direct financial help to the patients and their family. The study shows that only 2 institutions which are from Malappuram districts give financial help to the patients in the form of money. And around 47 per cent of the sample institutions offer transportation help to the patients in the form of money depending upon the needs of the beneficiaries. All palliative care institutions in the sample survey provide wheel chair and water bed to the bedridden people.

Table: 3.19 Kinds of non medical care (% of institutions)

Non medical care	Wayanad	Kozhikode	Malappuram	Total
Financial help	0	0	2	2(5)
Transportation help	6(42.85)	5(45.45)	8(53.33)	19(47.5)
Wheel chair and water bed to the needy people	14(100)	11(100)	15(100)	40 (100)
Food and clothing	14(100)	11(100)	15(100)	40 (100)
Children's education	9(64.28)	9(81.81)	11(73.33)	29(72.5)
Job training	0	9(81.81)	11(73.33)	20(50)

Source: Field survey, figure in the bracket are the percentage

Whenever a disease captures the family it adversely affects the source of income and thereby it affects poverty. All palliative care institutions provide continuous foods and clothing to the patients and to their family even after patient's death.72.5 per cent of the institutions provide help to the family for children's education. An emerging strategy of care givers to protect family from the economic deterioration is the self employment training to the family members. Kozhikode (81.81 of sample institutions) and Malappuram (73.33 %) have been successfully adopting this approach for last few years. This approach is more helpful to the family when the head of the family or earner of income is the victim of the disease. However, this approach has not been developed in Wayanad and recently, they have planned to develop it immediately.

Even though their approach to nonmedical care is appreciable, they have been facing lot of challenges in its operation. Major challenge is the lack of fund. 90 per cent of the institutions do not have enough funds to meet its nonmedical activities. In Wayanad (100 per cent) all institutions have been experiencing the issue of insufficient funds to manage its operation. The corresponding figure for Kozhikode and Malappuram are 90.9 and 80 respectively. Poor infrastructure facilities also prevent them to extend the nonmedical care to the patients and their families effectively. 75 per cent of the institutions do face the problem of poor infrastructure facilities. It is apparent from the study that lack of fund and poor infrastructure facilities are severe in Wayanad as compared to other two districts. That could be due to the poor economic status of the district as compared to other two districts.

Table 3:20 Challenges in meeting nonmedical needs of patients (in number)

Challenges	Wayanad	Kozhikode	Malappuram	Total
Lack of fund	14(100)	10(90.9)	12(80)	36(90)
Poor infrastructure	14(100)	7(63.66)	9(60)	30(75)
both	14(100)	7(63.66)	9(60)	30(75)

Source: Field survey, figure in the bracket are the percentage

3.3.7 Questions for the future

Community based palliative care institutions have several persistent weaknesses in its institutional arrangement. Most of the sample institutions (95 per cent) are not certain with the sustainability of the palliative care system because of challenges standing ahead. First and foremost challenge is the financial sustainability in the long run. Without permanent and continuous source of revenue one could not expect long run sustainability of the programme. 75 per cent of the institutions view is that without integration of palliative care with the various components of health sector it is not possible to give continuous and sustainable care to the patients. At the same time 50 per cent of the institutions worrying about retreat of local people's participation when government interferes in management and administration.

Increase the coverage of care and ensure good qualities of care are difficult task and challenges as far as palliative care institution is concerned. It is important to ensure that coverage in palliative care does not involve an acceptable fall in the quality. The community based palliative care in Northern Kerala is a typical one. The organizers of programme and policy makers are worry about the transplantability of the programme to other district or states of the country. Is the success of palliative care movement in Kerala related to the literacy and the progressive society? If so, how long will it take for the movement to achieve coverage in the rest of the country? Poor infrastructure facilities in palliative care institutions have been restricting the good quality of care to the patients. In Kerala 95 per cent of the institutions view that building sound infrastructure facilities is a challenging task. The table 3.21 demonstrates the major challenges and factors which prevent smooth functioning of community based palliative care in Northern Kerala.

Table: 3.21

Challenges ahead (Percentage of institution)

Challenges ahead	Wayanad	Kozhikode	Malappuram	Total
Financial sustainability	100.00	100.00	86.67	95.00
Integration	64.29	72.73	86.67	75.00
Interference of government	35.71	54.55	60.00	50.00
Quality of care	85.71	81.82	73.33	80.00
Coverage	71.43	63.64	73.33	70.00
Transplantability	85.71	90.91	86.67	87.50
Infrastructure facilities	100	100	86.67	95

Source: Field survey

3.4 Conclusion

The study find that local community such as Non-governmental organisations(NGO),religious organisations and other social organisations have played key role in the development and determination of palliative care service in Northern Kerala. The basic motive behind the emergence of community based palliative care in Northern Kerala is to ensure better quality of life to the chronically and terminally ill patients. Moreover, the insufficient government mechanism to absorb the terminally ill patients and catastrophic medical expenditure has demanded the need for community based palliative care.

The initial stage of development its services were limited to specific diseases like cancer. However later caregivers have extended the coverage to other diseases like AIDS, asthma, tuberculosis, , heart disease, accidental cases etc. Economic condition of the patients, the nature of disease and age are the significant criteria use to select patients. Outpatient treatment with a supportive home care service was adopted as the main mode of operation. Most of the institutions prefer home based care to inpatient care because of two reasons. Firstly, inpatients facilities are very weak in most of the institution. Secondly, in home based care both family members and caregivers can work together to give better quality of care to the patient. And it is obvious that most of the patients want to spend their last moments of life with the family members.

Infrastructure facilities in most of the institutions are very weak. Basic infrastructure facilities like beds, building, ambulance, etc are not sufficient to give better care to the patients. The study brought out that infrastructure facilities are very weak in Wayanad as compare to other two districts. The study discovers that 62.5 per cent of the institutions do not have all essential drugs in their institution reveals poor availability of drugs. The level of integration of palliative care with the other health sector is in the initial stage of development. 40 per cent of the institutions are not integrated with any of the hospitals and primary health centres. The level of integration is very poor in Wayanad as compare to other two districts.

All the sample institutions provide medical and non medical care to the patients and their family. However, the study shows that lack of fund and poor infrastructure facilities prevent to give nonmedical care to the patients. It is apparent from the study that lack of fund and poor infrastructure facilities are severe in Wayanad as compared to other two districts.

The detailed investigation reveals that donations from the public are the key source of revenue to the community based palliative care. Around 80 per cent of money comes from public in the form of donations various sections of people. However, all sample institutions have been experiencing financial shortage in the path of its development. More over grants from local self government are not sufficient to meet its expense. In this context the financial sustainability of the programme in the long run is an emerging issue.

As far as supply side is concerned palliative care institutions in Northern Kerala do have lot of constraints in its structure and process. One positive factor is that community participation in the process of care. However, the sustainability of palliative care service is remaining to be seen due to challenges standing ahead.

Chapter IV

Socio Economic and Health Profile of Palliative Care Patients

4.1 Introduction

In the third chapter we find that palliative care institutions in the Northern Kerala have lot of organizational weakness in its arrangement including poor infrastructure facilities, financial constraint, less integration with public and private health care system, lack of essential drug availability etc. Due to poor infrastructure facilities in institutions most of the caregivers not only in Northern Kerala but also in all parts of the Kerala prefer home based care in which family members have key role in caring the patient. In this context this chapter analyses demand side perception about the care. As far as demand side is concerned socio economic condition of the patient is an important factor which affects demand for health care. It is essential to look at the socio-economic and health profile of the patients and their health expenditure pattern which helps to identify the actual care that they require. Basically aim of this chapter is to study how the palliative care strategies cope up with the demand side requirement which determines the quality of care. Specifically, the objectives of this chapter are

- To study socio economic and health profile of the palliative care patients
- To study health expenditure of palliative care patient and coverage of social security schemes among them

4.2 Methodology

The study area is restricted to wayanad; one of the districts where community based palliative care is very active. In chapter 3 we find that palliative care institutions in this district have been facing several organizational difficulties as compared to other two districts, Malappuram and Kozhikode. In this context it is interesting to see the socioeconomic and health profile of the patients in wayanad district and what kinds of care they getting from the institutions. In order to analyse above objectives 100 samples were taken randomly from three palliative care institutions in wayanad district. All sample units are including in the category of home based patients. Three institutions were selected on the basis of institutional survey conducted for chapter 3. The selected intuitions have been facing lot of constraints in its operation as compared to other institutions. With several organizational constraints how they meet the socioeconomic need of the patients need to be understood. Due to poor infrastructure facilities Palliative caregivers prefer home based care which is considered as better substitute for inpatient care. Home based care is meaningful and most appropriate one in many contexts. One is that family members themselves can act as care givers, so that continuous care can provide to the patient. Secondly, patient can spend their last stage of life with family members.

Questionnaire (see appendix 4.1) were constructed in such a way as to collect information related to various aspects including socio economic and health condition, health expenditure, coverage of social security schemes, kinds of care getting from palliative care institution, perception related to quality of care were asked to patients and their family members. Most of the patients selected for the study are bedridden people and they were not able to participate in the discussion. Family members helped to finish the questionnaire.

4.3: Socio economic and health profile

In this section we examine socio economic and health characteristic of the selected patients. This section is essential to understand what kinds of care actually patients and their family members require. Table 4.1 shows age wise distribution of sample patient across gender.

Table 4.1 Age wise distribution of Patient across Gender (in percentage)

Age groups	Gender		Total
	Male	Female	
15-45	10	3	13
46-60	12	19	31
61-80	31	16	47
Above 80	4	5	9
total	57	43	100

Source: Field survey

Age wise distribution of sample shows that 57 per cent of the selected patients are include in the age group of 61 and above and 31 per cent contains in the age group of 46-60. 13 per cent of the total patients come in the age group of 15-45. Among the total sample 57 per cent are male and 43 per cent are female. 47 per cent, high representation of sample population is in the age group of 61-80, among this 31 per cent are male and 16 per cent are females. Most of the study population is aged or very close to aged. This could be due to high prevalence of morbidity and disability among this age group. However, 13 sample units are include in the age group of 15-45 reveals the fact that palliative care is not only specifically for aged people but also for other needy population.

Table 4.2 category wise educational level of sample population (in percentage)

Education	category				total
	OBC	SC	ST	General	
primary	17	6	0	25	48
secondary	0	0	0	12	12
HS	4	0	0	4	8
GRA	0	0	0	1	1
illiterate	3	7	16	5	31
total	24	13	16	47	100

Source: Field survey

The table 4.2 shows that in the sample units 24 per cent of the patients are include in the category of OBC,13 per cent of them are SC,16 per cent are ST and remaining 47 per cent treated as general category. In the sample population 31 per cent of the patients are illiterate. Around 48 per cent of the patients are having education up to high school. The cross tabulation table shows that the educational attainment of scheduled tribe is very low. All ST patients are illiterate gives fact that information related to the available health care facilities would be low among SC and ST. Most of the sample patients are aged and illiterate which makes them more helpless population.

Table 4.3 Religious characteristics of patients across gender (in percentage)

religion	Gender		Total
	Male	Female	
Hindu	32	21	53
Christian	14	22	36
Muslim	11	0	11
total	57	43	100

Source: Field survey

Even though sample institutions are functioning closely with religious organisation, they are not following any discrimination in selecting patients on the basis of religion. Table 4.3 shows that the study population consists of 53 per cent of Hindus, 36 per cent of Christian and 11 per cent of Muslims. The share of Hindu and Christian population is higher than Muslim may be because of domination of these two populations in the selected district.

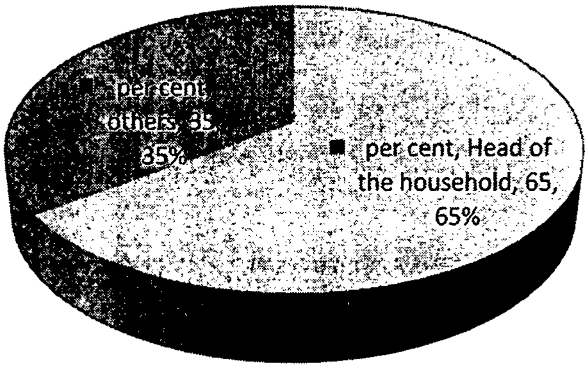
Table 4.4 Marital status of study population across Gender (in percentage)

Marital status	Gender		Total
	Male	Female	
Married	44	28	72
Single	1	3	4
Widowed	12	12	24
Total	57	43	100

Source: Field survey

Table 4.4 shows the marital status of sample population across gender. Around 72 per cent of the sample patients are married; 4 per cent of the patients are never married; 24 per cent of the population is widowed. This indicates that absence of caregivers in the family is not the only reason for admitting in palliative care institutions. Marital status of the sample population shows that all kinds of patients such as married, single and widowed are the beneficiaries of palliative care service. Since all patients are home based patients it is clear from the study that health care from either spouses or family members are available for all sample population. They would like to spend their last stage of life in home.

Figure 4.1 Household status of study population



The sample population characteristic shows that 65 per cent of the patients selected for the study are head of the family. Whenever a disease captures the head of the family it will have multiple impacts on the family. They may not able to meet their daily expenses leads to less consumption, no saving and thereby low productivity.

Table 4.5 Occupation wise distribution of sample population across various age groups (in percentage)

Occupation	Age				Total
	15-45	46-60	61-80	above 80	
Wage labour	11	12	25	4	52
Own cultivator	0	0	5	0	5
Livestock rearing	0	4	0	0	4
Collection of forest produce	0	4	8	0	12
HH works	2	7	9	5	23
Self employed	0	4	0	0	4
total	13	31	47	9	100

Source: Field survey

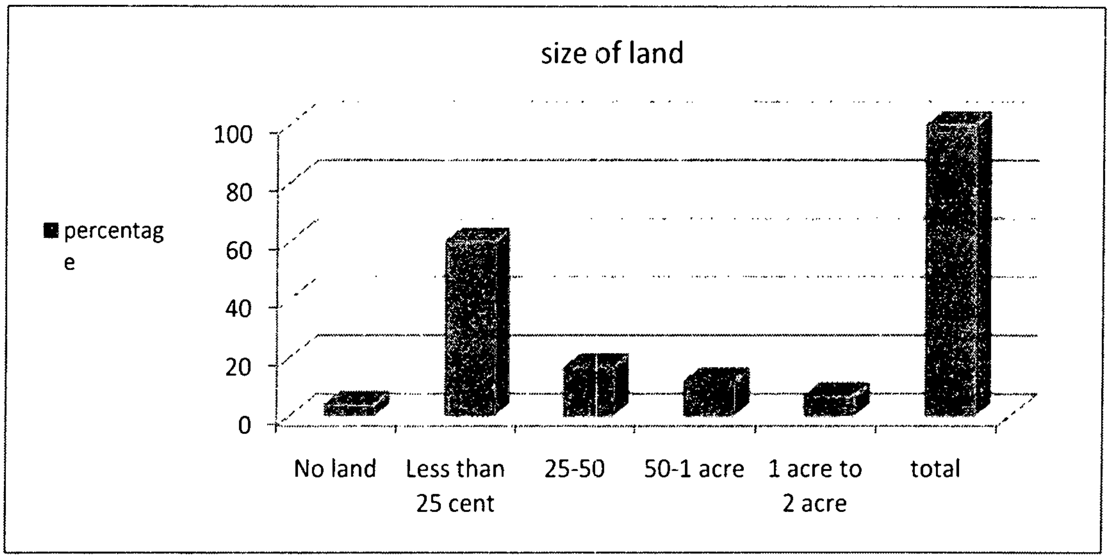
Table 4.5 the occupation wise distribution of sample population across various age groups. It is previous (before affecting diseases) occupation status of population. Currently most of them are not able to work and thereby no earnings. It indicates that 52 per cent of total sample populations were wage labours, 23 per cent of sample units were engaged in household activities, for 12 per cent of the sample population collection of forest produces were the main source of livelihood. 5 and 4 per cent of sample populations were considered as own cultivators and livestock rearing workers respectively. The main inference from the above analysis is that the occupational status of most of the sample populations was low in the sense that they were engaged in traditional activities which are not high income generating activities. This phenomenon is common for all age group.

4.3.1 Asset position of household

All the sample households are including in the BPL category shows their poor socio economic condition. The average monthly income of the families is less than RS.750. No sample households have savings either in bank or any saving strategy. The study shows that the percentage of household having land less than 25 cent is 60 per cent. 17 per cent of population having land size between 25 and

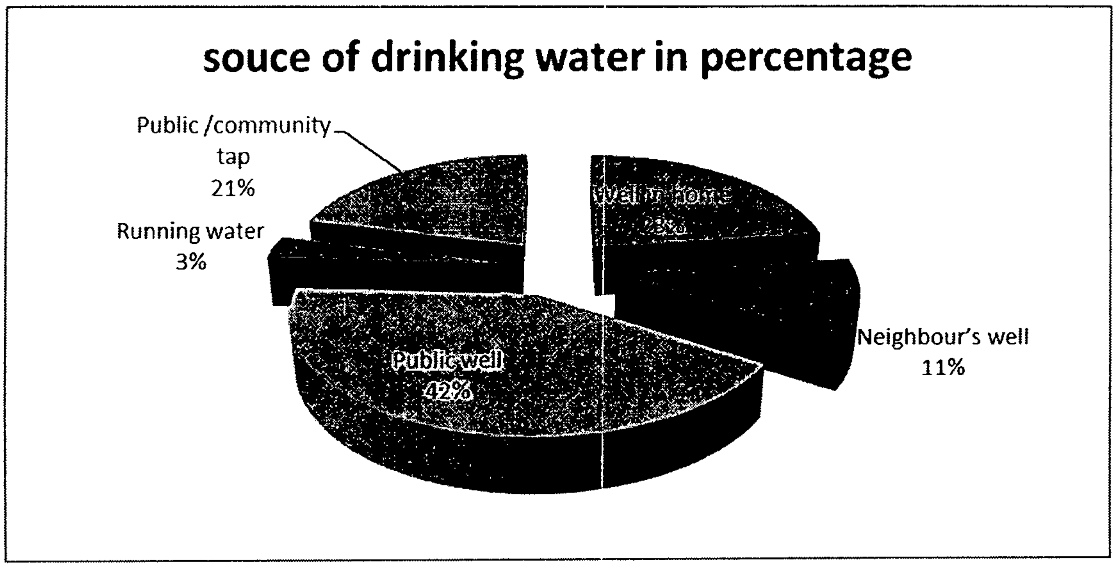
50 cents. 4 per cent of household have no land. The study finds that 17 per cent of the study population having at least half acre of land.

Figure 4.2 size of land holding of sample population in percentage.



68 per cent of the study population belongs in the kacha house and remaining 32 per cent lives in semi pucca house. Majority of study population (42 per cent) depend on public well for drinking water. It was found that around 23 per cent of respondents utilize their own well for the drinking water. However, majority of study population (74) depend on other sources (neighbor well, public well, community tap) for drinking water. It means that most of the study population depends on others for drinking water.

Figure 4.3 source of drinking water of study population.



It has been observed that 16 per cent of sample populations have no electricity. Majority of them belongs in the category of scheduled caste and scheduled tribes. Annual income of 68 per cent of the sample population is between RS. 5000 and 10000 and remaining 32 per cent have annual income between RS.5000 and 10000. The study finds that selected patients are vulnerable section of the population in many senses. Most of them are socially and economically deprived and depend upon family members to meet their basic needs.

4.3.2 Diseases, Medical expenditure and social security schemes

The study of disease pattern and distribution helps to understand what kind of diseased patients are in palliative care institution. The literature shows that palliative care is especially for terminally ill and chronically ill patients.

Table 4.6 Diseases pattern of sample population across various age groups (in percentage or number)

Kinds of diseases	Age groups				Total
	15-45	46-60	61-80	Above 80	
Cancer	4	24	20	4	52
Tuberculosis	0	0	4	4	8
Asthma	0	0	4	0	4
AIDS	2	7	3	1	13
Heart diseases	4	0	0	0	4
Accidental cases	3	0	0	0	3
Multiple disability	0	0	16	0	16
Total	13	31	47	9	100

Source: Field survey

The table 4.6 shows that 52 per cent of study populations are affected by the disease cancer. The number of cancer patients is high in two age groups, 46-60 and 61-80, which are 24 and 20 respectively. The study shows that 8 per cent sample population are affected by tuberculosis, 4 per cent of patients are victims of asthma,13 per cent of patients are infected AIDS,4 per cent patients are affected heart disease,3 per cent of patients are accidental cases and 16 per cent of sample populations have multiple disabilities. Most of the patients come under the two age groups, 46-60 and 61-80 which account 78 per cent of total sample population.56 per cent of study population are in the age group of above 60. It is obvious from the table 4.6 that major diseases among younger age groups are cancer, AIDS and accidental cases which are the emerging health diseases or concerns in the state.

Table 4.7 Diseases of sample population across gender (in percentage)

Diseases	Gender		Total
	Male	Female	
Cancer	32	20	52
Tuberculosis	4	4	8
Asthma	0	4	4
AIDS	10	3	13
Heart diseases	4	0	4
Accidental cases	3	0	3
Multiple disability	4	12	16
Total	57	43	100

Source: Field survey

It is clear from the table 4.7 that most of the palliative care patients are cancer patients. Cancer and AIDS diseases are high among men than women in our study population. However, multiple disability and asthma are high among female than male population. The study population consist patients with multiple diseases like chronic diseases, terminally ill patients, and multiple disabilities. It indicates that in wayanad the coverage was extended to all kinds of diseased people rather than giving care to terminally ill patients. There is no gender disparity in selection and provision of palliative care.

Table 4.8 Cross tabulation of period when disease diagnosed and period seeking palliative care (in percentage)

Disease diagnosed	Seeking palliative care							total
	Less than 10	1 month	2 to 4 month	4 to 8 month	1 year	2 year	2 to 4 year	
1 year	4	8	9	0	0	0	0	21
2 to 4 year	7	8	8	15	9	0	0	47
4 to 6 year	0	5	0	4	4	8	3	24
6 to 10 year	0	0	0	4	0	4	0	8
Total	11	21	17	23	13	12	3	100

Source: Field survey

The study shows that most of the palliative care patients seek care at the latest stage of their diseases. The above table demonstrates that the existence of huge gap between periods when disease diagnosed and seeking palliative care. The reasons behind the late admission are essential to understand in order to success palliative care service in future. This could be due to two reasons; supply and demand side preferences. Basically supply side prefers the patients with incurable and chronic diseases. As far as demand side considered lack of modern facilities in the palliative care institutions would prevent them to arrive in the palliative care institutions at the earlier stage of their disease. However, still palliative care patients require specialized and better treatments like radiation, dialysis etc to give peaceful and good quality life in their last stage of life.

Table 4.9 cross tabulation of timing of referral and reason for delay (in percentage)

Timing of referral	Reason for delay			total
	Ignorance of availability of palliative care	Lack of modern facilities	Attitudinal problem	
Middle stage of disease	4	8	0	12
Advanced stage	29	51	8	88
Total	33	59	8	100

Source: Field survey

In the table 4.13 reveals that most of the patients admit in the palliative care institutions in the advanced stage of diseases. It also gives reasons for delay in admitting palliative care institution. We find that 88 per cent of the patients were receiving palliative care in advanced or terminal stage of disease. Ignorance of availability of palliative care (33 %), lack of modern facilities (59%), and attitudinal problem (8) etc. are the reasons for the late coming in the palliative care. We need to find ways to provide supportive care earlier in the course of the disease, by sensitizing health professionals and general public. For that better health care facilities should create and steps should start to create awareness among the people about the palliative care.

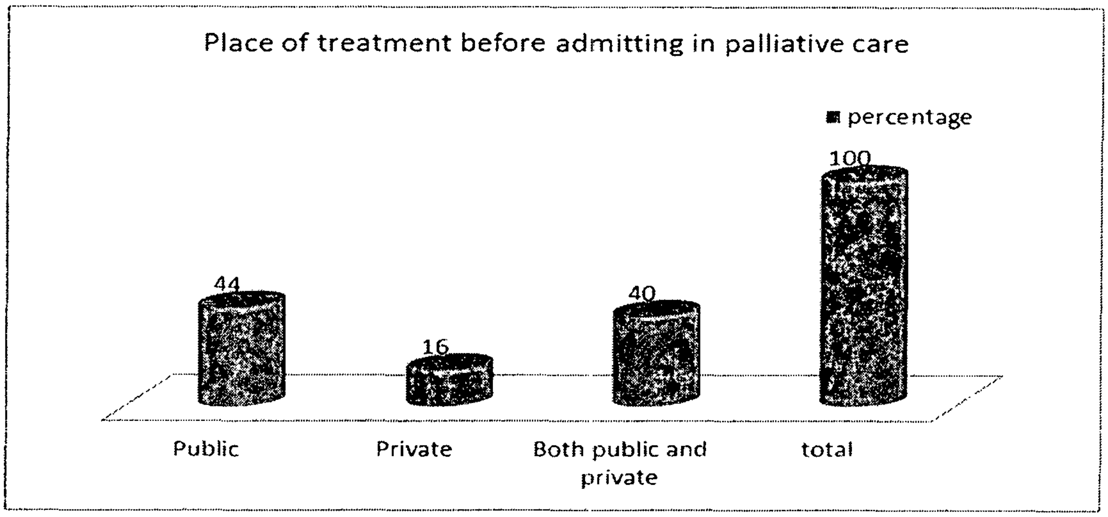
Table 4.10 Reasons or seeking palliative care (in percentage)

disease	Reason for seeking palliative care			Total
	General debility	Financial problem	Multiple reasons	
Cancer	9	24	19	52
Tuberculosis	4	4	0	8
Asthma	0	4	0	4
AIDS	0	13	0	13
Heart diseases	3	0	1	4
Accidental cases	0	0	3	3
Multiple disability	0	11	5	16
Total	16	56	28	100

Source: Field survey

The common reason for seeking palliative care was financial problem, which accounted for 56 per cent of the cases. General debility (16 %) and multiple reasons (28%) were other common reason for seeking palliative care. The multiple reasons include pain, general debility and financial problem.

Figure 4.4 place of treatment before admitting in palliative care institutions



The figure 4.4 shows the place of treatment before admitting in the palliative care institution. It is clear that 44 per cent of study populations have been depended on public health care institutions and 40 per cent depended on both public and private institutions. However, only 16 per cent of the patients have been depended on private institutions alone. This gives the fact that most of the people were not able to pay high health care expenditure charged by private institutions. Lately, all of them were shifted to palliative care institutions due to high health expenditure.

Table 4.11 Total Medical expenditure incurred across various diseases of sample population (percentage)

diseases	Medical expenditure incurred (in RS)				Total
	10000 to50000	50000 to 1 lakh	1 lakh to 3 lakh	3 lakh to 5 lack	
Cancer	1	27	20	4	52
Tuberculosis	0	4	4	0	8
Asthma	0	0	4	0	4
AIDS	4	5	4	0	13
Heart diseases	0	0	4	0	4
Accidental cases	0	3	0	0	3
Multiple disability	0	8	8	0	16
Total	5	47	44	4	100

Source: Field survey

The table 4.9 shows total medical expenditure incurred since the inception of the diseases. It shows that 47 per cent of the study populations have been experienced medical expenditure between RS 50000 to 1 lakh and 44 per cent of population have been incurred medical expenditure between RS.1 lakh to 3 lakh. And 4 per cent of the sample patients have been incurred expenditure between RS 3 lakh to 5 lakh, all of them are cancer patients. All study populations are the victims of catastrophic medical expenditure. Since their economic background is bad, this catastrophic medical expenditure might have affected them terribly in various ways.

The table 4.10 shows monthly medical and non -medical expenditure patients since disease has been diagnosed. For 68 per cent of the sample population the monthly non- medical expenditure is between RS.1000 to 2500. As far as medical expenditure is concerned 59 per cent of the sample population comes in the expenditure category of RS.1000 to 2500. Looking at medical expenditure alone not make much sense. The study finds that patients have been facing problems in meeting their nonmedical needs. The monthly expenditure incurs on medical and nonmedical expenditure is more or less same.

Table 4.12 monthly medical and non medical expenditure of sample population (in percentage)

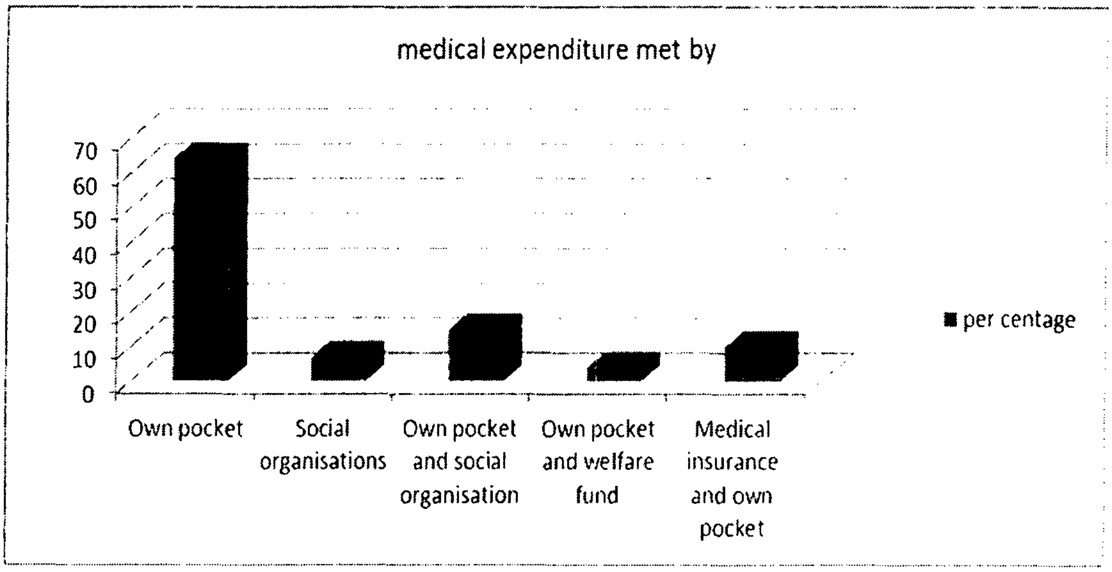
Monthly medical expenditure	Monthly nonmedical expenditure			Total
	100-500	500 to 1000	1000 to 2500	
100 to 500	0	4	0	4
500 to 1000	4	4	29	37
1000 to 2500	0	20	39	59
Total	4	28	68	100

Source: Field survey

64 per cent of the study population met medical expenditure from own pocket,7 per cent from social organisations, 15 per cent met through own pocket and social organisation , 4 per cent met medical expenditure through own pocket and welfare fund and finally 10 per cent of the sample populations have got medical benefit from insurance coverage. A state like Kerala where large number of social security schemes and medical insurance(both public and private) schemes exist,

major section of sample population meets their medical expenditure through own pocket.

Figure 4.5 Medical expenditure met by the sample population through various sources of finance(in percentage)



Major section of the sample population met their medical expenditure through borrowing money from various sources and by selling their assets like land ,livestock etc.The table 4.11 reveals that 77 per cent of the sample populations have experienced depletion of assets like land, livestock and vehicle in order to meet both medical and nonmedical requirements. Out of 77 of sample population 21 have sold their land, 41 sold livestock, and 15 sold vehicle to meet expenditure. 53 per cent of the sample populations borrowed money from various sources like bank, money lenders, and social organisations.

Table 4.13 Borrowing and selling assets to meet medical expenditure (%)

Amount	Asset depletion				Borrowing			
	Land	livestock	vehicle	total	bank	Money lender	Social organisation	Total
Less than 10000	0	4	0	4	0	0	0	0
10000 to 50000	4	29	8	41	7	24	2	33
50000 to 1 lakh	12	8	4	24	0	20	0	20
1 lakh to 3 lakh	5	0	3	8	0	0	0	0
total	21	41	15	77	7	44	2	53

Source: Field survey

22 per cent of the sample populations have membership in any of the welfare fund schemes. Among this 15 per cent (out of total sample) have Membership in

Kerala Building and Construction Workers Welfare fund (KBCWWF), 4 per cent have membership in Kerala Toddy Workers Welfare Fund (KTOWWF), and 3 per cent have membership in Kerala Tailoring workers welfare fund (KTAWWF). However, only 3 per cent of the sample populations have been benefited from the welfare fund. The amount given was also not sufficient to meet their medical expenditure

Table 4.14 coverage of Welfare fund and duration of membership among sample population (%)

Name of membership	Duration of membership				Total
	1 to 3 year	3 to 5 years	5 to 10 years	More than 10 years	
KBCWWF	0	9	3	3	15
KTOWWF	0	0	4	0	4
KTAWWF	3	0	0	0	3
All	3	9	7	3	22

Source: Field survey

The study finds that most of the sample units are the victims of catastrophic health expenditure and suffering from multiple problems. Their social, economic and health profile reveals that they need multiple kinds care rather than giving medical care alone. The study finds that the share of elder people is higher in the palliative care institutions with chronic and other diseases.

4.4 Care from the palliative care institution

Palliative care patients have been getting multiple kinds of care from the institution. It includes both medical and non-medical care with continuous care. However, one problem is that the late admission of patients to the institutions which prevent the caregivers to minimize the burden of disease on the family. Palliative care institutions provide medical and non -medical care to the patient if they require it. The sample study shows that all patients get medical care from the institutions. However, only 57 per cent of the sample populations get both medical and nonmedical care. It is also clear from the table 4.15 that Patients' diseases are not criteria for giving nonmedical care.

The kinds of medical care include supply of essential medicine, nursing and consultation. 74 per cent of sample home care patients have been getting both medicine and nursing service, and remaining 24 per cent getting essential medicine only. Palliative care team visits all the patients at least once in a week, and gives medicine and information to family members about how to manage care in home without professional caregivers

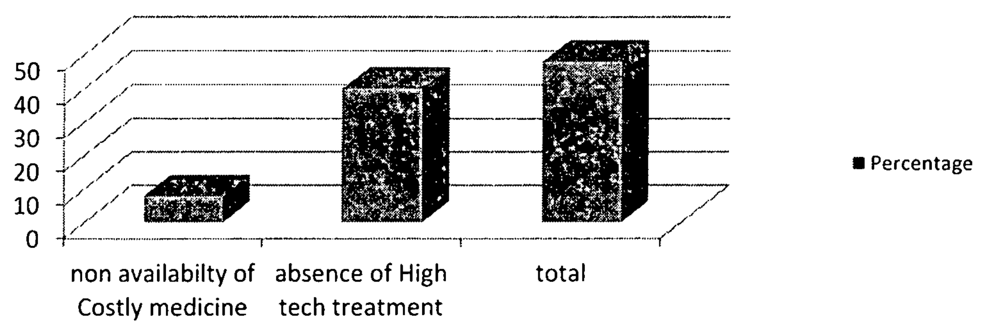
Table 4.15 kinds of care getting to the sample units (%)

Disease	Kind of care		Total
	Medical	Medical and Non-medical	
Cancer	28	24	52
Tuberculosis	4	4	8
Asthma	0	4	4
AIDS	4	9	13
Heart diseases	0	4	4
Accidental cases	0	3	3
Multiple disability	7	9	16
Total	43	57	100

Source: Field survey

The figure 4.6 shows that 48 per cent of the respondents are not satisfied with the available medical care in the palliative care institutions. The reasons for the dissatisfaction are the nonavailability of costly medicine and high tech treatment in the institution.In the third chapter we found that even essential drugs are also not available for patients in the pallitive care institution.Since most of the palliative care patients are chronically ill patients ,they need specialised and high tech treatment to give good quality of life at the last stage of life. However,institutions provide only the basic medical care like nursing, medicine etc which is not sufficient to care chronically ill patients.

Figure 4.6 percentage of study population dissatisfied with the medical care



Though medical care is specifically targets to patients, nonmedical care is not specifically to patients. It is one way of giving total care to the patient and family.

The non-medical care includes food and cloth, transport expenses, children's education, job training to family members, water bed and wheel chairs, and financial help. 57 per cent of the patients from the sample population have been getting food and clothing from the institution, 16 per cent get transport expenses, 24 per cent get benefit for their children's education, 20 per cent get job training to family members, 28 per cent get water bed and wheel chairs especially for cancer and immovable patients, and 16 per cent of the study population get financial help.

Table 4.16 kinds of non medical care available to the patients (in percentage)

Diseases	Non -medical care					
	Food and cloth	Transport expense	Children's education	Job training to family members	Water bed and wheel chair	Financial help
Cancer	24	12	8	12	20	0
Tuberculosis	4	0	0	0	0	0
Asthma	4	0	0	0	0	4
AIDS	8	0	8	4	0	4
Heart diseases	4	0	4	4	4	0
Accidental cases	4	4	4	0	4	0
Multiple disability	9	0	0	0	0	8
total	57	16	24	20	28	16

Source: Field survey

From the table 4.16 we find that all patients are not getting non medical care, only 57 per cent of the sample units are getting non medical care. It reveals the fact that some criteria are adopting by the care givers to provide nonmedical care.

Table 4.17 Non medical care across various age groups (in percentage)

Non-medical care	age				Total
	15-45	46-60	61-80	Above 80	
No	1	21	21	0	43
Yes	12	10	26	9	57
total	13	31	47	9	100

Source: Field survey

The study finds that nature of disease is not a significant factor in determining the availability of non-medical care. However there are some significant factors which affect the availability of nonmedical care to the family. Age of the patient is important in the sense that the percentage of study population getting nonmedical care in some age groups is higher than other groups. The table 4.17 shows that in the two age groups 15-45, the working age group, and above 60, highly dependent population, the percentage of people receiving nonmedical care is higher than that of other two groups.

The coverage of nonmedical care among SC, and ST are higher than other population category. This might be because of socioeconomic backwardness of this section population. All scheduled tribe patients have been getting nonmedical care. Palliative caregivers might have identified their needs and requirements.

Table 4.18 Non medical care across various category of sample population (in %)

Non-medical care	Category				Total
	OBC	SC	ST	General	
No	16	4	0	24	44
Yes	8	9	16	23	56
total	24	13	16	47	100

Source: Field survey

The study shows that the significant association between patients occupation and coverage of non-medical care. The coverage of non-medical care is higher among two occupational groups i.e. wage labour and those who collect of forest produces, as compared to other occupation groups. Detailed examination reveals that these two age groups are the most economically and socially deprived section in the study.

Table 4.19 Non medical care across various occupations (in percentage)

Non-medical care	occupation						Total
	Wage labour	Self employed	Own cultivator	Livestock rearing	Collection of forest produce	HH works	
No	19	4	5	1	0	15	44
Yes	33	0	0	3	12	8	56
total	52	4	5	4	12	23	100

Source: Field survey

It is obvious from the below that significant association between coverage of non-medical care and earning members in the family. The study finds that the all families with no earning members get non -medical care from the palliative care institution. As earning members in the families increase the proportion of families get non-medical care decreases. It reveals that palliative care institutions provide nonmedical care to those families if head of the family is the patient.

Table 4.19 Non medical care across number of earning members in the family (in percentage)

Non-medical care	Earning members in the family				Total
	0	1	2	3	
no	0	13	26	5	43
yes	11	37	8	0	57
total	11	50	34	5	100

Source: Field survey

4.5 Conclusion

The socio economic profile of the palliative care patients shows that they are one of the vulnerable sections in our society. Most of the patients are affected by the chronic diseases such as cancer, AIDS,etc. Most of them are socially and economically deprived section and depend upon family members to meet their basic needs. The study finds that most of the sample patients are aged and illiterate which makes them more helpless population. The occupational status of most of the sample population was low in the sense that they were engaged in traditional activities which are not high income generating activities. The study shows that most of the palliative care patients seek care at the latest stage of their diseases. The reason for the latest admission is lack of better medical facilities in palliative care institutions. There is no gender disparity in selection and provision of palliative care.

All study populations are the victims of catastrophic medical expenditure. Most of the people were not able to pay high health care expenditure charged by private institutions. Since their economic background is bad, this catastrophic medical expenditure has affected them terribly in various ways. The study finds that most of them were sold their assets and borrowed money from various sources to meet their medical and nonmedical needs. The study discovers that in a state like Kerala where large number of social security schemes and medical insurance(both public and private) schemes exists, major section of sample population meets their medical expenditure through own pocket.

The study finds that common reason for seeking palliative care was financial problem, which accounted for 56 per cent of the cases. However, some sample units are not fully dissatisfied with the available medical care in the palliative care institutions. The reasons for the dissatisfaction are the nonavailability of costly medicine and high tech treatment in the institution.The study finds that Patients' diseases are not criteria for giving nonmedical care. However some factors like age, occupation, category and number of earning members in the family are significant in getting non-medical care.

Chapter V

Measuring the Quality of palliative Care: Satisfaction of Family Members

5.1 Introduction

This chapter tries to measure the quality of palliative care from the perspective of patients and their family members. Literature related to the quality of palliative care reveals an increasing emphasis upon the importance of care satisfaction judgments made by patients and their family. Usually the constant support to the patient is the family, although the degree of involvement of families in the patient's care experience varies. Families are facing an imminent loss and may experience anticipatory grief and as participants and observers of patients' care they often encounter a myriad of stressors. To provide care that promotes family satisfaction and minimizes this potential burden, it is therefore essential to measure family satisfaction. Quality of care is important from the perspective of both demand and supply side which leads to long run sustainability of the programme. By measuring the quality of the care we can understand the institutional soundness in providing the health care which is essential for long run sustainability. Literature shows that outcome measure, i.e. family satisfaction has been using widely among the health economist to check the sustainability of the health care programmes.

5.2 Methodology

We used the FAMCARE[1], which is one among several instruments used in measuring the family's satisfaction with palliative care for cancer patients. The FAMCARE scale was developed by Kristiansen LJ, Faculty of Nursing, and University of Manitoba, Canada. The FAMCARE was developed to measure the degree to which family members are satisfied with the health care received by

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[1] *(Kristjanson 1986, 1989, 1993) - A scale developed based on qualitative research that asked family members to list indicators of quality of palliative care from their perspective and the patient's perspective. This list was shortened to a 20 item scale based on a Q-sort and examination of the psychometric properties.*

both the patients and the family with respect to the following four components of care: information giving, availability of care, psychological care and physical patient care. Some FAMCARE items were excluded and some new items are included from the study to make them relevant in Kerala context.

The FAMCARE (see appendix 5.1) items used for the present study are the patients pain relief (Q1), Speed with which symptoms are treated(Q2), Doctor's attention to patient's description of symptoms(Q3), Coordination of the care(Q4), The way the family is included in treatment and care decisions(Q5), Community involvement(Q6), Information given about how to manage the patient's pain(Q7), Information given about the patient's tests(Q8), Availability of hospital bed to the patient(Q9), Availability of nurses to the family(Q10), Availability of the doctor to the patient(Q11), Availability of medicine(Q12), Availability of non-medical care to the family(Q13).

In order to measure the satisfaction of family 100 samples were selected. The sample units were selected from the same families used for analyzing chapter 4. The sample comprised family members close to patients. All the respondents were the educated persons of the corresponding families. Questions (FAMCARE items) related to the various aspect of the care were asked to the family members. It includes questions about how satisfied close family members are with care provided by the palliative care institution. The FAMCARE items are scored from 1 to 5 so that high values indicate high satisfaction with the care component. Simple descriptive statistics and factor analysis [2]have been used to measure the satisfaction of family members.

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[2] *Factor analysis is a method for investigating whether a number of variables of interest Y1, Y2, : : :, Yl, are linearly related to a smaller number of unobservable factors F1, F2, : : :, Fk . Factor analysis usually proceeds in two stages. In the first, one set of loadings is calculated which yields theoretical variances and covariance that fit the observed ones as closely as possible according to a certain criterion. These loadings, however, may not agree with the prior expectations, or may not lend themselves to a reasonable interpretation. Thus, in the second stage, the first loadings are rotated" in an effort to arrive at another set of loadings that fit equally well the observed variances and covariances, but are more consistent with prior expectations or more easily interpret. There is considerable subjectivity in determining the number of factors and the interpretation of these factors. There are several methods for obtaining first and rotated factor solutions, and each such solution may give rise to a different interpretation.*

5.3. FARMCARE Scale interpretation

Table 5.1 The FAMCARE items and descriptive statistics=100

No.	Items[3]	Mean	Std.	% satisfied		% dissatisfied	
				4+5[4]	5	1+2[5]	1
1	The patients pain relief	3.72	0.96	66	16	20	0
2	Speed with which symptoms are treated	3	0.75	28	0	28	0
3	Doctor's attention to patient's description of symptoms	2.72	0.60	8	0	36	0
4	Coordination of the care	4.08	0.75	84	28	4	0
5	The way the family is included in treatment and care decisions	4.24	0.43	100	24	0	0
6	Community involvement	4.16	0.47	96	20	0	0
7	Information given about how to manage the patient's pain	4.08	0.69	88	24	4	0
8	Information given about the patient's tests	2.96	.90	32	0	29	7
9	Availability of hospital bed to the patient	2.56	0.50	0	0	44	0
10	Availability of nurses to the family	3.88	0.43	84	4	0	0
11	Availability of the doctor to the patient	2.6	0.57	4	0	44	0
12	Availability of medicine	4.08	0.56	96	16	4	0
13	Availability of non-medical care to the family	3.68	0.68	56	12	0	0

Source: Field survey

The table 5.1 gives an overview of the 13 items in the FAMCARE scale and descriptive statistics. High item values indicate high satisfaction with care. Most of the respondents reported to be either very satisfied (5) or satisfied (4) on the most of the items. The following items: 'the way the family is included in treatment and care decisions', 'Community involvement', 'Information given about how to manage the patient's pain', 'Coordination of the care', 'Availability of medicine' and 'Availability of nurses to the family' indicated the highest satisfaction with the care(ie.mean score from 4.24 to 3.88). On the other hand, the items: 'Availability of hospital bed to the patient", 'Doctor's attention to patient's description of symptoms', and "Availability of the doctor to the patient', and "Information given about the patient's tests", indicated the lowest satisfaction with the care (i.e. mean score from 2.56 to 2.96). However, no respondents reported that they were very dissatisfied with these items, except for item 8 with 7 % very dissatisfied. Respondents are highly satisfied with community involvement in the care process.

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[3] The response categories are: 1. Very dissatisfied, 2.dissatisfied, 3. Undecided, 4. Satisfied, 5. Very satisfied.

[4] 4+5: includes the two highest response categories: very satisfied and satisfied, while 1 includes the highest response category.

[5] 1+2: includes two lowest response categories: very dissatisfied and dissatisfied

5.4. Dimensionality -factor analysis

To explore the dimensionality of 13 items we perform a factor analysis. Due to poor correlation with other variables we avoided two questions from analysis (2, 9). Multicollinearity is not a problem for these data because value of determinant is .042 which is higher than the necessary value of 0.00001. To sum up, 11 questions out of 13 correlate fairly well and none of the correlation coefficient are particularly large.

Table 5.2 Factor analysis of the FAMCARE items with factor loading

No	Items	F1	F2	F3	F4	F4	H2[6]
5	The way the family is included in treatment and care decisions	**0.856**					0.779
6	Community involvement	**0.747**					0.775
4	Coordination of care	**0.691**					0.831
7	Information given about how to manage the patient's pain		**0.889**				0.879
8	Information given about the patient's tests	0.453	**-0.64**				0.707
10	Availability of nurses to the family			**0.864**			0.835
11	Availability of the doctor to the patient			**-0.69**			0.595
12	Availability of medicine				**0.811**		0.781
13	Availability of non-medical care to the family				**0.643**		0.645
1	The patients pain relief					**0.814**	0.701
	Eigenvalue, initial	2.35	2.11	1.45	1.23	1.05	
	Eigenvalue, rotation	2.19	1.89	1.58	1.32	1.22	
	Variance explained	19.91	17.22	14.42	11.99	11.13	74.70

Source: Calculated from Field survey

The component matrix before rotation contains the loading of each variable onto each factor. All loadings less than .4 be suppressed in the output and so there are blank spaces for many of the loadings. At this stage we have five factors extracted. Both rotated and unrotated solutions show that variables are loaded in to five factors. The suppression of loading less than .4 and ordering variables by loading size also makes interpretation considerably easier.

The factor analysis provides five factors[7], F1, F2, F3, F4, F5, with Eigenvalues 2.19, 1.89, 1.58, 1.32, and 1.22 respectively. It is an indication of multidimensionality of

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[6] *H2: Communalities, the proportion of the variance in each item which is explained by the factors.*

[7] *F1,F2,F3,F4,F5: factor loading for rotated solution,F1- coordination of care,F2- general information,F3- availability of health professionals,F4- general care,F5- physical care*

11 items. These four factors together explain 74 percent of variation. The most reasonable interpretation of the factor analysis is that the FAMCARE items tap multidimensions. Since scale is multidimensional, patient and family members require multidimensional care to make them more satisfied.

The questions that load highly on factor 1 seem to all relate to participation of different kind of health caregivers. Therefore we might label this factor **Coordination of care**. The questions that load highly on factor 2 all seems to relate to information giving to the family members about the patient illness. Therefore we might label this factor **General information**. The questions that load highly on factor 3 all seems to relate to availability of doctors and nurses. Therefore we might label this factor **Availability of health professionals**. The questions that load highly on factor 4 contain medical and nonmedical help to the patient and family members. Therefore we might label this factor **General care**. Finally there is only one question loaded on factor 5 relate to the relief from pain. Therefore we might label it as **Physical care**.

The factor score for each respondent has been normalized to measure the degree of satisfaction. In the normalized score 0 denote low degree of satisfaction and 1 represent high degree of satisfaction. For the convenience of interpretation, normalized score can be divided in to five classes on the basis of degree of satisfaction. The normalized score between 0-0.2 indicate very low degree of satisfaction,0.2-0.4 indicate low degree of satisfaction, 0.4-0.6 indicate moderate degree of satisfaction,0.6-0.8 indicate high degree of satisfaction and finally,0.8-1 indicate very high degree of satisfaction.

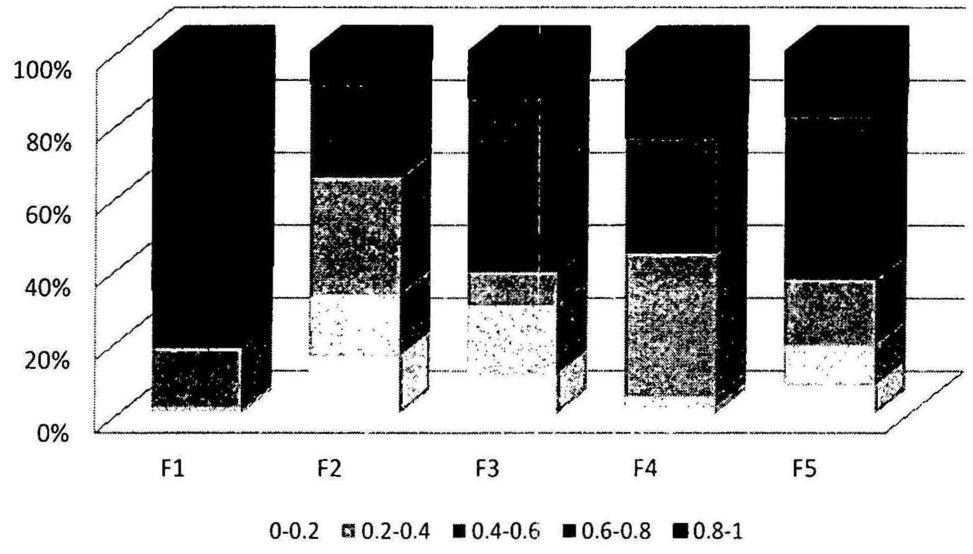
Table 5. 3 Normalized score of factor analysis coefficient (percentage of respondents)

Normalized score	F1	F2	F3	F4	F5
0-0.2	1	16	11	2	8
0.2-0.4	1	17	19	3	11
0.4-0.6	16	32	9	39	18
0.6-0.8	16	26	48	32	45
0.8-1	66	9	13	24	18
total	100	100	100	100	100
Mean score	0.8091	0.5233	0.5469	0.6554	0.6206
Standard deviation	0.191	0.2741	0.24421	0.1841	0.2274

Source: calculated from Field survey

It is obvious from the table 5.3 that the more number of respondents indicate very high degree of satisfaction in factor first (Coordination of Care) with mean score 0.8091 and standard deviation 0.191. 66 per cent of the respondents are very satisfied with the coordination of care. As far as second factor (General Information) is concerned, only 9 percentage of respondents are very satisfied, with mean score 0.5233 and standard deviation 0.2741.At the same time 33 per cent of respondents indicate less satisfaction in factor second. Major section of the respondents indicated either moderately or highly degree of satisfaction with the General information.

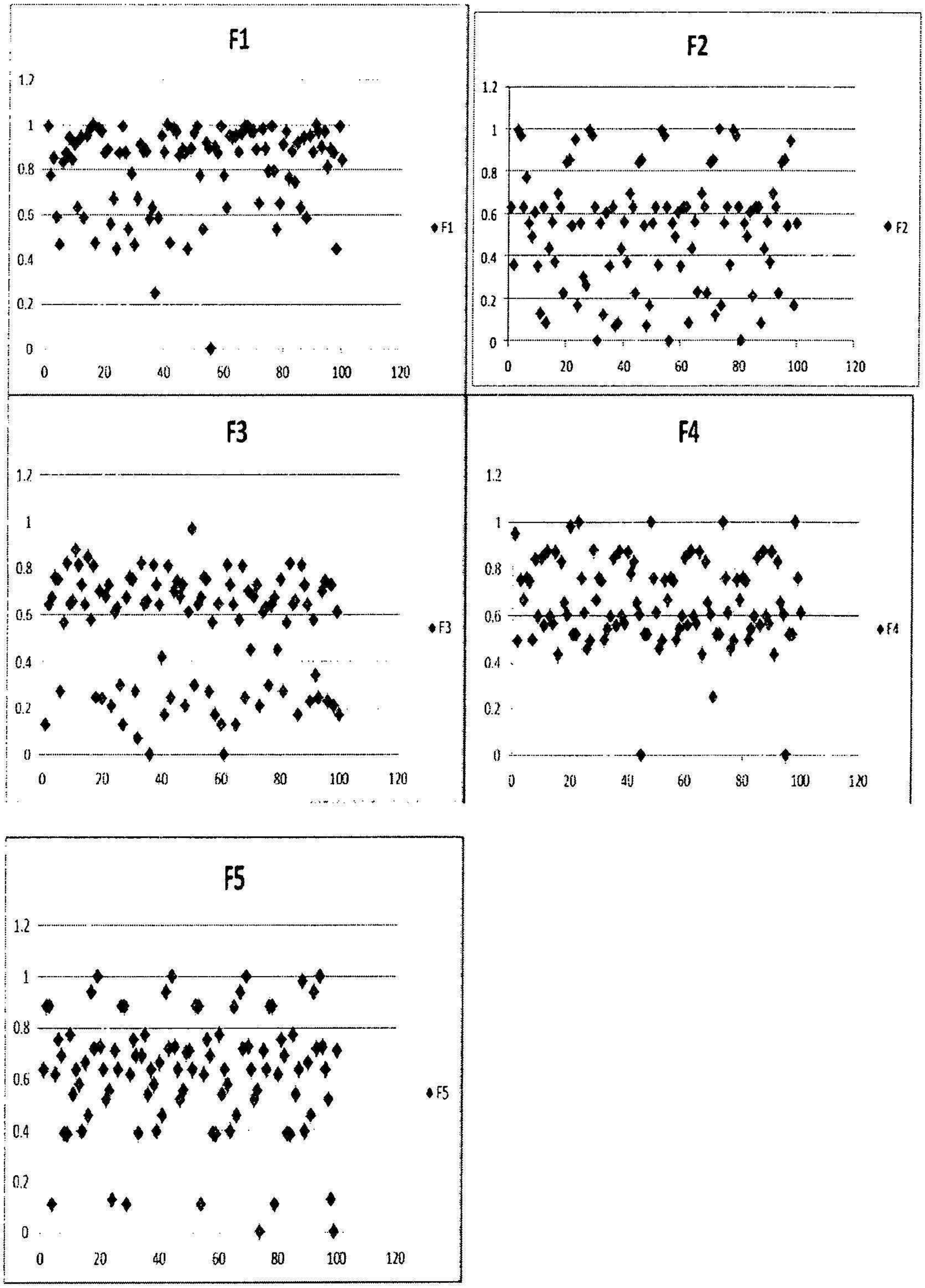
Figue 5.2 Number/Percentage of respondents for normalised score across factors



This kind of variation can be seen in factor three (Availability of health professionals) with mean score 0.5469 and standard deviation 0.244. 13 per cent of the respondents come in the normalized score class of 0.8-1 (very high satisfaction). 48 per cent of respondents are highly satisfied with the availability of health professionals. For factor four (General Care) most of the respondents are either very satisfied or moderate satisfied with mean score 0.6554 and standard deviation 0.1841. It is clear from the table 5.3 that for factor five (Physical Care) most of respondents indicate moderate degree of satisfaction. The diagram 5.2 clearly shows the number/Percentage of respondents for normalized score across each factor.

Scatter plot of normalized score of each factor has given in the figure 5.1.

Figure 5.1 scatter plot of normalized scores for each factor



Scatter plot of normalized score shows that some factors scattering widely especially factor F2, F3 and F5 indicates that for these factor individual indication of satisfaction varies depending on some other factors. However, F1 and F4 most of the points concentrate on one place indicate same level of satisfaction

5.4 Conclusion

We found that the respondents reported highest level of satisfaction with the following items: 'the way the family is included in treatment and care decisions', 'Community involvement', 'Information given about how to manage the patient's pain', 'Coordination of the care', 'Availability of medicine' and 'Availability of nurses to the family'.The number o f respondents is dissatisfied with the care components was low for most of the items. In our study, only 7% of the respondents reported to be 'very dissatisfied' with 'Information given about the patient's tests'. Furthermore we found that the items on 'Availability of hospital bed to the patient", 'Doctor's attention to patient's description of symptoms', and "Availability of the doctor to the patient', indicated the lowest satisfaction with care. The study finds that respondents are highly satisfied with the coordination of care with the community participation. However, the components related to the infrastructure facilities of the institutions like availability of hospital bed and doctor indicates less satisfaction.

Factor analysis provides five factors indicate multidimensionality of FAMCARE items. Factor analysis result shows that respondents are highly satisfied with two factors i.e. Coordination of care and General care. The study finds that except for factors F1 and F2, individual factor scores (normalised) have widely scattered reveals variability in indication of satisfaction by the respondents for different components of FAMCARE.

Chapter VI
Summary and Policy Suggestions

6.1 Introduction

Population ageing has emerged as the grand challenge of this century; for policymakers, care providers and society as a whole. As age advances, numerous physical and psychological changes in life style assume significance among the elderly. Furthermore, the situation is made worse by the fact that such health problems lead to major disabilities and restricts their movements, which makes their life miserable. Studies have shown that elderly people in India suffer a double-whammy effect; the combined burden of both infectious chronic and lifestyle related diseases.

In addition, high prevalence of cancer, AIDS, heart attack and accident among younger age groups create doubt about the quality of life of the people. Literatures note that Kerala is one of the states with high health risk factors and rapid epidemiological and demographic transition. In this context, giving good quality of care to the terminally and chronically ill person is a major challenge before policy makers and society as a whole. The revolution of Community Based Palliative care in Northern Kerala has attained much attention from both developed and developing countries mainly because of successful experience of the programme in a resource poor environment. However, literatures related to Community Based Palliative care in Northern Kerala show that quality and sustainability of the programme in the long run are the key issues. In this context, the present study analyzed the quality and sustainability of the programme in terms of structure, process and outcome.

6.2 Summary

In the second chapter, we have analyzed the importance of community based health care in Kerala in the context of aging, morbidity and disability, high health risk factors, catastrophe health expenditure and low level of public spending by using various NSSO round data and other available secondary data. It has been found that Kerala is a state with highest proportion of elderly population as compared to other states of India. The number of elder people in Kerala has been increasing and likely to reach 36.9 per cent of the total population in 2061.

Aging has multiple impact on a state like Kerala where large scale migration (both internal and external migration) happening, low public spending on health care services, reduction in family size etc are the key issues. Due to low fertility and higher life expectancy, young age dependency ratio is coming down while that of old age group is rising rapidly. NSSO 60th round survey on 'Morbidity, Health Care and Condition of Aged' brought out that around 75 percent, highest among Indian states, of elderly people in Kerala is economically dependent on others for meeting their basic needs. Elder section of the people is one of vulnerable sections of the population because of high prevalence of chronic diseases and disability among them. The reported prevalence of illness is substantially higher for the elderly population compared to non elderly population as per NSSO 60th round survey.

The study revealed that Kerala has entered into the fourth stage of the epidemiological transition with rising tendency of life style related diseases. Diarrhea, tuberculosis, asthma, fever of unknown origin, accident, heart diseases are the major hospitalized cases in Kerala. Both NSSO study (2006) and Aging Survey (2005) shows that hypertension, diabetes, heart diseases are the major chronic diseases among the aged people. In Northern Kerala the share of Diarrhea, fever of unknown origin, hypertension and cancer in the total hospitalized cases are very high as compared to Southern Kerala. The study also noted that the occurrence of cancer and other tumors are high in Northern Kerala as compared to Southern Kerala. More importantly, the prevalence of cancer diseases in Kerala has been increasing over the years. Since cancer is not an age specific disease, health requirements of all age groups are important. Moreover, the NSSO Survey shows that accident cases, high among younger age groups, are another major hospitalization case in Kerala. The study observed that the rate of hospitalization is very high in Kerala as compared to other states of India. That could be due to high intensity of morbidity in the state.

The study brought out that Kerala people have been experiencing severe health expenditure. Kerala is the state where people devote major share of their income for the consumption of medicine and most expensive state in terms of both inpatient and non inpatient health care services in the country. The total per capita hospitalization cost is highest for Kerala as compared to other states of India. In Kerala the per capita hospitalization cost is RS.509, on the other hand the all India average hospitalization cost is RS. 187. Further the study revealed that the per capita hospitalization cost for elderly is around four times higher than that of the non elderly. The problem of catastrophic health expenditure needs attention because of slow withdrawal of government from health sector investment. In Kerala the Government health expenditure as a percentage of GSDP in 1995-96 is 1.31 which is decreased to 1.17 in 2004-05. The slow withdrawal of government from the health sector would adversely affect the poor peoples' accessibility of health care.

Kerala's sound health indicators are attractable to all policy makers. However, the quality of life of the people is doubtful in the context of high prevalence of diseases and existence of high health risk factors in the state. As far as poor family is concerned the higher cost of medical expenditure is unbearable. In Kerala, there are large numbers of social security schemes and medical insurance exists, however, the amount is not sufficient to meet the catastrophic health expenditure. Government hospitals have a limit to give total care and continuous care to chronically and terminally ill person. It is the responsibility of both government and society to give better quality of life to this people.In this context a mechanism in the form of social organization to save poor from the hand of horrible health expenditure is necessary one. The experience of palliative care services in Kerala has been showing that this is the feasible mechanism to ensure better quality of life to the chronically ill patients.

The third Chapter discussed the Evolution, Structure, Process and Persistent Challenges of Community Based Palliative Care of Northern Kerala based on primary survey conducted in 40 palliative care institutions in three Northern districts of Kerala. The study found that local community such as Non-governmental organisations (NGO), religious organisations and other social organisations have played key role in the development and determination of palliative care service in Northern Kerala. The basic motive behind the emergence of community based palliative care in Northern Kerala is to ensure better quality of life to the chronically and terminally ill patients. In the initial stage development its services were limited to specific diseases like cancer. However, later caregivers have extended the coverage to other diseases like AIDS, asthma, tuberculosis, heart disease, accidental cases etc. Economic condition of the patients, the nature of disease and age are the significant criteria use to select patients. Outpatient treatment with a supportive home care service was adopted as the main mode of operation.

The study noted that infrastructure facilities in most of the institutions are very weak. Basic infrastructure facilities like beds, building, ambulance, etc are not sufficient to give better care to the patients. The infrastructure facilities are very weak in Wayanad as compared to other two districts. The study brought out that 62.5 per cent of the sample institutions do not have all essential drugs in their institutions reveal poor availability of drugs. The level of integration of palliative care with the other health sector is in the initial stage of development. The study found that 40 per cent of the institutions are not integrated with any of the hospitals and primary health centres. The level of integration is very poor in Wayanad as compare to other two districts.

Donations from the public are the key source of revenue to the community based palliative care. Around 80 per cent of money comes from public in the form of donations from various sections of people. However, all sample institutions have been experiencing financial shortage in the path of its development. Moreover, grants from local self government are not sufficient to meet its expense. In this context the financial sustainability of the programme in the long run is an emerging issue.

It has been observed that all the sample institutions provide medical and non medical care to the patients and their family. However, lack of fund and poor infrastructure facilities prevent them to give continuous nonmedical care to the patients. It is apparent from the study that lack of fund and poor infrastructure facilities are severe in Wayanad as compared to other two districts.

As far as supply side is concerned palliative care institutions in Northern Kerala do have lot of constraints in its structure and process. One positive factor is that large scale community participation in the process of care. However, 95 per cent of sample institutions are not certain with the sustainability of palliative care system because of challenges standing ahead. The study brought out that major challenges of community based palliative clinics in Northern Kerala are financial sustainability in the long run, low integration with other health sectors, lack of infrastructure facilities, quality of care etc.

The fourth Chapter analyzed the socio economic profile of the palliative care patients on the basis of sample survey conducted in Wayanad district where palliative care institutions functioning under severe organizational constraints. 100 home based patients were selected randomly from the three institutions. Detailed examination of the survey data revealed that palliative care patients are one of the vulnerable sections in our society. Most of the patients are affected by the chronic disease like cancer AIDS,etc. Most of them are socially and economically deprived section and depend upon family members to meet their basic needs. It has been shown that most of the sample patients are aged and illiterate which makes them more helpless population. The occupational status of most of the sample population was low in the sense that they were engaged in traditional activities which are not high income generating activities. It has been observed from the sample survey that 88 per cent of the palliative care patients seek care at the latest stage of their diseases. The reason for the latest admission is lack of better medical facilities in palliative care institutions. There is no gender disparity in selection and provision of palliative care.

It has been observed that all sample populations are the victims of catastrophic medical expenditure. 47 per cent of the study populations have been experienced medical expenditure between RS 50000 to 1 lakh and 44 per cent of population have been incurred medical expenditure between RS.1 lakh to 3 lakh. And 4 per cent of the sample patients have been incurred expenditure between RS 3 lakh to 5 lakh. Most of the people were not able to pay high health care expenditure charged by private institutions. The study also noted that 77 per cent sample patients have experienced depletion of assets in order to meet the medical expenditure and 53 per cent of patients were borrowed money from various sources to meet their medical and nonmedical needs.

All sample patients have been getting medical care from the palliative care institutions. However, 47 per cent of the respondents are not fully dissatisfied with the available medical care in the palliative care institutions. The reasons for the dissatisfaction are the nonavailability of costly medicine and high tech treatment in the institution.The study brought out that Patients' diseases are not criteria for giving nonmedical care. However, factors such as age, occupation, category and number of earning members in the family are significant in getting non-medical care.

The socioeconomic profile the patients reveal that the needs and requirements of patients are multiple. However, palliative care institutions are not able to satisfy all needs of the patients due to weaknesses in structure and process of palliative care programme.

Chapter five measured the satisfaction of family membrs with the palliative care by FAMCARE Scale.We found that the respondents reported highest level of satisfaction with the following items: 'the way the family is included in treatment and care decisions', 'Community involvement', 'Information given about how to manage the patient's pain', 'Coordination of the care', 'Availability of medicine' and 'Availability of nurses to the family'.The number of respondents dissatisfied with the care components was low for most of the items. In our study, only 7% of the respondents reported to be 'very dissatisfied' with 'Information given about the patient's tests'. Furthermore we found that the items on 'Availability of hospital bed to the patient", 'Doctor's attention to patient's description of symptoms', and "Availability of the doctor to the patient', indicated the lowest satisfaction with care. The study found that respondents are highly satisfied with the coordination of care with the community participation. However, the components related to the infrastructure facilities of the institutions such as availability of hospital bed and doctor indicates less satisfaction.

Factor analysis result brought out that respondents are highly satisfied with two factors i.e. coordination of care and general care. It has been observed that except for factors F1 (Coordination of care) and F4 (General care) individual factor scores (normalised) have widely scattered reveals variability in indication of satisfaction by the respondents for different components of FAMCARE.

The study found that quality and sustainability of community based palliative in Northern Kerala is a major challenge before the policy makers and care givers. The process and activities of community based palliative care in Northern Kerala are constraint by structural weakness. Resources from community alone is not sufficient to break the constraints, an effort from government is required. Palliative care policy of Kerala in 2008 is the first step to boost the revolution of palliative care movement which has incorporated lot of components to solve the weakness of palliative care institutions in Kerala. However, the success of policy is depends upon the proper implementation without delay. The study also noted that implementation of palliative care policy is in the rudimentary stage in the state.

6.3 Policy suggestions

- A concrete mechanism should be created to provide essential medicine to palliative care patients through palliative care units / Primary Health Centres/other government hospitals.
- Advanced palliative training centre should be established in each district for advanced training and nursing.
- Infrastructure facilities both basic and modern facilities must be improved to give good quality of care to the people.
- Palliative care units should start in every hospitals of the state with advanced technology.

- An institutional mechanism should be implemented by government to ensure sufficient source of revenue to the palliative care institutions.
- Government or public can increase the awareness among the people about the palliative care services and issues through various Medias.
- Social security schemes and insurance should be established for palliative care patients separately.
- Improve the accessibility of palliative care to all needy population.
- Enhance the integration of palliative care services into broader health plans and/or improve integration between different services
- Establish/improve monitoring and evaluation of outcome of the care like satisfaction of family and patient
- Develop or conduct research on palliative care to identify the ongoing issues

BIBLIOGRAPHY

Arun,B and Varatharajan,D(2005). *Appraising Government Health Care Expenditure in Kerala Using NHA Framework.* Paper presented at Forum 9, india on 12-16 september.

Ashokan(2009).*Acute Morbodity in Rural Kerala:Levels,Differentials and Determinants*:An article published in edited book entitled perspective of Health Economics,pp.96-107

Ashokan(2009).*Health Care Sector in Kerala: Some issues and Policy Options* : An article published in edited book entitled perspective of Health Economics,pp.148-166

Axelsson, B and Sjöden, P(1999).*Assessment of Quality of Life in Palliative Care (Psychometric properties of a short questionnaire)*:*Acta Oncol*, 38(2),pp.229-23

Behmann,M. LückmannS,L and Schneide,N(2009). Palliative care in Germany from a public health perspective:qualitative expert interviews:*BMC Research Notes* 2009, 2:116,PP.1-6

Bernard.Quill,T and Tulsky, J.(1999).*Discussing Palliative Care with Patients*: Annals of Internal Medicine ,Volume 130, Number 9,PP.745-749.

Billings, J(2000). *Recent Advances: Palliative Care*: British Medical Journal, Vol. 321, No. 7260 , pp. 555-558

Bollini,P.,Venkateswaran,c.,and Suresh Kumar,K(2004).*Palliative Care in Kerala ,India: Model for Resource Poor Setting*,onkologie,Volume.27,No.2, PP.138-142

Boulghourjian,C(1997). *Psychosocial,Health,and Economic Aspects of an Elderly* Armenian population in lebanon: American university of Beirut,Lebanon.

Brunner,Eric(1999).*when Does Cardiovascular Risk Start? Past and Present Socioeconomic Circumstances and Risk Factors in Adulthood,*Journal of Epidemiology and community health,Vol.53

Cella D, Tulsky D(1990).*Measuring Quality of Life Today:* Methodological Aspects:*Oncology* , 4,pp.29-38.

Cleary, P.D and McNeil(1988). *Patient Satisfaction as an Indicator of Quality Care. Inquiry*: 25:25-36

Dilip,T.R(2002).*Undeerstanding Levels of Morbidity and Hospitalisation in Kerala,india,*bulletin world health organisation,vol.80,No.9,PP.746-751

Dilip,T.R(2009).*Inpatient Treatmet from Private Hospitals in Kerala: Equity Implications Based on Trends in Out Pocket Expenditure*: An article published in edited book entitled perspective of Health Economics,pp. 136-147.

ERF (2006). *Government Health Expenditure in India: A Benchmark Study:* MacArthur Foundation, India

George,Asish Thomas(2006).*Catastrophic Health Expenditure and Impoverishment in Kerala: An Analysis Based on NSSO 55th round,*1999-2000,thesis of Mphil 2003-05,centre for development studies,Trivandrum

GoI(2004). *Report of the Twelfth Finance Commission*: Ministry of Finance,Government of India.

Government of Kerala (2008).*Palliative care policy of Kerala,*report,pp.1-33

Government of Kerala (2009) *Economic review2008,* State Planning Board,thiruvanathapuram,Government of Kerala

Hearn,J and Higginson,J(1997). *Outcome Measures in Palliative Care for Advanced Cancer Patients: A Review*:Journal of Public Health Medicine Vol. 19, No. 2, pp. 193-199

Higginson IJ, Bruera E(2002). *Do we need palliative care audit in developing countries?* :Palliat Med,16:546–7

Higginson,I and Wade,A and McCarthy(1990). *Palliative Care: Views of Patients and Their Families*:BMJ, Volume 301,PP.277-281

Hockley,J and Clark,D(2002*).Palliative care for older people in care homes*:Edited book,open universitypress,Philadelphia

Ian, R M. Martin, J B. Allan D(1994). *Evaluation Of A Palliative Care Service: Problems And Pitfalls*: BMJ: British Medical Journal, Vol. 309, No. 6965, pp. 1340-1342.

IAPC (2007).*Guidelines for Home Based Palliative Care Services:* Developed under the government of India-world health organisation collaborative programme (2006-2007),pp.1-40

Irudaya Rajan ,S and K C Zacharia(2008).Long Term Implication of Low Fertility in Keral:.Asia Pacific Population ,Journal,volume.13,No.4,pp..41-66

Irudaya Rajan,and Sabu Aliyar(2004),*Gender,Aging and Social Security:* Journal of women studies,volume.IV,No.2

Jagwe, J and Merriman ,A(2007).*Palliative Medicine, an Urgent Public Health Need in the Developing World.*:J Public Health Pol.;28(1):40–1.

Jayaram,R and Ramakrishnan,N(2008).*Cost of Intensive Care*:Indian Journal of Critical Care Medicine,volume.12,issue 2,pp.55-61

Jeucken,P(1994). *Health Transition in Kerala: Searching for the Cultural,Social and Behavioural Determinant of Health*: vrije universiteit,Amsterdam

Joseph,N.,Jayarama,S and Kotian,S(2009). *A comparative Study to Assess the Awareness of Palliative Care Between Urban and Rural Aareas of Ernakulum Districts,Kerala,India*: Indian Journal of Palliative Care, volume 15, issue 2.pp.112-126

Kabir,M and Krishnan,T.N(1996).*Social Intermediation and Health Changes:Lessons from Kerala*,in Monica Dasgupta(eds) Health,Poverty and Development IN india,Oxford University Press,New Delhi.

Kenneth, A. Candice, B,.Roberta, A, Baugher,R. (1988). *Comparing the Quality of Death for Hospice and Non-Hospice Cancer Patients* :Medical Care, Vol. 26, No. 2, pp. 177-182

Kim,A.Fall,P.Wang, D(2005). *Palliative Care:Optimizing Quality of Life*:JAOA,Supplement 5 • Vol 105 • No 11

Koshy,C.(2009).*The Palliative Care Movements in India: Another Freedom Struggle or a Silent Revolution?*: Indian Journal of Palliative Care, volume 15, issue 1.pp.10-13

Kramer,M . Shaughnessy, P.Bauman, M.Kathryn and Crisler(1990). *Assessing and Assuring the Quality of Home Health Care: A Conceptual Framework*,The Milbank Quarterly, Vol. 68, No. 3 , pp. 413-443

Krishnan,M(2002).*Access to Health and Burden of Treatment in India: An Interstate Comparison in Mohan Rao(ed) Disinvestment in Health*: the world bank's prescriptions for health,sage,new delhi,PP.208-232

Krishnan,T.N(2000). *Acccess to Health Care andB of Treatment in India:An Interstate Comparison,i*n Rao(eds) investing in Health: New Delhi,Sage publication,pp.212-230

Kumar S, Rajagopal ,MR(1996). *Palliative Care in Kerala: Problems at Presentation in 440 Patients with Advanced Cancer in a South Indian State*: Palliat Med, Volume.10,PP.293–8.

Kumar,p.(2008).*Showing the Way Forward :Pain and Palliative Care Policy of the Government of Kerala:* Indian Journal of Palliative Care, volume 14, issue 1.pp.51-54

Kumar,S and Numpeli.(2005).*Neighbourhood Network in Palliative Care*: Indian Journal of Palliative Care, volume 11, issue 1.pp.8-9

Kutty,R and Panikar,PGK(1995).*Impact of Fiscal Crisis on the Public Sector Health Care System in Kerala:* A research report ,achutaha menon centre for health science studies, sree chitra tirunal institute for medical sciences and technology,Trivandrum.

Leela,Gulati and S,Irudaya Rajan(ends)2003.*An Aging India:Perspectives,Prospects,and Policies.*the Haworth press Inc,new deli,united states

Mor V(1987). *Hospice Care Systems: Structure, Process, Costs, and Outcome*: Springer, New York.

National Sample Survey Organisation (2006). *Morbidity,health care and the condition of the aged,*National Sample Survey:Report.No.507Ministry of Statistics and Programme Implementation,Government of India

Navaneetham,K(2005).*Demographic Transition,Economic Growth and Human Development in Kerala,*Background paper prepared for the kerala human development report,centre for development studies,Trivandrum

NSSO(2003).*Disability Person in India*:NSS 58th round 2002, Ministry of Statistics and Programme Implementation,Government of India, Report No. 485 (58/26/1)

Paleri,A and Numpeli,M.(2005).*The Evolution of Palliative Care Programmes in North Kerala*:Indian Journal of Palliative Care,volume 11, issue 1.pp.15-80

Pamela, H. Mitchell and Norma, M. Lang(2004*). Framing the Problem of Measuring and Improving Healthcare Quality: Has the Quality Health Outcomes Model Been Useful?* : Medical Care, Vol. 42, No. 2, pp. II4-II11

Panikar,K and Soman,CR(1984). *Health Status of Kerala- The Paradox of Economic Backwardness and Health Development*:centre for development studies ,Trivandrum.

Panikar,P.G.K(1999).*Health Transition in Kerala*,Discussion paper ,No.10,KRPLLD,centre for development studies,Trivandrum

Plessen,C V and Aslaksen,A(2005). *Improving the Quality Of Palliative Care For Ambulatory Patients With Lung Cancer*: British Medical Journal, Vol. 330, No. 7503 , pp. 1309-1313.

Raghavan,B. Gayatri and Rajagopal,M.R(2005).*Are Our Patients Getting Palliative Care too late? An Audit*: Indian Journal of palliative care, volume 11, issue 2.pp.108-110

Rajagopal, M. R. and Palat,G (2002). *Kerala, India: Status of Cancer Pain Relief and Palliative Care:* Journal of Pain and Symptom Management Vol. 24 No. 2,PP.191-193

Rajagopal, MR (2001).*Medical use, misuse, and diversion of opioids in India*: Lancet, 358(9276), pp.139–43

Rajagopal, MR and Venkateswaran, C(2003). *Palliative Care in India: Successes and Limitations*:J Pain Palliat Care Pharmacother,17(3–4):121–8,

Rao and Choudhary(2008).*Interstate equalisation of health expenditures in Indian union* :National Institute of Public Finance and Policy, New Delhi

Rhodes, V and McDaniel,W(2001*). Nausea, Vomiting, and Retching:Complex Problems in Palliative Care*:CA Cancer J Clin ,51:PP.232-248

Rinke, L (1987). *Outcome Measures in Home Care*: Research. New York: National League for Nursing, Vol. 1.

Rinke,T and Wilson,A(1986). *Outcome Criteria: Public Health Nursing and Home Care Services. In Outcome Measures in Home Care*: Minnesota Department of Health, New York, Vol. 2.

Sallnow,L and C,shabeer (2005). *The Role of Religious, Social and Political Groups in Palliative Care in Northern Kerala*: Indian Journal of Palliative Care, volume 11, issue 1.pp.10-14

Schipper,H. Clinch, J. and McMurray, A(1984). *Measuring the Quality of Life of Cancer Patients: The Functional Living Index?Cancer*. Development and validation. J Clin Oncol,2:472-83.

Selman,L and Harding,R(2010). *How can we improve outcomes for patients and families under palliative care? Implementing clinical Audit for quality improvement in resource limited settings*,volume.16,issue.1,pp.8-15

Sepúlveda,C. Marlin,A and Yoshida,T(2002). *Palliative Care: The World Health Organization's Global Perspective:* Journal of Pain and Symptom Management,Vol. 24 No. 2 ,PP.92-96

Singh,D,P(2010).Quality of Life in Cancer Patients Receiving Palliative Care: Indian Journal of Palliative Care,vol. 16,issue-1,pp.36-43

Stanfill E P, Harvey ,C and Gilden KM(2008).*Developing and Financing a Palliative Care Program*:American Journal of Hospice & Palliative Medicine,Vol. 25, No. 5, PP.379-384

Stjernsward,J(2005).*Community Participation in Palliative Care*: Indian Journal of Palliative Care,volume 11, issue 2.pp.111-117

Stjernsward,J(2007). *Palliative Care: The Public Health Strategy*: J Public Health Pol. 28(1):PP.42–55.

Thomas,S, Mathew,A and Dass,p(2007).*Community Based Palliative Care Initiative*:Paper published at edited book of centre for development studies of Kerala's demographic future,Trivandrum,pp.300-315

Varatharajan(1998).*Provision of Health Care by Government*:Indian journal of medical ethics,volume.2,No.4pp.601-617

Venkateswaran,C and Kumar,T(2006). *Psycho-oncology in India: Emerging trends from kerala:* Indian Journal of Palliative Care, volume 12, issue 1.pp.34-38

Vohra,U(1999).*Family Planning Success Based on Equity: Human Development,Health and Governance in the Indian state of Kerala,*Health for the Millions,vol.25,No.2,pp.40-42

Walker,A.e. and Becker,N.G(2005).*Health Inequalities Across Socioeconomic Groups:Comparing Area Based and Individual based iIndicators,*public health ,VOL.199

Webster ,R and Lacey,J(2007). *Palliative Care: A Public Health Priority in Developing Countries*: Journal of Public Health Policy ,volume. 28, pp.28–39

WHO (1990). *Cancer Pain Relief and Palliative Care:* Report of a WHO Expert Committee: Technical Report, Series No. 804), Geneva

WHO (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines,* 2nd ed. Geneva: World Health Organization

World Health Organization(1990*). Cancer Pain Relief and Palliative Care: A Report of a WHOExpert Committee:World Health Organ Tech Rep Ser.,*804,PP.1–75.

Zacharia,Kc and Irudaya Rajan(2004).*Kerala's Demographic Transition:Determinant and Consequences*: sage publications,New Delhi.

Appendix 3.1

Centre for Development Studies

Mphil programme in Applied economics, 2009-11
Questionnaire for field survey

Palliative care in Kerala: Institutional survey

Date of survey :
Name of interviewer :

A. History and agents

1. Name of the institution :

2. When it was started :

3. Who owns this institution :

1.Govt	2.Religious organization	3.NGO	4. Christian organization	5.Charitable organization	6. others

4. Who taken the initiatives to start the institution:

1.Govt	2.Religious organizations	3.NGO	4. Community

5. Reasons for the emergence of palliative care in this region:

A:
B:
C:
D:

6. What are the other institution and organization and social group have significant role in this palliative care institution:

1	Political parties
	Student organizations
	Kudumbasree
	Govt employees organization
	clubs

B. Capacity

7. What is the maximum capacity to take
Patient at your institution :

8. This institution is meant for :

1.Chronically ill patients	2.Terminally ill patients	3.Old people	4.(1+2+3)

9. Number of patients (present)

Out patients	Inpatients	Home based patients	Total

10. Infrastructure availability

No. of bed	Ambulance	Medical stores	Building

11. Man power in the institution

1.Doctors	2.Nurse	3.volunteers	4.Other workers	5.total

12. Have you providing salaries to the all
Workers in this institution :

13. If no, who are and how many paid workers :

14. Are you satisfied with the present level
of infrastructure facilities? :

15.If not why :

C. Integration with health sector

16. Have any of the following hospital / health sector component integrated with your institution

1.Govt hospitals	2.Private hospitals	3.primary health centre	4.medical collage

17. If yes, in what sense
it is integrated :

a) Supply of medicine
b) Supply of medical staff
c) Transferring technology
d) For basic amenities like bed, ambulance
e) others, specify

18. Are you getting any medical Facilities in nearest
Government Hospital to treat patient :

19. Do you believe that present level of
Integration of the institution with other health
Sector is sufficient :

20. If no, what would be
your suggestions :

A:
B:

D. Identification of patient and care

21. How you identifying the patients those who need care

1.through volunteers	2. through media	3. through hospital	4. patient's direct contact	5. others

22. Have you following any criteria for
selection of patients :

23. If yes, what are the Criterias for selection of patients?

1.Economic background	2.Social	3.Disease	4.Age	5.Accessibility of health care

D.Medical and non medical care

24. What kind of care you are giving to the patient? :

1. Medical	2. Non- medical

25. What are the non medical help?

1	Financial support	
2	Rehabilitation support	
3	Food and clothing	
4	Psychological support	
5	Children's education	
6.	Job training	

26. Are you bearing all kind of medical costs? :

27.Are you charging any fee from the patients? :

28.Are you facing any challenges in meeting the
non medical needs of the patients and their family :

28.If yes what are they :
A:
B:
C:

29. Have you providing any help to the
family after patient's death :

E.Community participation

30. Community comprises

1.Local people	2.volunteers	3.Students and other social organizations	4. Political parties	5.Religious group	6. All

31.How community involve in this process

1.	Revenue mobilization
2	Identification of patient
3	Medical care to the patient
4	Organizing the activities
5	Decision making
6	Others ,specify

32. Are the current level of Community participation
is sufficient for long run sustainability :

33.If no, why :

F. Financial aspect

34.How do you mobilizing the money for its expenses

1.Donations	2.Grants	3.Its own revenue sources	4.External sources	5.others

35.what is the main source of revenue to the institution

1.Donation from public	2.Grants

36. Are you getting any financial help from the local self govt? :

37. Are you getting any financial help from NRHM or any other govt health shemes :

38.On an average how much percentage of money collecting money from public :

39.Is the current level of financial status is Sufficient to maintain the sustainability of the institution :

40:If no, suggestions :

G. Palliative care policy and role of govt

41. Have you know about the palliative care policy of govt :

42. What is opinion about that? :

H. Future

43. Are you satisfied with the present level of govt support :

44. If no what should be the govt role :

45. Is financial viability an emerging issue :

46. What are the main challenges in the future? :

Appendix 4.1

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Questionnaire for field survey

Socio-economic and health condition of palliative care patients

Patient's level survey

Name interviewer :
Date of interview :

1.House hold Profile

Sl No:	Name	Relationship to patients	Age	Gender	Religion	Category	Marital status	Education	Occupation
			1	2	3	4	5	6	7
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									

Note:

***Age:** (1) <5, (2) 5-9, (3) 10-14, (4) 15-19 (5) 20-24 (6) 25-29 (7) 30-34 (8) 35- 39 (9) 40-44 (10) 45-49 (11) 50-54 (12) 55-59(13) 60-64 (14) 65-69, (15) 70 and above. **Gender**: 0- Male; 1- Female. **Religion:** 1- hinhu,2 Christian ,3 muslim,4-other. **Category**: 1- OBC,2-SC,3-ST, 4-General.**Marital status**: (1) Married (2) Single (3) Widowed (4) divorced (5) Others. **Education:** (1) Primary (2) Secondary (3) Higher secondary (4) Graduation (5) P.G. (6) Illiterate. **Occupation classification**: (1) Wage labour (2) Agriculturist including farm and plantation, own cultivator (4) livestock rearing (5) collection of forest produce (6) HH works, Employed in govt. service (8) employed in private (9) student.*

2. Patient details

1.House hold nature	
2.Disease	
3.Patients category	
4.When disease started (years)	
5.Palliative care has been getting since	

Note:

Household:** head of household-1, 2- others. **Diseases**: cancer-1, tuberculosis-2, asthma-3, AIDS-4, heart diseases-5, accidental case-6,any disability-7,others. **Patient's category**: inpaient-1, out patient-2, home based patients- 4.**when started:** 1 year-1, 2 to 4 year-2, 4 to 6 year-3, 6 to 10 year-4, more than 10 year-5 **Palliative care getting

since: *Less than 10 days-1, one month-2, 2 to 4 month-3, 4 to 8 month-4, 1year-5, 2 year-6, 2 to 4 year-7, more than 5 years-8* **2.**

3.Asset position of Household

Sl No:	Name of the asset	1.Yes/No	2.Ifyes,amount/quantity/characteristics
1	Land		
2	House		
3	Saving		
4	Own toilet facility		
5	Drinking water		
6	Electricity		
7	Income (annual)		

Note

*yes-1;no-0,**Land:** 1-< 25 cent,2- 25-50,3- 50-1 acre,4- 1 acre to 2 acre,5-above 2 acre, **House:** 1-pucca,2-semi pucca,3-kacha,**Savings:** 1- less than 1000,2-1000-5000,3-5000-15000,4-15000-50000,5-1 above 50000,**Drinking water:** 1-well,2- running water ,3-public/community tap . **Income:** less than 5000-1, between 5000 and 10000-2, 10000 to 20000-3, 20000 to 40000-4, 40000 to 70000- 5, 70000 to 1 lakh-6, 1 lakh to 1.5 lack-7, more than 1.5 lack-8*

4. Medical expenditure

SI.No			A: previous treatment details	B: In palliative care institution
1	Place of treatment			
2	Expenditure (total)			
3	Monthly expenditure	Medical		
		Non medical		
4	Expense met by			
5	Have you sold any asset/property to meet medical expenditure			
6	If yes, its worth			
7	Did you borrow money from any sources to meet expenditure			
8	If yes, how much			

Note

Place of treatment: *1-public hospital,2- private hospital,3 -both.* ***Expenditure:*** *1- less than 10000,2-10000 to 50000,3- 50000 to 1 lakh,4-1 lack to 3 lakh,5-3 lack to 5 lakh,6- more than 5 lakh.* ***Monthly expe:*** *1- less than 100.2- 100 to 500, 3- 500 to 1000,4-1000 to 2500,5 -2500 to 5000,6- 5000 to 10000,7- more than 10000.**Expense met by** : 1- own pocket,2- welfare fund, 3-govt, 4- palliative care institution,5- both own pocket and palliative care institution,6-others,**Asset depletion:** 1- land,2- live stock,3-vehicle,4-others,5 -none.* ***Worth of asset:****.1- less than 10000,2- 10000 to 50000,3- 50000 to 1 lakh,4-1 lack to 3 lakh, 5-3 lack to 5 lakh,6- more than 5 lakh.* ***Borrowing:****1-no,2-banks,3 money lenders,4-social orgnisation,4- others.**How much borrowed** .1- less than 10000,2- 10000 to 50000,3-50000 to 1 lakh,4-1 lack to 3 lakh, 5-3 lack to 5 lakh,6- more than 5 lakh*

5. Membership in welfare fund and medical insurance

Particulars	Welfare fund	Medical insurance
1.Membership in welfare fund /MI		
2.Name of the welfare fund /MI		
3.Duration of membership/insurance coverage		
4. Monthly contribution/premium		
5.have you received any medical benefit from fund/scheme		
6. if yes ,how much amount received		
7.Do you have believes that amount that received are sufficient		
8.If no why		
9. Whether you are become a member of comprehensive health insurance programme of government (2008)		
10. If yeas how much financial amount got from the scheme.		

Note:

1-yes ,2-no. **Duration of membership**:*1- less than one year, 2- 1 to 3 year, 3- 3 to 5 years,4- 5 to 10 years, 5- more than 10 year.* **Have you received any medical benefit from fund/scheme**. *1-yes,2-no*
How much: *1- less than 1000,2-1000 to 5000,3-5000 to 10000,4- 10000 to 25000,5- 25000 to 50000,6- more than 50000.**Sufficient(7):*** *1-yes,2-no.* ***8. if not why:*** *1- insufficient to meet expenditure,2- delay in getting the amount,3-1 and 2,4- other.* ***9 (CHIP).*** *1-yes,2-no.* ***10. How much:*** *1- less than 1000,2-1000 to 5000,3-5000 to 10000,4- 10000* to 25000,5- 25000 to 50000, 6- more than 50000

6. Care in the palliative care

Particulars	
1.Reason for seeking palliative care	
2.how did you know about palliative care	
3.Timing of referral to palliative care	
4.If admitted in advanced stage reason for delay	
5.what kinds of care are you get from institution	
6. do you have to pay for the services	
7.in home who usually do care you	

Note

***1**: **1-pain, 2- general debility, 3- financial problem,** 4- poor care by family members, 5- accessibility.6-others.*2*:1- through volunteers,2-direct contact, 3-through hospital,4-through media.*3*: 1-initial stage of diseases, 2- middle stage of diseases, 3- in advanced stage.*4*: 1- ignorance of availability of palliative care, 2- modern facilities are not available from institution, 3-attitudanal problem,4- others.*5*: 1- medical, 2- non medical, 3-both.*6*: 1- pay for the all service, 2- pay for the medical care only, 3- pay for the nonmedical care only, 4-absolutely free services.*7:1-family members,2-care givers,3-both

7: Medical care and non-medical care in the institution

Medical care			
1. What kinds of medical care are you get from institution			
2.is this institution meets all your medical needs			
3.if no, what are the medical services that are not accessible from the institution			
4.how many time do you visit in the clinic in a week (outpatient)			
5. How many time palliative care team visits in your home in a week (home care patient)			
Non medical care			
		a. Yes/no	b. If yes How much/what kind per month
6.what are the non medical care you get/getting from the institution	1		
	2		
	3*		
	4*		
	5		
	6		

Note 1: 1- medicine,2-nursing,3- inpatient treatment,4- xray,5-radiation,6- dialysis, 7- other 2: 1- yes,2- no 3: 1- medicine,2-nursing,3- inpatient treatment,4- xray,5-radiation,6- dialysis, 7- others.4: 1-one time,2- two ,3-three,4- four,5- five,6- six,7- all days5: 1-one time,2- two ,3-three,4- four,5- five,6- six,7- all days 6: 1-food and cloth: (a)1- yes, 2- no,(b) 2-Transportation expenses: 1- yes,2- no.3*-childrens education: 1- yes,2- no ,(b)- 1- cloth,2 -fees,3-study materials,4- others 4*-job training to family members: 1- yes,2- no,(b)-5- Water bed and wheel chair: 1- yes,2- no . 6-financial help: 1- yes,2- no

Appendix 5.1

Centre for Development Studies

Mphil programme in Applied economics,2009-11

Questionnaire for field survey

FAMCARE Scale to Measure the Quality of Care

Respondent details

Name	Relationship to patients	Age	Gender	Religion	Category	Education

FARMCARE Scale

1. The patients pain relief

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

2. Speed with which symptoms are treated

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

3. Doctors attention to patients description of symptoms

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

4. Coordination of the care

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

5. The way the family is included in treatment and care decisions

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

6. Community involvement

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

7. Information given about how to manage the patient's pain

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

8. Information given about the patient's tests

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

9. Availability of hospital bed to the patient

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

10. Availability of nurses to the family

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

11. Availability of the doctor to the patient

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

12. Availability of medicine

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied

13. Availability of non medical care to the family

1. Very satisfied, 2.satisfied, 3 undecided, 4.dissatisfied, 5.very dissatisfied