COPING WITH CANCER:

An Exploratory Study of Cancer Patients and Their Care Givers, Medical College Hospital, Kottyam, Kerala

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CERTIFICATE

This dissertation entitled "**Coping with Cancer: An Exploratory Study of Cancer Patients and Their Care Givers, Medical College Hospital, Kottayam, Kerala**", is submitted in partial fulfilment of six credits for the award of the degree of **Master of Philosophy (M. Phil.)** of this university. This dissertation has not been submitted for the award of any other degree of this university or any other university and is my original work.

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CONTENTS

List of Tables

Introduction

The present age is characterised by rapid scientific and technological advancement. It is also characterised by changing lifestyles, occupational and diet patterns, and transition in various fields of social life. It is also coupled with changes in certain features of health of the people. New diseases and new health problems are coming up despite the achievements that man has made in medical care. Non-communicable diseases are one such category that has started dominating the health problems of the public in recent decades especially in the developed world. Among them, cancer is an important health problem, which had become a major cause of death all over the world. Globally it stands second to cardiovascular diseases in terms of death toll (Marmot & Freeney, 1997; Souhami & Tobias, 1998). Though there is a history of its presence even in B.C., its contribution to total death was considerably less in the beginning of twentieth century (Rao, 1996). However, towards the end of the last century cancer mortality had increased considerably. Researchers observed this as a resultant effect of the increased life expectancy and the transition occurring in the global health situation (Seale, 2000). This transition is characterised by the dominance of chronic, degenerative diseases over infectious diseases especially in developed countries. This form of health transition raises the question that whether these diseases are the after-effects of the development that humanity achieved.

Despite many developments in medical science and technology, the actual causality of cancer is not clear to mankind. Though most of the explorations on cancer are mainly concentrated on the biomedical dimensions, still these understandings are not fully developed to give a clear picture of the disease and its causal relationships. This uncertainty is a major hurdle that retards the effectiveness of the medical intervention in checking cancer and its consequences.

The mainstream health sector orientation lacks the broad view of health as not only physical but also psychological and social well being. It is dominated by the biomedical and curative orientation. It is more disease centred and in this orientation, a positive approach is lacking. Health can also be conceptualised positively as the ability of the individual to function properly than absence of disease. The consequences of the disease and ill health, in this biomedical orientation, are analysed in terms of the physical malfunctioning. The limitation of this approach in incorporating the psychological and social consequences of ill health in the medical intervention in health care is the major demerit. The present study is an attempt to explore the health care dimensions of cancer in a broader level, focusing on the patients and their caregivers in their family environment.

Family is the primary agency in the health care of an individual. The very definitions of health and illness are interlinked with the interactions that are taking place in family. In India, unlike western societies, it is primarily the responsibility of the family to take care of its members at the time of their ill health. Since the social institutions are strongly influencing the well being of individuals and groups, no health intervention can be successful without comprehending the 'caring' dimension as well as 'curing' dimension of disease. Especially in the case of chronic illnesses like cancer, the caring dimension is significantly important and an intervention to the health of the affected population must incorporate caring as well as curing. However, as mentioned earlier, generally biomedicine is concerned with the physical dimension of health and does not cover the psychological and social aspects of the health of the public. It might be because of this reason Virchow stated, "medicine is a social science in its very bone marrow...... No physiologist or practitioner ought ever to forget that medicine unites in itself all knowledge of the laws which apply to body and mind" (Clark, 1976, p.6).

In the late nineteenth and early twentieth centuries, the dominant paradigm of scientific explanations and theoretical formulations was developed to explain the cause-effect relations in disease occurrence. It received wider acceptance and appreciation in the beginning. But it was also criticised for its reductionist tendency. The suggested alternate approach is a broader understanding of the disease and it distribution in the population.

The consequences of cancer range from individual patient level to family and community levels. Its impacts are in physical, psychological, economic and social aspects of one's life. In addition to the worsening of physical health of the affected person, it creates a phobia in the community that it is an end to life of the affected. As the disease progresses, in most of the cases, the physical deformity and malfunctioning force the patient to be more dependent on the family. It also brings changes in the employment pattern, diet pattern and even in the behaviour of the individual patient. These changes are not in isolation but they are interconnected with the dynamics that takes place within the individual, family and in the community. Cancer restricts the physical mobility and social interaction especially in the advanced stage. Since it is a chronic disease, the consequences of cancer are long term and gradual. So the priorities of the families also change as the disease progresses. While the patient remains cancer centred throughout the disease episode, the family may go back to the normal functions in some period of the disease of their relative.

Coping with cancer has got more emphasis recently and it is from the wide range of its consequences. Present study looks at the coping pattern of cancer affected patients and their family and the response of the community to the disease. It is widely accepted that cancer is a disease that affects the control of the patient over his/her life and disrupts the continuity of the life of the affected. The importance of the coping strategy, which helps the affected to deal with the ill effects of the disease, comes at this point. Like Gotay observes, "coping with cancer is coping with death" (Gotay, 1996, p. 42), to most of the cancer affected it is a synonym of death. For this reason, it is significant to understand the coping style adopted and response to the disease, in the quality of life of the affected.

The coping pattern of the individual and family are interconnected and influenced by the response of the community towards the disease and the patient. On the other hand, the response of the community to the disease is also derived out of the experiences of the affected and the information they had received from different sources. Thus there is a two-way relationship between coping with cancer and the community response. Socio-economic, cultural and personality factors also contributing to the coping strategy one adopts. Thus coping is a broader concept that covers the processes of dynamics between a variety of structural and functional factors and the interaction between these factors are determinant factors in the quality of life of the cancer affected.

Quality of life is a subjective concept. Some researchers have used it synonymously with well being. But the common understanding of good quality of life is that it is a state of good physical functioning and good mental well being, as well as financial security and social functioning. In present study the concept of quality of life is operationalised in terms of six variables, which covers these aspects. They are the stage of disease, degree of deformity, coping with the disease, present feelings of the patients, family support and financial background of the family.

The population selected for this study is the people seeking treatment for cancer in the department of radiotherapy in medical college hospital, Kottayam in Kerala state. It was a purposive selection for the convenience of fieldwork and data gathering. The study sample covered a total of one hundred and fourteen respondents from four categories i.e. patients, caregivers, health care professionals, and general public. Required data were collected through field by the researcher for a period of four months from October 2002 to January 2003.

Organisation of the Study

The contents of this study are organised in six chapters. After the introductory chapter, in the first chapter, a detailed review of literature is done on various aspects of cancer and its management. In the first part of the chapter, the disease burden of cancer is reviewed globally, in all India level and in the state of Kerala. In the next part, the causal associations and the consequences of cancer are reviewed. Review of the major themes of the study- coping with cancer, treatment seeking behaviour and the quality of life of the patient- as well as different models in health behaviour contribute to the last part of the first chapter.

Second chapter explains the methodology and design of the study. In the first part of the chapter the major concepts of the study are defined based on the understanding developed from the reviewed literature. The objectives of the study are listed out and the data gathering process is explained in the chapter. Subsequent chapter details the profile of the study population. It covers the demographic, socio-economic and disease specific factors of the participants of the study. It also looks at the time trend of cancer in the studied population with the help of the data collected from the hospital registry.

Fourth chapter is exploring the experience of the participant patients, care givers and public with cancer disease. The understandings of the population under study and their perception regarding the causes and consequences of cancer are also covered in this chapter. The associations between the experience, understanding and perception of the participants of the study are analysed with the help of collected data. Different aspects of home care in cancer are also explored in this chapter and are illustrated through a case study.

Fifth chapter explores the various dimensions of treatment seeking behaviour of the cancer affected in the population under study. It outlines the actions taken by the patients and family on symptom identification and diagnosis of the disease. A detailed analysis is made on the delay factor in cancer. Various dimensions of the coping strategies and their associations with the experiences, knowledge and perception of the patients as well as the families are also analysed using the data collected from the sample. A case study is used for detailing the coping pattern and response of the patients to cancer. In the final section of this chapter, the quality of life of the cancer patients is assessed using the six variables mentioned earlier and they are compiled. The final chapter summarises the findings of the study and discuss them in a broader frame of public health.

1

Review of Literature

Introduction

There is a general feeling that cancer is a disease of modern times. But there is evidence that it existed in ancient times also. Ancient Indians of 2000 B C and the Egyptians of 1500 B C were aware of it. The father of modern medicine, Hippocrates, had also mentioned the growth of tumours, which he called 'cancer' (Rao1996, Meleka, 1983). However, today, globally cancer has developed as the second major cause of death. Cancer and cardiovascular diseases are the most important health hazards of the developed countries (Souhami & Tobias, 1998; Marmot & Freeney, 1997). Data show that cancer is diagnosed in one out of every 250 men and one among every 300 women in developed countries every year. More than half a million people in the USA and more people in Europe and Asia die of cancer (Senn & Glaus, 2002). The health transition that has happened in the world explains the progress of non-communicable and degenerative diseases. Seale observes that the control of infectious diseases, the gain in life expectancy, and the shift from infectious diseases to degenerative diseases as the cause of death are the major characteristic features of this transition in health (Seale, 2000; DiMatteo & Martin 2002). In 1985, it was estimated that 75 million cancer cases were diagnosed all over the world and 5 million people die of cancer every year. It was projected that 7.1 million deaths would occur due to cancer in the year 2000 (Armstrong, 1999). "Globally, the burden of new cancer cases in 2000 was estimated to be 10.1 million with 53% in the developing world. This is projected to increase remarkably to 20 million by 2020 with 70% in the developing world which has only 5% of the resources".[1] However, these calculations and estimations are merely numbers and inadequate to give the real and full picture of the deaths due to cancer.

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[1] http://www.globalcancerconf.uicc.org/opening/oc4.

Despite the large number of people suffering from cancer, while in the present global health situation, especially in the more developed countries, the major causes of both mortality and morbidity are non-communicable diseases and in the case of poor countries it is still communicable diseases. The question here is whether these non-communicable diseases are a feature only of developed societies or can we call them as diseases of development?

The very nature of cancer is a major issue in its prevention and treatment. Medical field is still not sure of the causes of cancer and so it has been unable to check the disease properly. In this chapter a review of relevant literature is done on the causes and consequences of cancer. A review of the studies on the coping pattern of cancer patients and an attempt to analyse the health seeking behaviour of the public in the context of cancer are also made.

Scenario of Cancer

Global Cancer Situation

Cancer is a disease of cells (Rao, 1996). The incidence of cancer is found to be increasing both in the developed and the developing countries. Though the rate of cancer incidence is higher in developed countries, it has been predicted that, in the year 2015, two-thirds of all cancers will occur in the developing countries (Gotay, 1996). In absolute numbers, the cancer cases will be more in the developing world as great majority of world population belongs to developing or underdeveloped regions. Table: 1.1 shows the proportion of estimated and projected cancer mortality rates according to sex and region around the world.

There are a variety of cancers depending upon the site at which it occurs. All over the world, the most frequent forms are stomach cancer and lung cancer in total population. However, it has been estimated that cancer affects three out of four families in the United States (Vincent & Mirand, 1991). And it is the second leading cause of death in USA (Croghan & Omoto, 1991). Table: 1.2 gives a detailed picture of the top ten types of cancers in men and women. Specifically among males, the most frequent type is lung cancer and secondly stomach cancers and among females breast cancer and cervical cancer occupies first and second positions. A major portion of these cancers is from developing world (UICC, 2003).

Table: 1.1 Estimated and Projected Proportions Rates of Cancer Mortality to Deaths Due to All Causes According to Sex and Region (per 100,000)

Region	1970		1985		2000		2015	
	M	F	M	F	M	F	M	F
World	7.3	7.5	10.1	9.6	12.5	12.2	14.6	14.7
Developed Countries	15.8	15.2	19.4	17.0	18.3	17.7	18.3	17.8
Developing Countries	4.9	5.0	7.3	7.0	10.8	10.4	13.5	13.7
Asia	5.5	5.2	8.8	7.8	12.9	11.8	15.6	15.4
Lat. America, Caribbean	7.2	8.4	8.6	9.9	13.9	15.4	16.9	18.4
Sub-Saharan Africa	2.4	3.0	3.0	3.8	4.5	5.4	6.3	7.6
Mid-East &North Africa	3.8	3.7	5.5	5.4	8.9	8.5	11.7	11.2

(Source: Bulatao, 1993, p. 50-51)

Table: 1.2 The Most Frequent Human Cancers in the World

Males		Females		Total	
Rank	**Cancer site**	**Rank**	**Cancer site**	**Rank**	**Cancer site**
1	Lung	1	Breast	1	Stomach
2	Stomach	2	Cervix	2	Lung
3	Colon / Rectum	3	Colon / Rectum	3	Breast
4	Oral / Pharynx	4	Stomach	4	Colon / Rectum
5	Prostate	5	Uterus	5	Cervix
6	Oesophagus	6	Lung	6	Oral / Pharynx
7	Liver	7	Ovary	7	Oesophagus
8	Urinary bladder	8	Oral / Pharynx	8	Liver
9	Lymphoma	9	Oesophagus	9	Lymphoma
10	Leukaemia	10	Lymphoma	10	Prostate

(Source: Rao, 1996, p. 12)

However, there are differences in the types of cancer sites between the developed countries and the developing countries. Armstrong (1999) classifies cancers into two groups as those affect wealthy countries and those generally affect the poor countries. Cancers of the colon and rectum, lung, skin, breast, prostate, kidney, lymph and leukaemia are the major ones in the wealthy countries. Cancers of digestive system and cervix are common among the population in poor countries (Armstrong, 1999). There are considerable geographic variations as well in the global incidence of cancer. Table: 1.3 gives an idea of the geographical variations of cancer risk across the world. It is argued that these variations are the result of differences in the culture, socio-economic factors and lifestyle over societies (Meleka, 1983; Gotay, 1996).

Table: 1.3 Global Geographic Variations in the Incidence of Cancer

Type	Ratio (High: Low)	High incidence	Low incidence
Oesophagus	200:1	Kazakhstan	Holland
Skin	200:1	Queens land	India
Liver	100:1	Mozambique	Birmingham
Nasopharynx	100:1	China	Uganda
Lung	40:1	Birmingham	Nigeria
Stomach	30:1	Japan	Birmingham
Cervix	20:1	Hawaii	Israel
Rectum	20:1	Denmark	Nigeria

(Source: Souhami & Tobias, 1998, p. 7)

Social class differences also do have a bearing in the distribution of cancers. Based on the data collected from twenty-one countries, Faggiano and others (1997) conclude that certain types cancers are more common among particular social classes. According to them low class men are more prone to cancers of the oral cavity and lung while men from higher social class are more prone to colon, brain and skin cancers. Similarly among women from low class, incidence of cancers of cervix, corpus uteri and stomach are more and cancers of ovary and colon are common among higher-class women (Faggiano et, al., 1997).

Time trends of the largest group of cancers show that the rate of digestive system cancers is relatively stable. It has been argued that this observed stability is because of the decreasing rate of stomach cancer, which is balanced by the increasing rate of cancer in the colon rectum. A similar balance is found in the case of cancers of female genital organs. The decreasing rate of cervical cancers is balanced by the increasing rate of corpus uteri and ovary (WHO, 1980).

Cancer in India

In India, while infectious diseases continue to be the major cause of both mortality and morbidity, the disease pattern is changing towards the dominance of chronic diseases as a result of the control over communicable disease and a variety of other factors. In the case of mortality due to major diseases, infectious diseases still stand first (GOI, Survey of causes of death, 1998). India being a developing country and being in the early stages of health development, non-communicable diseases like cardiovascular diseases or cancers are not of an immediate priority in health care intervention. That does not mean that the incidence of cancer is negligible in the population. In India, the average number of cancer cases per year per 1,00,000 population is 70 for males and 80 for females. Thus it has been estimated that 0.65-0.7 million new cases add up to the total population every year (Rao, 1996; Kishore, 2001). This number is always on an upward trajectory and another calculation states that every year 0.8 million new cases are diagnosed in 100 millions of Indian population or one in every nine of the Indians will have cancer in their lives (Maneksha, 2002).

The latest Survey of Causes of Death-Rural (1998) shows that among the ten top killer diseases of India, cancer stands in fifth position with a contribution of 5.0% of overall death. For the period of 1990 to 1994, it was in the sixth position (GOI, Survey of causes of death (Rural), 1994, 1998). Cancer is the fourth major cause of death in old age. In some states like Gujarat, Haryana, Kerala, Punjab and Rajasthan, contribution of cancer to the death during old age is far higher than the national average. In the terms of years-of-life-lost, cancer is the eighth major cause of death nationally. But in the states of Punjab and Kerala, it stands at third and fourth positions respectively (Indrayan et al., 2002).

Table: 1.4 shows the contribution of deaths due to cancer to the total deaths in India during the period 1990 to 1994. In the year 1990 it was 4.5 percent and showed a decline in the next three years. In the year 1994, it had recorded a sudden growth from four percent to five percent.

Table: 1.4 Percentage of Death Due to Cancer in India, 1990 – 94

Year	% of death due to cancer
1990	4.5
1991	4.1
1992	4.1
1993	4.0
1994	5.0

(Source: Survey of Causes of Death (Rural), 1994 & 1998, GOI)

Gender differences are also observed in mortality due to cancer over different age groups. While women are more prone to cancer in the middle age, old age is an unfavourable period for men in terms of cancer.

When compared to the incidence of cancer in urban population all over the world, five urban centres studied in India show comparatively less but significant incidence rate of cancer (ICMR, 2001). Table: 1.5 shows the Crude Rate (CR), Age Adjusted Rate (AAR)[2] and Truncated Rate (TR)[3] of cancer incidence in five major urban centres and Barshi a rural area in Maharashtra in India as recorded by the cancer registry programme of Indian Council of Medical Research (ICMR).

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[2] Number of cancer incidence per one Lakh population adjusted to World Standard population (developed by Boyle and Parkin, 1991). This is calculated for the purpose of comparing cancer incidence in different parts of the world.

[3] Incidence rate calculated for the truncated age group of 35-64 years.

Table: 1.5 Crude (CR), Age Adjusted (AAR) and Truncated (TR) Incidence Rates of Cancer per 100,000 population in different Cancer Registries (1990-'96)

Registry	Males			Females		
	CR	AAR	TR	CR	AAR	TR
Bangalore	62.4	97.8	162.2	79.9	122.1	254.0
Bhopal	56.9	100.4	180.6	55.6	92.2	205.2
Chennai	78.6	104.6	188.5	91.4	115.3	253.7
Delhi	73.8	121.9	207.9	87.3	135.3	289.1
Mumbai	72.9	115.4	176.1	82.1	119.1	227.9
Barshi	*38.1*	*46.2*	*72.6*	*48.5*	*57.7*	*137.2*

(Source: Consolidated Report of The Population Based Cancer Registries 1990-96, ICMR)

Cancer in Kerala

Kerala, although being one of the smaller states of Indian Union, is always a place of attraction for its better social development indices even within the slow economic growth (Ramankutty, 2001). In terms of health indicators, it is far ahead of other states of the country. This achievement is attributed to a variety of factors like political commitment to social welfare even during the princely ruling, the influence of Christian missionaries in the field of health and education, strong history of social movements and the far-reaching political culture especially in favour of poor strata of society (Franke & Chasin, 1991) and the strong political awareness as well as better access to health care services (Nag, 1989). Some other researchers relate the low mortality and high morbidity situation in Kerala that started in the beginning of 1980s to universal literacy and wider access to medical facilities. This better access has resulted in earlier diagnosis and detection of diseases than ever before and increased use of health care system (Dilip, 2002). The state checked the incidence of infectious and communicable diseases to a great extent very early i.e. in the 1970s and 1980s and non-communicable diseases like cardiovascular diseases, cancers, accidents and suicides have became the major causes of mortality from the 1980s itself (Kunhikannan et. al., 2000).

Table: 1.6 Major Causes of Death in Kerala in 1987 & 1996

Cause of Death	1987		1996	
	Percent	*Rank*	*Percent*	*Rank*
Heart attack	10.4	1	14.28	1
Cerebral Thrombosis	2.4	7	14.28	1
Cancer	7.4	2	8.57	2
Accidents	3.6	4	5.7	3
Suicide	3.0	5	2.8	4

(*Source: Kunchikannan et al. KRPLLD- 2000, p. 9.*)

In the state of Kerala, in terms of overall causes of death, cancers with an 8.57% share of death toll in 1996 has kept its second rank behind cardiovascular diseases and cerebral thrombosis. This was 7.4% in 1987 and cancer is one of the major causes of morbidity as well in Kerala (Kunhikannan et. al., 2000). Survey of causes of death (1998) shows that, in Kerala, the contribution of cancer deaths to the total deaths due to ten top killer diseases is 15%. In comparison with the all India level of 5%, states like Karnataka (8.7%) and Gujarath (7.2%) are behind Kerala and Orissa stands last with a contribution of 1.8% of deaths due to cancer to its total deaths due to the ten top killer diseases (GOI, Survey of Causes of Death, 1998).

Deaths due to cancers are distributed over different age groups in a non-uniform pattern. Tables: 1.7 show the distribution of cancer deaths over different age groups in the years 1994 and 1998 in India and Kerala.

Table: 1.7 Distribution of Cancer Deaths over Different Age groups in India & Kerala, 1994 & 1998 (in %)

Age-group		0 - 1	1 - 4	5 - 14	15 - 24	25 – 34	35 - 44	45 -59	60 +
India	**1994**	0	0.6	1.5	4.8	7.2	11.1	26.5	48.2
Kerala	**1994**	0	0	1.2	2.4	0	6.0	31.1	59.5
India	**1998**	0.7	0.8	2.5	3.3	6.3	12.3	28.8	45.3
Kerala	**1998**	1.1	0	1.1	4.5	1.1	3.4	20.5	68.2

Source: GOI, Survey of Causes of Death, 1998

Approaches to Cancer Research

The dominance of non-communicable diseases cannot be reduced to any single reason and specifically in the case of cancer wider understanding is needed. The individual's interactions and behaviour within the family as well as community and socio-political contexts as well as intrapsychic contexts shape human health (Cancela et al., 1998). By this very reason itself, the understanding of external factors is essential in the formulation of health status. The three distinct approaches to health are *Biomedical approach*, which focuses on the physiological state of the individual; *Psychological approach* which emphasises the subjective feelings of well being of the individual and the *Social Science approach* that emphasises the cultural and social dimensions of health (Weiss & Lonnquist, 1997).

Research studies in the field of cancer are concentrated on its biological aspects, especially on the practice and the biomedical aspects of the cancer treatment (Mohanti et. al., 2001). "Because of its reductionist tendency, conventional medical understanding also typically fails to capture the embodied experience of illness..." (Little et. al., 1998, p.1486).

Thus the biomedical approach, which is significantly important in health care, has a tendency to reduce human health only into the frame of biological dynamics within human body, which of course is an important factor. McKeown noted that since seventeenth century, the concept of health is defined in terms of the understanding of the structural and functional aspects of human body and the process of disease that influence this structure and function (McKeown, 1971). This led to the emergence of a health culture centred on disease and the institution of hospital. Medical research is also influenced by this orientation. Another reason for the concentration of researches on cancer in the biomedical frame could be the inadequacy of medical knowledge and technological inability to check the disease properly. The political economy of health care is also a major factor that plays in this kind of a focus. Pearce also explains, this tendency to concentrate in biomedical aspects of disease only since the interests of the funding agencies are mainly in the biological aspects. The sources of funding have little interest or sympathy for the non-clinical factors of health (Pearce, 1997). Health psychologists place health in a wider and more abstract plane. Psychological health involves acknowledgement of the influences of chronic illness, infectious disease, transmission of disease and societal and institutional pathologies, internal oppression and environmental factors, on health and well being of communities (Cancela et.al., 1998). In community health psychology approach to health, a cultural competence from the part of the professionals is proposed in which the understanding of health problems in a wider level is demanded.

Social science approach to health is important for a variety of its merits. Precisely it is argued that, the social structures and social institutions significantly influence the functioning of health care institutions, which translate relevant medical knowledge into health care activities and programmes (Coe, 1978). Therefore, while biomedical approach emphasises the physical aspects of health, the social science model incorporate the non-clinical consequences of ill health of the affected in a broader plane.

Biomedical factors are necessary but not sufficient to understand and explain health as well as illness. Biomedical model, as Charlton notes, is more lenient to mainstream technology based skill and training than wisdom and education in a broader sense (Crossley, 2000). George Engel has put forward an alternative to biomedical model in the form of 'Biopsychosocial Model', which recognises the social and psychological aspects of health along with the biological aspects (DiMatteo & Martin, 2002; Crossley, 2000). It explains health as an inextricable unification of physical and mental well being. This model is significant in the case of 'lifestyle diseases' and chronic diseases as psychosocial factors play potential role in the onset and progression as well as the coping strategies of the disease. It is widely accepted as the basic framework of contemporary researches in the field of health.

Studies show that a close association can be observed between socio-economic disadvantages and the incidence and prevalence of diseases in the community (Maleka, 1983; Gotay,1996; Dayal, 1987; Kegeles,1976). The transformist approach to health argues poverty as the cause of disease. People with poor socio-economic background in general are found less healthy and show higher mortality rates than those from better off groups. This shows that health cannot be understood as mere absence of disease or it cannot be reduced to the human body only rather it should be placed in a wide realm of bio-psycho-socio-economic environment.

In the case of cancer also, a better understanding of the socio-economic and psychosocial dimensions is needed. Studies show that even among the more developed world, major causes of death are more common among the population from lower social status (Marmot & Freeney, 1997; Faggiano et. al., 1997). Pearce finds lifestyle risk factors are mainly the outcome of socio-economic disadvantage and so they are the intermediary factors in the causal pathway from socio-economic factors to disease (Pearce, 1997). According to him "in many instances there is clear evidences that cancer is related to socio-economic factors, but this does not appear to be fully explained by known risk factors. More importantly, there is little evidence to which socio-economic factors are of most importance, or whether it is the overall 'package' of social inequality that is responsible for the differences in cancer risk" (Pearce, 1997, p. 22). One important fact is that these socio-economic factors are intrinsically intertwined and that they cannot be disaggregated to assess their correlations with health.

Thus along with the biological and clinical dimensions, understanding of the role of social environment, social structure, psychological dynamics of the interaction between the individual and the immediate environment including formal and informal health care providers, and the response from the environment to the suffering and ill health of the individual are also important in comprehensive cancer care and management.

Social science is important as the growing understanding of the role of both social and physical environment and lifestyle factors associated with cancer. It is argued by many that social structural factors are more important than behavioural factors in determining health (Denton & Walter, 1999). Thus it is suggested that structural factors like institutions and organizations in society and the dynamics within these structures are significantly important in health development. But the models in health emphasise the behavioural factors than structural factors. Review shows that there is a need for a bio-psycho-economic and social frame of analysis in our formulations of health research since the social environment, the assumptions and belief system of public along with the biological factors are very much interconnected with the quality of life of the individual.

We understand individuals to behave within family, community and even intra psychic contexts, which shape human health (Cancela et al., 1998). It is argued that the ability of epidemiological frame to examine demographic characteristics and the social forces within the group and correlate them with health status is its most important merit. This kind of an analysis framework is very much needed in the case of cancer research also.

Causes of Cancer

The biomedical model uses a reductionist approach to explain health as an outcome of biological factors. The notion of risk factors and their causal associations to cancer is a widely researched area (Pearce, 1997). Biological researches on cancer mainly deal with the causal relations like smoking and lung cancer, occupational hazards like exposure to asbestoses and pesticides and the occurrences of cancer, certain diet habits and genetic associations of cancer and so on. In the field of cancer management, the services and activities are generally concentrated on the treatment of the symptoms of the disease. In public health perspective, this kind of an analysis of the health of the people is inadequate as health is very much related to the environment both physical and social and the interaction of the individual with his/her environment.

Studies show that stressful life events are linked to a modest increase in risk of a variety of chronic diseases as well as an increase in recent health problems in those already suffering from disease (Cancela, 1998). Ancient Greek physicians observed that internalising, melancholic women were more prone to breast cancer than outgoing cheerful women (Rao, 1996). Even if the findings are controversial, Rao observes that there are a lot of studies on the association of psychological factors of the individual with cancer incidents. These factors include problems like loneliness, depression, childhood experiences, loss etc. Similarly later age at first childbirth emerged as stronger risk factors for breast cancer (Gajalakshmi, 1998). Positive family history or genetic reasons are also attributed to the occurrence of breast cancer.

Life-style has an established association with the occurrence of cancer. This is especially true in the case of lung and oral-cavity cancers. It has been calculated that smoking is responsible for 90% of lung cancer and its severity can be understood by the fact that without smoking, we can reduce cancer death by quarter (WHO, 1980).

"Almost 1.5 million cancer cases of tobacco related sites were diagnosed in the developing world in the year 2000. Up to 75% of lung and laryngeal cancer in men are attributable to tobacco smoking. Similarly a high proportion (66 %) of oral cancer is attributable to tobacco chewing. Therefore cancers at these sites are preventable with reduction of morbidity and mortality".[4] Though the absolute numbers are different, it is widely agreed by researchers and health professionals that tobacco use is the most important risk factor for cancers. Review shows that there is a general tendency to reduce the cancer risks to lifestyle factors mainly to smoking (WHO, 1986; Croghan.1991). In a study, an inverse relationship between Body Mass index (BMI)[5] and oral cancer has been found (Mia Hashibe et al., 2002). Though the relationship, as admitted by the researchers themselves, is spurious, in general, it holds true in the case of people from lower strata of society, where the general status of BMI is low due to variety of socio-economic reasons. Similarly, chronic Hepatitis-B virus infection found as causal factor in nearly 50-80% of liver cancers and human papilloma virus, which may transmitted through sexual relationships is associated with 90 % of cervical cancers in the developing world.[6] This kind of an analysis is incomplete and inadequate as the risk factors like smoking, dietary patterns and risky exposures in the workplace are acquired through social and economic processes.

Dayal, in his study among Americans, has observed a relationship between race/socio-economic status and cancer. Meleka argues that socio-economic factors influence the incidence of cancer more than racial factors (Meleka, 1983; Gotay, 1996). Ultimately these findings are derived from the association between socio-economic status and the physical, psychological, and social well being. The health care utilisation itself is a function of socio-economic status. Almost all of the studies on cervical cancer have found an inverse relationship between socio-economic status and the failure to receive effective treatment (Kegeles, 1976).

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[4] http://www.globalcancerconf.uicc.org/opening/oc4

[5] Body Mass Index (BMI) is the mathematical ratio of height to weight that can be linked with body composition (or body fat percentage) and with indices of health risk. People with a BMI of 25 to 29.9 are considered overweight, and people with a BMI of 30 or above are considered obese. A high BMI assumes a higher percentage of body fat, which places a person at greater risk for developing chronic diseases such as diabetes mellitus, hypertension, heart disease, and even cancer, Microsoft® Encarta® Reference Library 2003. © 1993-2002.

[6] http://www.globalcancerconf.uicc.org/opening/oc4.

According to American Cancer Society, 80 % of cancers of all types could be associated with environmental exposures and because of this they can be prevented by conscious intervention (Croghan & Omoto, 1991). According to them the causes of cancer can be classified as Inhaled carcinogens, Ionising radiations, Occupational factors, Life style, diet pattern and Viral Infections. However, the American Cancer Society, in this kind of an observation, does not address the structural reasons of the vulnerability to cancer. This kind of an assumption is derived from the political economy of the present cancer epidemiological researches that are often influenced by the personal and professional situations of the epidemiologists (Pearce, 1997).

Consequences of Cancer

The nature of cancer is very significant in the treatment and cure of the disease. It normally takes comparatively longer period to develop from the initial tumour to a serious health problem. Affected person may not be aware of the presence of the *malignant*[7] cancerous growth until it begins to disturb his normal functioning either through pain or other symptoms, which usually occur in advanced stage when it has *metastasised.*

The after effects of cancer in the patient are vivid. The consequences of this disease can affect the physical, mental or emotional well being of the patient and/or the socio-economic status of the patient. These can be either due to the disease itself or from the treatment for it. The deformities and terminal symptoms also influence the behaviour of the patient considerably (Crossley, 2000). Among the physical consequences, there are pain, fatigue and weakness, nausea, sleep disturbance, physical deformities and malfunctioning of body parts. Among these, pain is the most common and important (Senn & Glauss, 2002; Rao, 1996; WHO, 1980). Association for the study of Pain Subcommittee on Taxonomy of Pain Terms defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (WHO, 1986, p. 8.). Pain is always a subjective experience and varies from person to person (Meleka, 1983). Every individual learns the application of

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[7] **Tumors are classified as either benign or malignant. Benign tumors do not invade other tissues and are limited to one site. The most important property rendering a tumor malignant is the ability to invade nearby or distant tissues; this spread to distant tissues is called metastasis.**

the word through experiences related to some form of injury in life. It is an unpleasant sensation (WHO, 1980). Total pain is a combination of somatic hazards, depression, distress anger and anxiety (Twycross & Lack in WHO, 1980). About 50% - 80 % of the patients with advanced cancer experience pain during the disease course (Fanslow, 1991). Through various studies it has been revealed that pain is the most important symptom of more than 70% of the diseased. WHO estimates 3.5 million people suffering from cancer pain every day with or without satisfactory treatment. In other words, cancer is the synonym of pain in most of the cases.

Psychological, social, cultural and spiritual factors play an important role in the definition, aggravation or amelioration of pain (Ross, 1970; Gotay, 1996). The role of these non-medical factors along with medicine is emphasised in pain management. Effective pain management, particularly in patients with advanced disease, is one of the four priorities of the comprehensive cancer programme as advocated by WHO. The other three priorities are primary prevention, early detection and treatment of curable cancers (WHO, 1986).

From this explanation, it is understood that pain is not simply physical rather it is multifaceted sensation or experience. The shift from 'cure' to 'care' in cancer and the development of palliative care and hospice movement are centred on pain. WHO itself has developed a comprehensive pain management for cancer patients. The irreversible nature of cancer, in its advanced stage, and poor control of therapeutic interventions on the advancement of the disease force medical community to focus more on prevention of the disease and caring of the patient. (Croghan & Omoto, 1991)

Literature shows that other than pain cancer patients face variety of psychosocial issues. These may range from individual level to family and community levels. Some of the psychosocial impacts are change in family relationships, change or reorganization in roles, change in expectations from family members, personality and behavioural changes in sexual and cognitive functions (Ronson & Body, 2002). The very knowledge of having cancer causes notable impact on the behaviour and functioning of the individual and the family. Many patients experience anticipatory symptoms developed out of the anxiety regarding treatment and side effects and these psychological reactions to radiation may last three months after therapy (Kaplan et. al., 1993).

Little and others group these consequences into three. First is *cancer patientness*, which is the immediate impact on the patient from the very identification of him/ her as a cancer patient. Second is *communicative alienation*, which is characterised by the feeling of isolation from the common environment and routines and thirdly *boundedness* or limiting one's space, time and activities (Little et. al, 1998). Haddad and others have summarised the psychosocial hurdles facing the relatives of cancer patients. The uncertainty on the future, success of treatment and even about the life is a major impact of cancer. The feeling of helplessness of the relatives is a disturbing one when the patient is suffering from pain. Search for a meaning and explanation of cancer by both the family and the patient is another outcome of the disease. The meaning of cancer is related to a variety of factors and it is significant in coping. Sense of failure in preventing the occurrence of the disease and the feeling that their failure caused the disease of the dear one is a disturbing factor to many relatives. Stigma attached with cancer as contagious and ugly disease, labelling the patient as facing death and the sympathy expressed to them are also difficulties associated with cancer. Social isolation of both the patient and the family as a result of the limited mobility and reduced participation is another consequence. Lack of support and side effects of the treatment are the service related difficulties. The practical problems like losing job of the care giver, financial crises, changing roles are also affect the well being of both the patient and the family (Haddad et. al., 1996).

One important impact of the disease in the life of the patient is the change in employment. According to a study by Ronson and others, in general, 20–25 percent of cancer survivors are not able to work at the same level when they were full functioning as a result of having been treated for malignancy (Ronson & Body, 2002).

Survival rate of cancer, in the beginning of twentieth century was almost zero. Later it developed to one among five in 1930s and one among every four in 1950s. In 1970s, it had developed to one among every three incidents (Meleka, 1983). Here survival means an existence with cancer up to five years. The advancement of modern medical treatment techniques and technology are responsible for this kind of an improvement in the survival rate (Souhami & Tobias, 1998). This advancement in turn associated with more expense and thus lead to economic consequences. Apart from the expenses of treatment, changes in employment pattern as well as the reduced productivity of both the patient and the family members have significant impact on the economic security of the family especially among the lower classes.

Health Seeking Behaviour in Cancer

Disease perception is a significantly important factor in health and treatment seeking. This perception is influenced by a wide range of factors derived out of the immediate social environment of the individual. Ill health is first recognised and defined by this immediate environment, which include relatives, friends, neighbours, colleagues and other significant persons (Cancela, 1998).

In developed world, health behaviour is a widely used term. It is the combination of knowledge, practices, and attitudes that together contribute to motivate the actions an individual takes towards his health development (Kishore, 2002). The extent of this usage is reflected in the terminology of 'the holy four', which refers to the four important health behaviours say, smoking, alcohol abuse, poor nutritional intake and the low levels of exercise as the major associated lifestyle factors to which more than half of the premature deaths and morbidity are attributed to (Crossley, 2000).

Health behaviour is widely used to refer the preventive health behaviour of the individual. There are three different terminologies used in this direction: *Health behaviour*, which refers to preventive health behaviour, *Illness behaviour*, which refers to the seeking of diagnosis and treatment, and thirdly *Sick role behaviour*, which connotes the role behaviour in response to the health problem (Kasl & Cobb, 1966; Cockerham, 1992).

Different theoretical frames of analysis have been developed by health psychologists and sociologists to explain individual's behaviour in the context of his/ her health. In Rosenstock's Health Belief Model, it is argued that the perceived threat of the disease/health problem constructs the health behaviour of an individual and in this process, perceived value of preventive action is the most important intermediary variable. As Cockerham observes, this particular model is derived from Kurt Levin's theoretical explanation of life as a composition of positive and negative valances. Illness or ill health is considered as a negative valance/value from which an individual is desired and expected to be shifted to the positive valance, which is 'good health'. This shifting can be either through keeping away from the chances for being ill or consciously moving away from the negative. These two options can be compared to preventive health behaviour and curative intervention respectively. The benefits from being in the positive valance like ability to function better and expectation from the environment are the motivation for this kind of behaviour (Cockerham, 1992). Health belief model explains the continuum between individual perception and health behaviour. This model explains disease specific health behaviour rather than general health behaviour (Weiss & Lonnquist, 1997).

Theory of Reasoned action argues that health behaviour is a result of one's intention, which reflects commitment to one's self to take action, and is influenced by attitudes towards the subjective norms (DiMatteo & Martin, 2002).

Anderson and others find certain predisposing, enabling and need factors in the health seeking behaviour of an individual. Factors like socio-demographic variables, attitudes and beliefs regarding health are explained as the predisposing factors. According to their view, income source, accessibility and availability of services are enabling factors in health seeking. The individuals needs for better functioning, better health status and like are the motivating factors for his search for better assistance in health development (Cockerham, 1992). Kasl & Cobb from a review of a series of studies found out strong associations between variety of factors like age, gender, place of domicile and previous disease history and health behaviour (Kasl & Cobb, 1966). Also, from review, they observe an inconsistent association of the factors like income, socio-economic status, and education with health behaviour. Another study finds gender differences in health care utilisation. It also argues that women show comparatively higher rates of health care utilisation (Cashin, et al, 2002).

Mechanic's explanation and summary of the determinants of health behaviour is also symptom-centred and argues that the cognitive, cultural and socio-economic factors contribute to the health behaviour of the individual. It also covers the social structural factors that determine the access to health care services (Cockerham, 1992; Weiss & Lonnquist, 1997). This particular explanation covers both the individual specific factors and the environment.

While Mechanic's explanation covers the determinant factors of health seeking behaviour, Suchman analyses the process of health seeking. He classifies it into five stages. The first is the symptom experience where the individual identifies and interpret the presence of symptoms as the indication of something gone wrong. The second stage is the assumption of sick role by the individual who then tries to relinquish normal roles. In the third stage of medical care contact, the individual gets his sick role authorised by a professional. Up to this stage he might be undertaking lay remedial measures for his symptoms. At this stage i.e. third stage, the formal treatments are started and in the next stage of dependent-patient role stage the individual is fully accepting the professional advice. Recovery and rehabilitation is the final stage of this process (Cockerham, 1992; Coe, 1978).

Health behaviour is very much influenced by the type of disease. In other words, it is to a certain extent disease specific. This is very much valid in the case of cancer. The specific nature of cancer is a major factor that influences the treatment seeking of the patients. Clark summarises arguments in the field of researches regarding the less serious attitude of the public towards the warned life-style risk factors for cancer. Primarily, the slow and silent attack of cancer, which an ordinary person may not identify as a threat to his/her health, result in the late diagnosis of the disease. It will be a point of attention to many of the diseased only when it affects the normal physical functioning, which generally occurs in the advanced stages of the disease (Clark, 1976). Health behaviour is influenced and reinforced by the expectations and behaviour of the professional towards patients also (Green, 1976).

Most of the preventive health programmes are based on the Health Belief Model, which argues a linear relationship between belief and behaviour, that is, the health behaviour of the individual is based on his beliefs and perceptions about his susceptibility to disease, severity of the disease, and the input output rationality.

Delay in Seeking Treatment for Cancer

Delay in seeking treatment is a widely discussed issue in the case of cancer. All the studies on cancer support the finding that the delay in seeking treatment is a major hurdle in the effective management of cancer. Delay in seeking treatment is to be defined very carefully as it is a complex process. In one way it can be explained as, the time period between the symptom identification by the individual and the first attempt, consciously by himself/herself or with the help of some other significant person, to seek an external, qualified person's (normally physician) assistance in reducing the symptom experience and regaining the normal functioning. In a medical practitioner's point of view, it is the time gap between the symptom identification and the first visit to a physician. Here again it is complicated as whether the first visit to a doctor means that the process of the alleviation of the problem has been started. According to Kasl & Cobb, "the concept of delay has two possible meanings, depending on whether delay is computed from the date of first appearance of symptoms or from the time a complaint is recognised by the patient as requiring medical attention" (Kasl & Cobb, 1965, p. 257). There are different factors and forces that play in 'delay' and to a great extent it is subjective also.

Another issue in this definition of delay in treatment is the chance for blaming the victim. The general tendency is to assign the entire responsibility of seeking 'timely treatment' to the individual 'patient', rather than considering the multifaceted process of health seeking by individuals. Cognitive and attitudinal variables are explained as determinants of health seeking (Kegeles, 1976) and so the delay is explained as individual specific rather than social. Social, economic, cultural, psychological and political forces significantly play their roles (Gotay, 1996) as the very meaning of cancer is developed and conditioned by these factors. In a poor family, for instance, if the breadwinner is confronted with a health problem, it is more likely to have delay in seeking treatment as the employment of the person may get affected by the treatment procedures. Another possible argument is that, since the person being the key in it's economic security, the family will try to seek early treatment in order to make the person fully productive and functional as soon as possible.

Clark, in his review, identifies six factors in delay in treatment seeking in cancer. Firstly, the sociological background that include family history of cancer, culturally constructed ideas and attitudes towards cancer raised out of early experiences, gender, age, occupation, education, faith, economic security etc. Secondly, the disease specific factors especially the site of the cancer. Thirdly, the cognitive aspects, that is the cancer education and experiences which conditions both the diseased and the significant others substantially. Fear is the fourth factor, which is considered as 'the most potent single factor' in determining the health behaviour in the case of cancer. Different forms of fear are there but generally the fear of death, deformity and isolation, fear of the fate of the dependents etc. are the common ones. Fifth factor is, the evaluation of the problem by the patient and this evaluation is mainly in terms of the symptoms. Finally the management of cancer after diagnosis and before treatment influences the response of the individual to symptoms (Clark, 1976; Kasl & Cobb, 1965).

Cancer specific anxiety and social support are important factors that influence treatment seeking in cancer (Antonovsky & Anson, 1976). However Kasl & Cobb could not find any linear relationship between these factors and they argue that it is not clear as to how anxiety influences delay in seeking help. For them all is a matter of whether the individual patient takes anxiety and fear for constructive action towards treatment or is paralysed by it. Ignorance of the seriousness of the symptoms, fear, unwillingness to face the bad news which they suspect, financial circumstances and severity of symptoms may lead to delay in seeking appropriate medical intervention (Green, 1976). But most of the studies on health behaviour or delay in cancer treatment assume that there exist adequate services and programmes for the management of the disease. It is because of this assumption that they are not dealing with the accessibility or affordability of services. Most of these studies have been done in the developed countries, where there is the system of adequate health infrastructure and health insurance for many if not at all. However, this assumption cannot be accepted in its full sense even in developed countries. Another inadequacy is the minimum focus given to the socio-economic situation of the patients and their family. In a sense, it is blaming the patient for not utilizing the services. Most of these studies are in the premise of the behavioural modification of the public in health development by 'educating' them for healthy practices and keeping them away from 'risk factors'.

A study demonstrated that those who correctly identified their condition as cancer are early in treatment while those labelled it as benign growth were late. This shows that people are concerned of their health in normal conditions. Also assurance of curability may reduce delay in treatment. (Green, 1976).

Site also influences the delay (Green, 1976). This can be in three ways, one the difficulty in identifying the site itself, for example in the case of internal organs it is difficult to be diagnosed easily. Secondly, nondisclosure by the patient, for example in the case of lesions in genital organs, there can be shyness or fear of change in sex roles from the part of the patient and it is likely to be hidden till the time it cannot be concealed any more. Thirdly, the evaluation of the seriousness of the lesion or tumour by the patient himself can persuade the treatment. Lumps on the skin or certain external parts of body without pain, for instance, might be considered as not serious or as a normal thing by the patient. In a review of studies carried out by Kasl & Cobb it is found that there is no difference in delay depending upon the site being internal or external. But they have found the influence of age, religion and socio-economic status, early experience of cancer in family and the general habit of delay in seeking treatment in delay in seeking treatment specifically for cancer (Kasl & Cobb, 1965). Thus studies show contradictory results in the case of delay and its association with character of symptoms first observed and patient delay (Green, 1976).

Coping with Cancer

"No disease known to modern civilisation is looked upon with as much fear as cancer" (Rao, 1996, p.10). It is widely accepted that the impact of cancer diagnosis and treatment on both the patient and family is very traumatic as the health condition of many patients are beyond the control of modern medical science and many of them die from their disease (Souhami &Tobias, 1998).

The action, as Green argues, which an individual takes in response to his health problem, can be attributed to the way he copes with the anxiety and fear associated with it (Green, 1976). The foundation of coping with disease is laid by the physician, who is communicating the diagnosis to the patient. Depending upon the way of 'breaking of the bad news' and the attitude of the physician, the coping pattern of the patient and the family develop. "If the physician is honest and sincerely optimistic about treatment, the patient's ability to cope will be more" (Clark, 1976, p. 4). Many researchers are of the opinion that a multidisciplinary team approach can do a lot in both the coping with the disease and in ensuring quality of life of the patient (Fox, 1976). This kind of an approach is possible in hospital care only. The multidisciplinary team approach has its functional limitations in the case of home care.

Depression and the feelings of isolation and dependency are common and deep among cancer patients. In a study among the cancer patients in palliative care centres in UK, it was found that female patients are twice as likely and male patients are 1.3 times as likely to die of suicide as the general population and a far higher number of suicides than expected occur in patients with malignant cancer (Williams, 2002). A large proportion of "medical" illness behaviour is mainly, the manifestations of the unmet need for assistance for psychological problems (Kasl & Cobb, 1965). Here lies the importance of trained personnel's intervention in alleviating the psychological stress and helping him/her to cope with the situation.

The dreadful nature of cancer and the comparatively poor efficiency of modern medicine in preventing or curing cancer bring the notion of 'coping with cancer'. The general impression about cancer is that it is the most dreadful disease (Rao, 1996). The paradigm shift from cure to care, in the case of cancer is from the understanding of the poor efficiency of medical sciences to cure the disease (Senn & Glaus, 2002). In this respect, the concept of care took over the idea of cure in cancer. The general perception towards cancer is also formulated accordingly. This shift, of course, needed a strong backing of social science approach. This calls for a psychosocial understanding of the disease and its consequences. Various studies show the role of different psychosocial factors in coping with the disease. The quality of life of the patient is very much affected by such factors. Studies show that behaviour and coping of the patient with cancer are influenced by factors like ability to cope with stress, family relationships, cancer prognosis, socio-economic status, age, gender, belief system etc. (Schulz et. al., 1996; Meleka, 1983; Ronson & Body, 2002; Weihs & Reiss, 1996; Ohaeri et al., 1999; Gotay, 1996; Bloom, 1996; Haddad et. al., 1996).

Health care service system is secondary to family in the construction of health of an individual. There are differences in objectives, philosophy, processes and scope between family and health service system, in care for the patient. A kind of emotional detachment is practiced from the very beginning of the training of health care professionals (Crossley, 2000). But this kind of detachment or impersonal care is not possible in home care and that itself is the major factor that creates stress among the family members from the disease of their relative. This will be high if the patient is terminally ill or fully dependent like in most of the cases of cancer. Gotay has found differences in the meaning and the impacts of cancer in family depending upon their cultural conditioning (Gotay, 1996). Serious illness of a family member is always a stressor for family members and in many cases, cancer affects not only the mental health but also physical health of the family members (Weihs & Reiss, 1996; Vettese, 1976). In the initial stages of the disease, Weihs & Reiss observe, both the patient and the family are more connected to the disease and treatment and more 'cancer centred'. As the treatment progresses, gradually the family goes back to its daily activities and becomes more 'living centred' but not in the original form. Recurrence of disease pulls the family again back to cancer centred courses and gradually goes back to the normal. This happens again in the terminal stage of the patient. In short, time and situation rearrange the priority of the family. This can be considered as the coping process of the family with their relative's cancer. It is also observed that the 'rationality' in the behaviour of the family also affected by the disease as they may go for traditional healing practices although they are following modern values in the normal conditions (Gotay, 1996). Change in spirituality and the search for traditional / alternative medicines are examples for this. These could be considered as different forms of coping.

The social interaction of the patient is very significant in improving the quality of life. The diseased may participate or keep away from social interactions, depending upon the nature of the disease (Ronson & Body, 2002).

Socio-economic factors are found to be having association with coping levels. Dayal argues that socio-economic status may be related to the quality of care, to the support system and the physical condition of the patients, which in turn influence their coping with the disease (Dayal, 1987). Ronson's analysis finds that factors like employment, marital status, education etc. play significant role in coping with Hodgkin's disease.[8] The important thing here is that these associations are not one-dimensional. The disease and its influence on the socio-economic status of the patient are also considerably important. "More than half of the patients diagnosed with cancer have to cope with and live with an incurable disease at some stage of the disease trajectory" (Wong, et. al, 2002, p. 408). Patients with deformities and malfunctioning generally find it difficult to cope with the disease. The immediate social environment is important in coping with the disease. This immediate environment includes family and peer groups. The support from this primary environment is an important factor in the psychosocial rehabilitation of the cancer patient (Ronson & Body, 2002). Review shows that support is a source of coping through fostering positive thinking and promoting healthy behaviour. "Social support and family relationships might be two of the main spheres of life contributing to higher levels of quality of life and is an important stressor filter" (Molassiotis et. al., 1997, p.317). Denton and Walter (1999) in their study find that social support was associated with better health for both men and women but this was an especially strong relationship for women.

Communication between the family members and patient and between the professionals and the patient also is an important factor in coping with the disease and reducing the psychosocial consequences and thereby improving the quality of life of the patient. For patient and the family members, absence of proper information is a source of anxiety and it influences patient satisfaction (Wong et al., 2002; Ronson & Body, 2002; Fisher 1999). There are cultural variations in the communication and decision-making

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[8] Hodgkin's Disease is a less severe form of cancer that arises in the lymphatic system (network of small vessels that carry lymph, a fluid containing white blood cells of the immune system). Hodgkin's disease is characterized by usually painless but progressive enlargement of lymph nodes (or glands) and other lymphoid tissue. Generally the first symptom of the disease is swelling of lymph nodes in the neck, armpit, or groin. Later many other lymph nodes become involved, and the spleen becomes enlarged. Secondary symptoms include fever, chills, night sweats, weight loss, fatigue, and loss of appetite. The cause has remained unknown since the British physician Thomas Hodgkin first described the condition in 1832, Microsoft® Encarta® Reference Library 2003.

regarding health and help seeking. In the case of disclosure of the diagnosis also, there are cultural variations. In some American societies, the disclosure of diagnosis and prognosis are important part of medical assistance while it is less important in Asian societies. It is widely perceived that generally the disclosure may take away the hope from the affected (Gotay, 1996).

The burden of caring for patients is mostly borne by the family members. There is an assumption that joint or extended family system can be trusted for putting up with the burden of caring for chronically ill patients. Many researchers comment on the traditional family system in the studied societies, which assumes the primary care giver roles. (Weihs & Reiss, 1996; Gotay, 1996; Ohaeri et al., 1999; Bloom, 1996; Schulz et al., 1996; Loustanau & Sobo, 1997). They consider this as an advantage for the supportive care for the patient and to ensure quality of life. At the same time, they mention the changes that occur in the family system and the structural changes towards nuclear families, which can cause gradual decline in the supportive role of family in cancer or any other illness. "In third world countries, in spite of the paucity of normal institutional methods of care for cancer and the great reliance on relatives there has been no systematic attempt to assess the psychosocial and economic burden that such informal carers (relatives) have to bear"(Ohaeri et. al., 1999, p.1542). Thus it is a fact that cultural factors like values, assumptions and beliefs are important variables that along with the socio-economic status, life experiences and personality differences determine the meaning of cancer to individuals, families and to community and also the coping pattern they adopt.

Cancer and Quality of life

Quality of Life (QOL) is an abstract concept for which a clear definition is not possible. As it is a subjective idea of one's well being, the assessment of QOL is also difficult. This concept was first introduced in 1960s when surveys were undertaken on well being of population in USA (Cox, 2003). Though many authors use their own definitions, they commonly include physical functioning, one's own perception of psychological well being and social interaction. Researchers used QOL and well being interchangeably as both of them are subjective and they cannot be reduced merely into material parameters

(Priya, 2000). Most of the QOL measurement techniques rely on psychometric techniques (Kaplan, 1985). There are cultural variations in the perception of QOL. Anglo societies rate 'independence' and 'physical functioning' as the most important factors in QOL while, Chadurvedy's study shows that to Indians, these factors are less important and to them, 'peace of mind', 'spiritual satisfaction', 'satisfaction with religious activities' and 'happiness with family' are more important (Gotay, 1996).

One who researches on chronic illnesses cannot set aside the element of subjectivity, as the very basic concept of illness is very much subjective. In the case of cancer the associated hazards like pain and suffering are also subjective. Also the concept of the quality of life of the patient is much value loaded and subjective. Taylor argues that people in modern times live with their own unchallengeable frameworks. Subjectivity/morality and objectivity /scientificity are the two extremes. Thus when one talks about the quality of life, it is often derived from one's own subjective experience. As Crossely argues, the increased access to knowledge may change the application of subjectivity in health related situations like well being, death, abortion, euthanasia, terminal illness, quality of life etc. (Crossley, 2000). Also questions are being raised on the achievements in life expectancy, that whether the gain in years of life is really accompanied by proportionate improvement in quality of the life of the individual (Seale, 2000). Thus the notion of quality of life is a significant one in the field of health care development and it is an added value given to the achievements in the field of health of the public.

In improving the quality of life of the cancer patient, the focus is on two major areas i.e. rehabilitation and therapeutic management of pain. Rehabilitation involves a variety of programmes and activities and the thrust is on home-based rehabilitation. Institutionalised rehabilitation is also widely accepted in cancer care. In the case of pain management, different techniques like medication, meditation, hypnotherapy, music therapy etc. are used (Meleka, 1983). For ensuring quality of life of the cancer patient, almost all approaches or attempts emphasise effective pain management. Unrelieved pain can significantly diminish the quality of life of the patient (Fanslow, 1991). Studies in developed countries show that a shift has taken place in the responsibility of care for terminally patients. From formal institutions of health care like hospital and hospice, it gradually shifted to the family. Crossley explains this as the result of the attempt of the medical profession to keep death and dying away from its agenda.

Apart from cancer pain management, another concept that WHO has developed, is the idea of continuing care in ensuring quality of life to terminally ill patients. It is associated with the hospice movement in developed countries where the terminally ill patients are provided institutionalised care and assisted to 'die comfortably'. Continuing care recognises dying as a normal process and it does not hasten or postpone death (WHO, 1986). It is argued that this idea of continuing care, as perceived by WHO, that stemmed out of the concern that psychosocial well being of the patients and their families is an extension of traditional medical care practice (Seale, 2000).

In India, palliative care was introduced in 1986 and still it is in the infancy (Editorial NMJI, 2001). Some researchers argue that family based rehabilitation and palliative care services are ideal in a developing country like India (Mohanti et al., 2001). The reason they give for this is the inadequacy of health service system and the cost of health care. Interestingly they made this suggestion despite the fact that in their study more patients preferred institutionalised care.

The coping of the family members with the disease and their role in providing homely care is important in the better quality of life of the patient. The burden on the family is significant in the case of cancer care. Training and support to family members especially the primary care givers are essential part of cancer care management (WHO, 1986).

Evidences from studies show that psychological factors such as stress, depression and social support modulate many of the immunologic activities relevant to malignant cancer patients (Lutgendrof et al., 2002). This shows the importance of psychosocial intervention in cancer care. This intervention can be in the form of strengthening the family relationship, assisting both the patient and family in coping with the disease by professional techniques etc. which ultimately contribute to better quality of life of the patient.

In the quality of life of the patient, malnutrition is another major factor, which is a cause of morbidity and mortality among cancer patients. This malnutrition may occur from the disease itself or from the treatment of it. Anorexia – loss of appetite – is a frequent problem (Barale, 1991), which causes malnutrition among the patients, which in turn reduces the quality of the life of the patient. This problem is very significant in the case of patients receiving care in home, as the family members cannot "persuade" the patient to improve the food intake. But in hospitals, the same patient can be persuaded by the professionals, as it is a procedural and functional activity of the institution. Here the point to be noted is that the behaviour of the same patient can be significantly different according to the place where he/she is receiving care. But it has another side too that the patient can enjoy food of his interest in home, which is not usually possible in hospitals.

The social consequences of cancer disease is also important as the patient has to get support from the immediate environment, which is significant in the quality of life. Cancer causes an attitude of helplessness in many people - patients, relatives and many physicians - also leading to abandonment of patients by those who are supposed to be supportive (Clark, 1976).

Summary

Cancer is a global health problem and it is developing as one of the major causes of death in the developing world also. Though the 'cause – effect' relationship is yet not established, epidemiological explorations show that there are differences in the distribution of the disease across societies depending upon the cultural, social, economic and geographic differences. In India also the contribution of cancer to overall mortality and morbidity is increasing over the years. Unequal distribution of cancer incidence is observed state wise in India and Kerala is the most affected state.

From the reviews it is understood that cancer is an important but not properly explored health problem in the developing world. What we know is the understanding from various studies conducted in the developed world where there is a different health culture and practices are different from those in the developing countries. The health priorities are also different and so the assumptions on health of the people, interventions and programmes are also varied. Another observation made is the priorities within the cancer research programmes, which are determined by a variety of external forces.

In the case of health care provisioning for cancer also, there are differences in intervention strategies. The palliative care movements and the hospice movements, which are the most accepted modalities in the developed countries, are not replicable in Indian context due to sociocultural differences. Cancer affects not only an individual but the entire family also. So treating cancer patients means treating the family too as the trauma due to cancer is significantly high on family in Indian context. In the case of health behaviour, socio-economic factors extensively influence the treatment seeking behaviour of the public especially in cancer. Life style factors are intermediary variables in the causal association between socio-economic factors and cancer. But the political economy of cancer research, in an attempt to establish "practical linkages' emphasise the notion of risk factors. Coping patterns of cancer patient and family and the quality of life of the patient are least explored areas especially in the developing world. In a developing society where the health situation is changing towards the domination of chronic, degenerative diseases and non-communicable diseases, like cancer, more understanding in an epidemiological plane is needed in this direction and it is essential in effective cancer management.

2

Conceptualisation and Methodology

Introduction

Kerala, being one of the advanced states in India, in terms of social and health indicators, has its own public health characteristics. Various studies show its unique health status, which is characterised by the dominance of non-communicable and degenerative diseases as the major causes of morbidity and mortality. Among the major causes of death in the state, cancer stands second to cardiovascular diseases and cerebral thrombosis (Kunchikannan et. al., 2000).

Though many researchers have worked on the biological and clinical aspects of cancer, very few studies have been conducted on the non-clinical dimensions of this disease. The concept of comprehensive cancer care as proposed by WHO, gives more emphasis to the psychosocial aspects of cancer care (WHO, 1986) and this thrust reflects from the shift from 'cure' to 'care' in cancer cases. This study aims at an understanding of the psychosocial dimensions of cancer disease management focusing on family, which is the immediate environment as well as the health care system that helps the patient in coping with the disease and in improving the patient's quality of life. We also explore the dynamics of health seeking behaviour of the patients and, the response of community to cancer.

Conceptualisation

From the review of studies done in the previous chapter it is understood that cancer is a complicated health problem both clinically and socially. The biological complexities of the disease and medical inadequacies in checking it create a phobia and a feeling of helplessness towards the disease in society. Inadequate or incorrect knowledge among public about the disease and its consequences also contribute to this feeling. Public perceptions towards the disease is significantly linked with the response to it. In the case of cancer, the attitudes and perceptions towards cancer, as seen in literature review, are varied across groups and cultures. The general perception regarding the disease is that it is an end to life with prolonged, painful suffering. It brings an uncertainty in the life of the patient and the general feelings towards cancer in both the patient and family are varying degrees of fear, helplessness and hopelessness. Along with the biological consequences of the disease, factors like early life experiences, belief system, subjective understanding, social position and socio-economic status, personality, psychological factors and cultural factors are the important determinants of the response towards cancer.

Coping

This study aims at an understanding of the coping pattern of patient and the immediate community, mainly family and the peer group, towards cancer, and the various factors associated with their coping strategy. There are various definitions for coping. In present study coping is conceptualised as the conscious or unconscious response from the cancer patient and the family to deal with the consequences- physical, psychological and social- derived out of the disease. Coping with the disease is a significant factor in effective cancer care and management. It is influenced by socio-economic and psychological factors. The coping pattern of an individual with cancer can be understood by examining the linkages of these factors as well as the patients' perceptions and his/her feeling of well being. The prolonged period physical, psychological, social and financial impairments and suffering and the resultant changes in the perceptions and attitudes of the family, have significant relationship with coping patterns. The patient undergoes a series of mental processes from the very identification of the symptoms till his/her death. All these variety of stages and the mental processes help constitute the coping pattern. In cancer cases usually the survival rate is very low and so, coping with the disease is emphasised to improve the quality of life of the patient. Acceptance of and adjustment with the disease and its consequences are given thrust in cancer care. The question of coping is analysed in the context of family based cancer care as family is the most important social structural component that plays vital role in the personal and social life of an individual. There are other aspects like role of family, treatment seeking behaviour and quality of life associated with the cancer care, which are also explored through this study.

Role of Family

Family is the primary care giving agency in the Indian society, where health care development and healing are considered as a collective and shared responsibility of the individual, family and the health care system. The dynamics of variety of factors – political, economic, cultural and psychosocial – influence this provisioning of care through family.

A number of researchers emphasised the role of the family in cancer care as the consequences of the disease influence not only the patient but the family and community (Gotay, 1996; Weihs & Reiss,1996; Schulz et. al., 1996; Haddad et. al., 1996; Bloom, 1996). Here community refers to the immediate neighbourhood that include the peer group, the local village community, the co-workers and close-circle relatives. The meaning and definition of illness and well being are also influenced by this immediate environment. The nature of cancer is so significant that it often makes the patient more or less fully dependent on the family especially in the advanced stages of disease. Also the role of hospitals or other formal health care institutions like palliative care centres or hospices and after care homes are limited in Kerala. Though the health status of the state could be compared with that of the developed countries, the health care practices and health care provisioning are significantly different from that of the developed world and influenced by the rich traditional health practices and culture. The role of hospitals and other formal institutions is limited to curative intervention only and that also technology based treatment, which is very much impersonal. In the case of all illnesses, personalised care is equally important to medical care. For more personalised care as well as care after the treatment, family is responsible and this responsibility is associated with a variety of consequences. It is customary, also, to take care of the patient in home in Asian cultures (Gotay, 1996), which holds true in Indian context. The burden of care is generally added on to the existing workload on family members especially women. "Family is a code word used for women when discussing care at home" (Loustanau & Sobo,1997, p.25). So the dynamics associated with family/home care also need to be explored in understanding the coping strategies and quality of life of the patient and family members.

Treatment Seeking Behaviour

In comprehensive cancer care as perceived by WHO, early detection is given more emphasis than curative intervention. This is because of the limitations of modern medical and other external factors like delay in seeking treatment for cancer. The conceptualisation of cancer detection does not address the issue of technological backwardness of the developing countries in the areas of health care provisioning and the priorities in overall health development. It is in this context that an understanding of the health seeking behaviour of the patient is significant. Health seeking behaviour is derived from the complex process of interaction between the patient and external factors like the political components in health viz. policies, economic factors, access to health care service system, cultural factors like practices, beliefs and experiences with health care system.

Delay in seeking treatment is an important aspect of this complex process. Delay in seeking treatment is significant in the case of cancer as it causes advancement of the diseases in the form of spreading to the secondary sites. Thus the major hurdle to be overcome in cancer management is, the delay in treatment seeking and the diagnosis. Along with the early mentioned macro factors, a variety of socio-economic, demographic and psychological factors like age, gender, income, social networks, education and knowledge, beliefs, attitudes, perception, early experiences, social support etc. are also significant factors in treatment seeking behaviour. The association of these factors with treatment seeking behaviour of the patient is also explored through this study. Apart from the influence of these factors on the patient, the dynamics of the patient with the family, the caregivers and the public also influence the treatment seeking behaviour. The psychological distress attached with cancer is very much associated with these factors. The variety of beliefs and assumptions and their influence in individual's health seeking behaviour is also an area of exploration.

Quality of Life

The idea of quality of life is more of a qualitative and abstract one. It is problematic to define it and various researchers define it in their own way. One's perceptions and attitudes significantly determine the quality of ones life. Though it is an individual specific, subjective idea, for the purpose of analysis it is necessary to be operationalised. It is assessed in terms of tangible factors like independence, physical performance and absence of any disability or handicap (Kishore, 2002). The physical complications are also significant in the case of a diseased person. As it is more of a perceived state of ones functional existence in society, previously mentioned psychosocial factors have significant association with one's idea of quality of life. Knowledge and cognitive mechanisms like beliefs, aspirations, value systems and standards are also to be explored as all these factors could influence one's perception of his worth and value in the society or the community, which in turn determine the coping with the disease. In the case of cancer, it is a disease with a wide range of functional consequences both for the patient and the family/ community. The importance of the concept of quality of life of the cancer patient is that the very idea of cancer is developed in connection with the well being of the patient and so it is an important area to be understood.

The concept of quality of life, in the present study, is operationalised in terms of six variables. They are: present stage of the disease, degree of disability, current feelings regarding one's functional status, coping pattern, family support and financial status of the family. All assessments of quality of life cover physical functioning, psychological well being in terms of independence and feeling of worth, and social functioning. Among the above mentioned six variables, stage of illness, which may range from 'terminally ill' to 'survived' and degree of disability that ranges between 'fully dependent' to 'normal' deals with mainly the physical functioning of the patient. The variable 'current feelings' is based upon the direct response from the patient and is crosschecked by the variable 'coping', which is assessed, based upon the observation of the researcher. The variable 'family support' is to cover the non-medical support mechanism while the 'financial status of family' will cover the medical care part with the assumption that the accessibility to medical care system is determined primarily by the financial status of the patient. Thus a six variable, five-point scale is developed to assess the quality of life of the cancer patient.

Thus the present study is an attempt to explore the influence of the wide range of socio-economic and psychosocial components in treatment seeking behaviour and coping pattern of cancer patients and the role of the family and the community along with health care institutions in this process. The coping pattern and its association with quality of life of the patient are also explored. The specific objectives of the study can be summarised as follows:

1. To review the profile of the cancer cases in Medical College Hospital, Kottayam, Kerala.
2. To explore the existing services and programmes and provisioning of the services in cancer care in the Medical College Hospital, Kottayam.
3. To explore the care giving in hospitals and home in the case of cancer.
4. To study the experiences, perceptions and attitudes of patients, relatives, and health care professionals and general public regarding cancer.
5. To explore the factors influencing these experiences and perceptions.
6. To study the treatment seeking behaviour of patients with cancer.
7. To study the coping pattern of patients and their family members with cancer disease.

Methodology

Population

The study population consists of the cancer patients who are getting services from the department of radiotherapy in the Medical College Hospital, Kottayam, Kerala state. In public sector, there are six medical colleges in Kerala state, which are in Thiruvananthapuram, Alappuzha, Kottayam, Trissur, Kozhikkodu and Kannur districts. As part of the National Cancer Control Programme, Oncology departments have been set up in every medical college hospitals. From these, Kottayam medical college is selected purposively because of convenience and access for the study.

Sampling

The catchment area of medical college hospital, Kottayam spreads over five adjacent districts say Alappuzha, Pathanamthitta, Idukki, Ernakulam and Kottayam. Thus the services of the hospital cover a large geographic area. Patients from hundreds of kilometres away also visit the hospital. It was planned to conduct the study among the patients who are registered within last one year and receiving services continuously as out patients from the Medical College Hospital, Kottayam for cancer, and are staying with their families. A major criterion for sample selection access to the patients for meetings and follow up was.

Forty patients were listed out from the hospital register for the year 2002 purposively based on access to them in their home. Thirty-six patients from this list were covered in the study. These patients were spread in Kottayam district and within a radius of forty to fifty kilometres from the hospital. One of the primary caregivers of each patient is also selected purposively during house visits. The selection of the caregiver was also from the hospital register as there is a system of keeping the names of the caregivers when the patients are registered in the hospital. In the case of absence of the listed caregiver at the time of house visit, based upon the response of the patients, a caregiver in their home is selected.

From the group of health care professionals of the department of radiotherapy in medical college hospital, Kottayam, a group of twelve members were selected purposively such that it contains four physicians, four nurses and four paramedical staff. Here also the sample selection was based on access to them for interviews and follow up meetings and their readiness to respond. In the case of the general public, they were divided into two categories as those who are directly associated with health care services, and those who are not directly associated with health care provisioning. In the first category, it includes medical students, social workers etc. and in the second category, it consists non-medical professionals and lay people. From the first category a sample of ten and in the second category a group of twenty were selected purposively. Here again the criteria for selection were access and willingness to respond.

Thus the sample for the study contains totally 114 respondents. The detailed break-up of the sample is given below:

Patients	36
Relatives/ Caregivers	36
Professionals	
Physicians	4
Nurses	4
Paramedical staff	4
General public	
Category I	10
Category II	20
Total	114

Data Collection

Collection of data was through fieldwork by the researcher during the period of October 2002 to January 2003. During this period, the researcher visited various institutions both in private sector and public sector working in the field of cancer care, the Medical College Hospital, Kottayam, families of the respondent patients and a number of people associated with cancer care. A few NGOs working with cancer patients were also visited and informal discussions were held with the professionals in those organisations.

Sources of Data

Data needed for the study was collected from both primary and secondary sources. Primary sources consist of the patients, their family members, professional, general public and other key informants. Secondary sources were mainly published works, related literature and hospital records.

Tools of Data Collection

A set of different tools was used in the process of data gathering. The tools used were: Interview schedule, questionnaire, semi-structured in-depth interview, informal discussion, case studies and observation by the researcher.

Interview Schedule

Separate interview schedules were administered for collecting information from patients and their family (see appendix-I & II). It consisted of both open end and close end questions on the demographic and socio-economic details, disease related information and their attitudes and perceptions on cancer. It also covered details regarding the beliefs, assumptions and expectations of the respondents related to the disease and its treatment. It also traced through the schedules the consequences of the disease to the respondents at both individual and family levels.

In the case of the second category of the general public- those who are not directly associated with health care services- another interview schedule was administered, as most of them were not familiar/comfortable with the language used in the tool. The schedules contain both open end and close end questions related to the demographic, socio-economic and disease related information as well as questions on their perception and experiences with cancer disease

Questionnaire

General public who are directly associated with health care provisioning were approached with questionnaires of the same format of the interview schedules administered on the category public who are not associated with health care services (see appendix-IV).

Semi-structured Interview.

The researcher, with the help of a prepared semi-structured interview guide (see appendix-III), interviewed the sample of health care professionals. It covered information regarding their professional practice, experiences with cancer disease and patients, communication with the patients and family members and their perception and attitude towards the disease. Interview with the social workers of one of the leading NGO in New Delhi working with cancer patients also was done as part of the data gathering.

Observation

As the set of the information needed for the study were qualitative in nature, observation was one of the important tools used in data gathering. It was essential and significant during house visits. It helped in crosschecking the information given by the respondents. The dynamics within the family, social networks, communication pattern, physical condition of the patients, socio-economic status, hygiene factors, habits etc. were also observed during the house visits. Several visits were done in the medical college hospital also, where observation was important on various aspects like facilities and services, their provisioning, dynamics within the institutional structure, the communication between the professional and the patients etc. were the major areas of observation.

Informal Discussions

Informal discussion was another tool used in the data gathering process by the researcher. Medical care professionals from the population and outside it, teachers, employees, inpatients of the department of radiotherapy in Medical College Hospital, Kottayam, relatives of patients died of cancer, religious leaders, medical students etc. were participants in this process. A nearby hospice, and a private hospital were also visited as part of the fieldwork and the informal discussions with the authorities, the social workers and other caregivers were also helped in the data collection process.

Case study

From the house visits and interview with the patients and their relatives, two cases were identified for in-depth study. They were selected on the basis of continuous access for follow up visits, difference in site of the disease and present disease status (one is terminally ill and the other is 'recovered'). Several visits were done and the disease histories were traced through discussions with the patient, family members and close neighbours.

Process of Data Collection

The study population spread over five adjacent districts and Medical College Hospital, Kottayam, is almost in the epicentre of its catchments area. The hospital is situated at Gandhinagar, a village eight kilometres away from the Kottayam Township. The study sample was selected with the criterion of access to the patients and they spread over an area within thirty to forty kilometre radius from the hospital. Some of the families were in interior villages and follow up of those cases was a tough task.

The formal data gathering was through the fieldwork done by the researcher in the population for a period of four months, which started from October 2002 and ended up by the end of January 2003. In the first phase of the data collection, secondary data sources were covered to collect the disease details, time trends and disease distribution. Questionnaires were distributed among the first category of public in the beginning phase itself.

With the help of the list of patients prepared from the hospital register, patients and their caregivers were interviewed. Among the identified forty patients, only thirty six were successfully covered. The other four could not be completed due to the non-cooperation from three and one could not be traced. Interview schedules were used in this process. This continued till mid January 2003. In some household, the researcher had to visit several times to follow up the cases.

In those cases where in-depth study was planned, they were followed up through many visits and informal discussions with family members, neighbours and in-depth interviews with the patients and the primary care giver were used in collecting information regarding the cases. Data gathering from the professionals and the general public was according to their convenience and so it spread over the period of fieldwork.

Pretesting

Pretesing of the tools was done by administering them among a few patients and their relatives who had visited the outpatient division of the department of radiotherapy Medical College Hospital, Kottayam for treatment. Based on the results of the pretest, modifications were done on the tools.

Limitations of the Study

There are a few possible limitations in the present study. First one, is the dissipation of the information while translating them from the local language i.e. Malayalam in which the data collection was done to English. The intensity and the meanings of the responses may have got affected to a limited extent in the translation process. Extra care was taken in this regard by the researcher. Another limitation is the possible bias in the responses of those professionals who were willing to participate in the study, as they may be good in communication and more lenient towards the patients. Therefore there could have been some biased response from them towards the patients and their families. Another limitation faced in the study is the calculation of delay in treatment seeking by the patients and their families. Since the delay is calculated from the verbal responses of the respondents only, there can be some errors due to the tendency of the people to round up the time period. Also some of them do not remember the exact date of their symptom identification and visits to a doctor. But the researcher paid utmost care in interviewing them to reduce these kinds of limitations to the maximum possible extent.

3

Patients, Services and Trends in Cancer

The general understanding of profile of the study population is a basic requirement of every study. This chapter discusses the general profile of the cancer patients under this study. It covers the basic demographic profile of the patients, which include the age, sex, education, occupation, family structure, socio-economic status etc. In the second section of the chapter, the available services in the field of cancer care and the provisioning of these services in the population through Medical College Hospital, Kottayam are explored. In the final section, a detailed discussion of the time trend in the incidence of cancer in the population under study is made using the data available from the hospital records and it is crosschecked using the data collected from the sample.

Profile of the Patients

The study was conducted among patients who received treatment for cancer during the last year and are currently undergoing homecare. Among the thirty-six patients interviewed, there are equal number of males and females. Table 3.1 shows the genderwise distribution of the marital status of the patients.

Table: 3.1 Gender - Marital Status Distribution of the Patients

	Marital Status of the patient			**Total**
	Married	*Widowed*	*Unmarried*	
Male	12	4	2	18
Female	11	5	2	18
Total	23	9	4	36

Among the sample of patients, 23 (63.9%) are married, nine (25%) are widowed and four (11.1%) are unmarried. The sample consists equal number of Christians and Hindus. There are no respondents from any other religious groups.

Age of the Patients

In the study, the age of the participant patients ranges between five to eighty five years. The most frequent age group of the patients is 60–69 years i.e. 25 % of the sample followed by 50–59 age group with a contribution of 22.2% and 84% of the patients are distributed between the age group 30–79 years. Also there is a clustering of the patients towards the beginning of old age i.e. towards fifty to sixty years of age. The following table gives a detailed break-up of the age distribution of the patients under present study.

Table: 3.2 Age group - Gender Cross-tabulation of Patients

Age of the patient	Gender				Total	
	Male		Female			
	Number	%	Number	%	Number	%
0 – 9	1	5.5	0	0.0	1	2.8
10-19	0	0.0	1	5.5	1	2.8
20 – 29	1	5.5	1	5.5	2	5.5
30 – 39	2	11.2	3	16.7	5	13.9
40 – 49	1	5.5	4	22.2	5	13.9
50 – 59	4	22.2	4	22.2	8	22.2
60 – 69	7	38.9	2	11.2	9	25.0
70 – 79	2	11.2	2	11.2	4	11.1
80 and above	0	0.0	1	5.5	1	2.8
Total	18	100	18	100	36	100

Various studies on cancer had observed that among the total cancer cases, 60% of them belong to the age group of 35-65 years (Kishore, 2001). In present study also data from the hospital records support this finding as, for the years 2000 and 2001, a tendency of clustering of cancer cases in the population around the above-mentioned age group is observed. In the year 2001, as per the hospital registry, 1758 (59.2%) patients belong to the age group of 35-65 years. In the year 2000, 74.7% of the patients registered in the hospital belong to 30–69 age group.[1]

The public's perception, that cancer is generally a disease of the aged or it is associated with ageing might be derived from this kind of an observation. Literature also gives evidences for this tendency of more cancer incidence among the aged (ICMR, 2001; Gribble & Preston, 1993; Kishore, 2001). From the hospital records, it is observed that there exist gender differences in the distribution of the disease over different age groups. In the case of old age, i.e. above 55 years of age, more males are prone to cancer than females.

Data from present study show that in the sample of patients, 72.2% of the male patients belong to the age group of 50–79 years, whereas this is only 44.5% for females. But in the middle age, women are more prone to cancer than men as in the study it is shown that only 16.75% of male patients belong to age group of 30–50 years. At the same time, 38.9% of women patients belong to this age group, which is more than two times the number of men in that age group. In short women are more vulnerable to cancer during middle age and ageing is a risk factor for men in the case of cancer. The hospital records also prove this argument. One important aspect in this distribution is the large number of female patients with breast cancer. Most of them belong to the middle ages. This higher concentration of female breast cancer cases in the middle age can influence the entire distribution of cancer cases in women over different age groups.

From the hospital records, a slight difference is observed between the incidence of cancer among males and females. Among the total 3089 patients registered for cancer treatment in Medical College Hospital, Kottayam, during the year 2000, there were 1660 (53.8%) males and it was 1581 out of the total of 2972 patients i.e. 53.2% in the year 2001. In both the years 2000 and 2001, the proportions of women were less than that of men to total patients i.e. 46.2% in 2000 and 46.8% in 2001. It shows that on an average, small difference is there in the crude incidence rate of cancer in the population

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[1] The age of the patients in the hospital records of the years 2000 and 2001are compiled in two different class intervals.

between males and females. This is contrary to the all Kerala data on cancer incidence, which shows a higher incidence of cancer among women. The female–male ratio in cancer incidence per thousand population is calculated as 1: 0.81 in Kerala (State Economic Review, GOK, 2000).

Data from cancer registry programme of ICMR also shows the tendency (ICMR, 2001) of higher cancer incidence rate among women. But before reaching to this kind of a conclusion, one must look into the reasons and methodological issues. That is there could be chance for underreporting of cases, but observation shows that treatment seeking among men is comparatively poor and mostly in the advanced stage, and the common cancers among women are breast and genital organs, which are disclosed at a later stage due to shyness and inhibition. Thus one can assume that there can be a possible delay and underreporting in the case of both men and women, which needs more exploration before generalisation. But there is an established gender difference in the disease distribution among population both in number of cases and sites of the disease.

Education of the patients

In the study sample, out of the total thirty-six patients participated, nineteen (52.78%) are educated up to primary school level and fourteen (38.89 %) are completed their high school education. Two patients (5.55%) are higher educated and one of the patient is technically qualified. A detailed break-up of gender wise educational status of the patients is given in table 3.3.

Table: 3.3 Education of the patient - Gender Cross Tabulation

Education of the patient	**Gender**		**Total**	**Percentage**
	Male	*Female*		
Primary	10	9	19	52.8
High school	6	8	14	38.8
Higher education	1	1	2	5.6
Technical	1	0	1	2.8
Total	18	18	36	100

Occupation of the Patients

Cancer is a disease, which affect the life of the patient vividly. One important change that generally happens in the life of the patient is the employment pattern. Review of studies shows that majority of the patients cannot go back to their original occupation after the treatment for cancer either due to physical deformity, psychological or other reasons. Table 3.4 shows the previous occupation of the studied patients.

Table: 3.4 Previous Occupations of the Patients

Occupation	No of patients	Percent
Unemployed	1	2.8
Coolie	7	19.4
Unskilled regular	2	5.6
Skilled	2	5.6
Professional	1	2.8
Housewife	15	41.7
Farmer	4	11.1
Student	2	5.6
Retired	2	5.6
Total	36	100.0

In the present study it is observed that none of the patients is able to work after getting diseased. Out of the total eighteen female respondents fifteen are housewives, one is professionally employed one is a school going student and one was coolie worker. The housewife class include those who are aged and unemployed. None of them are healthy enough to go back to their original occupation. In the case of male respondents, most of them are coolie workers or farmers/ agriculture workers. None of them are now engaged in their previous occupation as a result of their ill health. In short to most of the cancer patient the disease means a total change in their occupation resulting into economic dependency, which can cause psychological pressure on the patient. Two of the respondents are school going students and both of them lost their current academic year due to their disease.

Age of the patient is a significant factor in deciding their inability to work. Fourteen of the total thirty-six patients (38.9%) are above sixty-five years of age and naturally their old age also is an important factor in their disability to work. Two patients (5.6%) are school going children. In the case of the rest of 55.5% of the patients, their disease is the most important factor in their inability to work.

Family Background of the Patients

The patients under this study are living either in their own family or with their children. Out of the total patients, 88.9% are staying in their own home and the rest are staying in their child's or close relative's home. 55.6% of the patients belong to extended families with children and grandchildren other close relatives and 36.1 % of the patients belong to nuclear families. Only three of the patients (8.3%) belong to joint family. The average family size of the respondents is 5.11.

Generally poor class and lower middle class people seek treatment in Medical College Hospital. Most of the higher-class people utilize highly sophisticated and specialised medical care system in private sector. In the case of cancer patients interviewed under present study and who seek treatment in Medical College Hospital, majority of them belong to lower class and middle class. Though a clear differentiation was not done in this area based on the observation of factors like their family income, occupation of family members, education, land holding, family size, housing condition, family assets, place of residence etc., it is found that fifteen patients (41.66%) belong to middle class and the rest twenty one (58.33 %) patients belong to lower class.

Hospital Admission of the Patients

Table: 3.5 Duration of Hospital Admission

Duration	No. of Patients	Percent
Nil	11	30.6
Less than 1 month	12	33.3
1 - 2 months	12	33.3
2 - 3 months	1	2.8
Total	36	100

As seen in table: 3.5, in the case of the duration of the hospital admission of the patients, of the total patients, 69.4% were admitted in medical college hospital for some time during their treatment. They were admitted in different phases of their treatment for cancer. Out of the total thirty-six, 33.3% of the patients had spent less than one month in the hospital and another one third of the patients had to spent a period of one to two months. One patient had spent more than two months for treatment as an in-patient in the Medical College Hospital. This is either in a single stretch or cumulative of multiple admissions. Currently all of them are in different stages of the disease and receiving care in home. Of the total patients, half of them are fully aware that their disease is cancer. 30.6% of the patients are unclear of their disease and the rest 19.4% don't know that they are cancer patients. This is mainly because of the nondisclosure of the diagnosis to the patient by the relatives and family members. All of them utilising the outpatient services in the Medical College Hospital. Following table gives details of the frequency of hospital visits by the patients.

Table: 3.6 Frequency of Hospital Visits

Frequency	No. of Patients	Percent
Twice a week	1	2.8
Weekly	11	30.6
Monthly	12	33.3
Not regular	12	33.3
Total	36	100.0

One of the patients makes two visits per week to the hospital for the purpose of follow up of the treatment. Among the total sample, eleven patients (30.6%) make weekly visits to hospital for the follow up of treatment and twelve patients (33.3%) make monthly visits to the hospital. Another one third of the patients are visiting the hospital not regularly. Their irregular visits are either because of the nature of the treatment they are receiving or because of their poor compliance with treatment due to various reasons.

In home, the close relatives of the patients are their primary care givers. In the case of the studied sample, for majority of the patients (44.4%), the primary care giver is the spouse of the patient. In the case of gender of the primary care giver, majority of them are women. 63.9% of the caregivers of the patients are women and the rest 36.1 % are men. Table 3.7 shows the relationship of the primary caregiver in family with the patient.

Table: 3.7 Relationship of the Primary Caregiver with the Patient

Relationship with Patient		No. of Patients	Percent
Mother		4	11.1
Spouse	Male	7	19.4
	Female	9	25.0
Son		4	11.1
Daughter		2	5.6
Daughter in-law		8	22.2
Others		2	5.6

While the burden of care is a collective responsibility in the family, generally the major portion of this responsibility is borne by women. It is mainly because of the gender roles assigned to women in nursing, caring and attending the ill. Another observation made is the nature of work of women caregivers, which is mainly home related. Majority of these women (61.1% of the care givers) are not working outside the family instead they are either housewives or unemployed who engage in managing their home, rearing their children or siblings and other family related petty works along with the caring of the patient. Some of them have to support their family through the supplementary income they earn from petty works like cattle rearing.

The patients who are receiving care in home are in need of special attention and support from the family especially in the areas of nursing care. Male family members, who are mainly working outside their home, to a great extent, are exempted from this primary responsibility because of their occupation or other cultural reasons. In the case of terminally ill patients, nursing care and other services like cleaning, feeding, assisting in toilet activities etc. are done by women in home. As most of the patients have visitors after getting diseased, receiving and entertaining them is also a major responsibility of the women. Most of these roles are culturally conditioned.

Life-style of the Patients

As lifestyle and habits are reported as one important causal component of cancer, food pattern and habits of the patients were studied. It is found that 97.2% of the patients were non-vegetarians and some of them are trying to change their food habits after getting diseased. The following table shows the gender-wise distribution of habits of the studied sample.

Table: 3.8 Gender-wise Distribution of Habits Among the Sample

	Smoking	**Chewing**	**Drinking**	**Nothing Special**	**Total**
Male	13 *(72.2%)*	2 *(11.1%)*	1*(5.6%)*	2 *(11.1%)*	18 *(100%)*
Female	1*(5.6%)*	2*(11.1%)*	0	15 *(83.3%)*	18*(100%)*
	14 *(38.9%)*	4 *(11.1%)*	1*(2.6%)*	17 *(47.2%)*	36*(100%)*

Among other habits, 38.9% of the patients were smokers, 11.1% used to chew tobacco, and 2.8% reported as regular alcohol consumers. Great majority of these sections is men. Among the total sample, 72.2% of the men are smokers, 2.2% of them are regular tobacco chewers and only one male patient is reported to be having regular alcohol consumption. 47.2% of the total patients reported no particular habits and most of them are women. One important thing reported is that there is a considerable change in the habits of the patients either because of the advice from the physician or by the persuasion of the family. As literature shows, it is found that statistically there is an association between tobacco consumption and cancers of lung/ oral cavity. Thus the data from present study also supports this argument of risk behaviours and their association with cancers. The changes in the life of the patients after getting diseased are discussed in detail in the next chapter. Also among those who are having these 'risk behaviours', 72.2% of them are having cancers in lung or mouth and related sites. Thus a primary analysis supports the argument that the risky lifestyles like smoking and tobacco chewing are major associated factors in the higher incidence of cancers of oral cavity and lungs.

Services for Cancer Care

Medical College Hospital Kottayam, Kerala (MCK) is one of the six medical colleges of the state in public sector. For the last forty years, this institution is engaged in the field of medical education as well as therapeutic intervention. The department of radiotherapy in the hospital is one of the important departments and offering services mainly to the population of five adjacent districts of Pathanamthitta, Alappuzha, Idukki, Ernakulam and Kottayam.

Being a tertiary care hospital, majority of the cases are based on referral from lower levels. It has a separate wing for cancer care with four wards with twenty-six beds each. A team of about thirty-five personnel including physicians, nurses and paramedical staff are engaged in the provisioning of cancer care services. The hospital is offering therapeutic services like chemotherapy, radiotherapy/ needle implantation and surgery. Even though it is in the public sector, the hospital charges user fees like hundred rupees for radiotherapy per episode and a registration fee of rupees ten from the patients. However, the staffs of the hospital explain this as nominal and meagre when compared to other private hospitals. Many poor patients mentioned the high cost of radiation therapy. Also the patients have to bear the cost of the drugs. The hospital staff also commented on the unavailability of essential drugs.

The hurdles before the hospital, according to the professionals, in offering effective treatment to cancer patients are mainly, staff deficiency especially physicians, inadequacy of equipments like radiotherapy machines and other infrastructure and the absence of provision for free medicine to patients. Both the public and the professionals are of the same opinion on this matter. There is a kind of stigma attached with the department also that generally the medical students also do not prefer posting in this particular department. One of the physician responded that generally medical students skip their posting in the department of radiotherapy as they consider this particular disease as something, which is nothing to do with, as most of the patients are terminally ill. He complained on the "culture" that is being created through the current curriculum of medical education, which pays "minimum attention to community health" and giving only biomedical orientation. The perceptions of medical students, who are a part of the public associated with the health care services, are discussed in the next chapter.

Both the patients and the caregivers are also with the opinion that the services in the hospital must be improved. One third of the caregivers did not identified any shortcoming in the hospital while two third of them mentioned inadequacies like absence of adequate infrastructure facilities, poor provisioning of medicine, long queues, unhygienic premises etc. Many patients and caregivers, especially those from far away places complained on the poor availability of services in their locality as a result of which they have to travel a long distance to reach MCK for treatment. The distance to the hospital is a major factor in the follow up of the treatment.

According to the professionals, who had participated in the study, the hospital faces resource constraints due to which it cannot organise community health camps, which are supposed to be conducted regularly. Community cancer screening camps are one of the main activities under the primary prevention program as visualised under National Cancer Control Program. But the hospital, according to the professionals, could not organise any such community cancer screening camps for the last few years. The hospital also faces shortage of consultant physicians as it deals with more than 200 patients on an average in out patient counters daily. Only one radiotherapy machine is available in the department of radiotherapy with which it is difficult to manage the needs. According to the radiographer, the actual capacity of the available machine is 32 radiations per day. However with that machine they are managing an average of 125-130 radiations per day. This shows the inadequacy of equipments for treatment. Many patients have to wait for another day for radiation therapy due to this limitation. This also is a factor in the delay of treatment and is discussed in the coming chapters.

As per the annual report, Medical College Hospital, Kottayam is one of the institutions, which received biggest amount of fund under National Cancer Control Program (NCCP)[2] for cancer treatment in the year 1999-'00. Under the assistance to Cobalt

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[2] National Cancer Control Programme was started in the year 1975 and revised in 1984-85.

Therapy[3] Medical College Hospital, Kottayam received Rs.200 lakhs in the year 1999-2000.[4] The only radiotherapy machine in the hospital is purchased under this scheme. According to the professionals interviewed, the hospital is in urgent need of two more radiation machines and adequate staffs for better provisioning of services. The hospital development society (HDS), which is a voluntary organisation functioning in the hospital, provides financial assistance to one medical shop that provides medicine to cancer patients on subsidised rates. The major sources of finance to this body are the user fees from the patients, fee from the visitors and donations. But these services are inadequate to meet the increasing needs of the public. From the response of the participants of the study it can be concluded that more effective intervention from the part of government and hospital authorities are needed towards the development of infrastructure and betterment of essential services.

Time Trend in Cancer

The trend in the incidence of cancer over time is very significant to analyse, as it is associated with the health transition that happens in society. The dominance of chronic diseases over infectious disease is a characteristic feature of this transition.

Table: 3.9 Number of Reported Cancer Cases in MCK, 1996-'01

Year	Number
1995	2152
1996	2588
1997	2947
1998	2959
1999	3033
2000	3089
2001	2972

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[3] A form of Mega voltage therapy provides more efficient and effective delivery of the intended radiation dose to tumours deep inside the body and, at the same time, spares the healthy skin and surrounding normal tissue from excess radiation. Microsoft® Encarta® Reference Library 2003.

[4] Annual Report, Ministry of Health and Family Welfare (2000-'01), GOI.

The above table shows the number of registered cancer cases in Medical College Hospital, Kottayam during the period 1996-'01. It shows an increment in the number of reported case every year except the year 2001. The explanation given for this reduction in number is the deficiency of staff, and transfer/retirement of few experienced doctors, which made some of the patients to seek treatment in their new places.

Data on the distribution of cancer cases registered in Medical College Hospital is available for the years 2000 and 2001 from the records maintained in the hospital. Diagrams 3.1 and 3.2 explain the distribution of cancer cases in different age groups in these two years in males and females separately.

From a comparison of the distribution of patients in 2000 and 2001 (see diagrams 3.1 & 3.2), it is observed that there is a slight shift in the distribution of the patients over different age groups (though the age class intervals are not uniform, taking the range between 0–90 years and only two years' data is available[5]). In both the years 2000 & 2001, the curves are negatively skewed. The mean age of the patients in 2000 was 57.18 years, and it reduced to 56.67 years in 2001, and the Mode value of the distribution reduced from 62 to 60.04 years. In other words there is a tendency, in 2001, to shift the mean age of cancer incidence that reported in the Medical College Hospital slightly towards the middle age. This can also be because of the comparatively higher reduction (4.76 %) in the number of registration of cancer cases among males than that of females (2.04%) in the year 2001 and because of the relatively higher incidence of cancers among women in the middle ages.

For both the years, the number of cancer incidence among women is less than that in men. But in the case of the year 2000, till the age of 50 years, the number of female patients is higher than that of males. After the age of fifty the trend is opposite. Also in the case of women, the incidence of cases is almost normally distributed over different age groups, which is negatively skewed in the case of men. This negative skewness continues for men in 2001 also but in the case of women it is positively skewed with a clustering in middle age with a mode of 53.07 years, which was 57.21years in 2000.

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[5] In the hospital records, compiled data regarding the registered cases of cancer, only for the years 2000 &2001 is available. These are tabulated in two different class intervals.

Diagram: 3.1 Registered Cancer Cases in Medical College Hospital, Kottayam, 2000

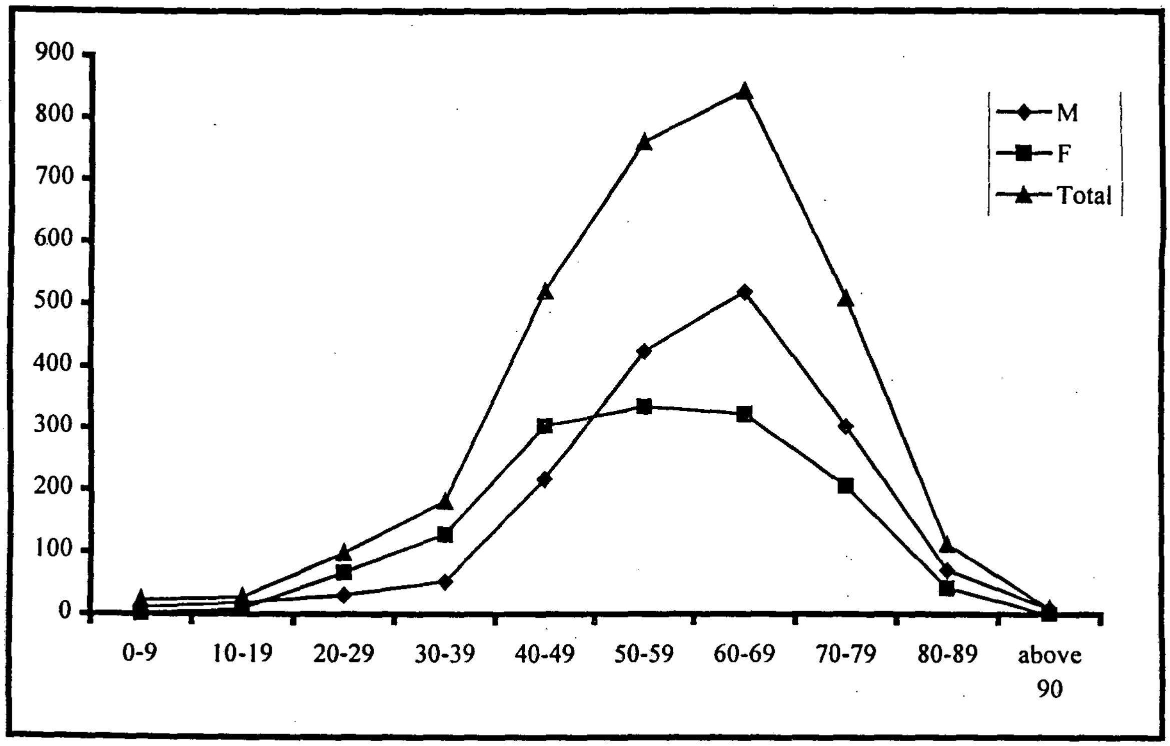
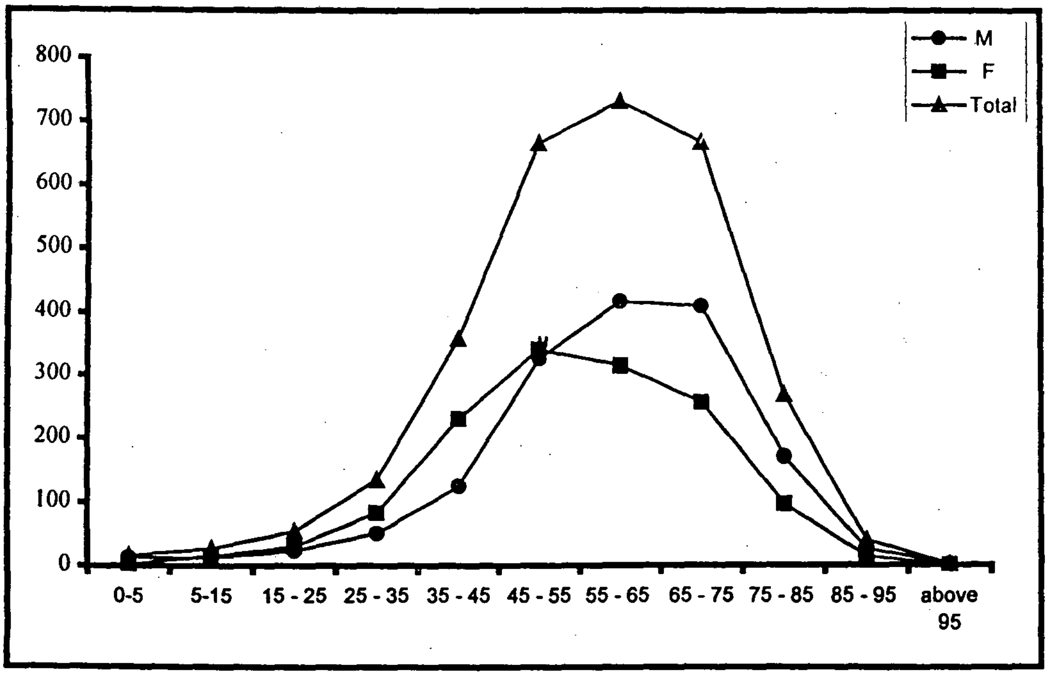


Diagram: 3.2, Registered Cancer Cases in Medical College Hospital, Kottayam, 2001



Regarding the time trend in the cases of cancer almost all the participants of the study are of the opinion that the number of cancer cases is increasing in Kerala especially in their locality. There is no difference in opinion between different groups of the respondents in this aspect. The professionals from the Medical College Hospital are also with the same opinion. But the hospital records show a decrease in number of registration in the year 2001. As per the hospital records in the department of radiotherapy, there is a reduction of 117 (3.8%) cases in the year 2001 when compared to that in 2000. The professionals of the department explain this as a few of the most experienced doctors left the department either on transfer or on retirement resulting the patients to seek treatment in other hospitals. Also this trend in reduction in number is attributed to the emergence of some private hospitals. A nearby private hospital recently established department of oncology, which deals with mainly breast cancers. Few super speciality hospitals were also come up in the catchments area of Medical College Hospital, Kottayam. All these might have contributed to the reduction in the number of registration in the year 2001.

In the case of the trend in age at which cancer is affected, 41.7% of the professionals observed a tendency of clustering of the age of the patients between 30–60 years. Previous analysis done in this chapter also supports this observation. 25% of the professionals observed a clustering in the 'old age' and another 25% could not notice any such clustering.

But literature as well as the hospital records shows the tendency of clustering of the incidences of cancer in old age. Similarly, as per the hospital records, in the year 2000, 61.2% of the registered patients belong to the 'age of dependency' i.e. below 15 years and above 55 years. This was 59.1% in 2001. It can be inferred from these data that a majority of the patients belongs to the 'age of dependency' (below 15 years and above 55 years).

Table: 3.10 shows the site-wise distribution of cancer cases registered in Medical College Hospital, Kottayam for the years 2000 and 2001. It shows that the most recurrent type of cancer is breast cancers followed by cancer of oral cavity.

Table: 3.10 Site-wise Distribution of Cases in 2001 and 2000

Site of the Disease	2000			2001		
	M	F	Total	M	F	Total
Oral Cavity	260	122	382	274	107	381
Pharynx	134	16	150	117	14	131
Larynx	92	8	100	89	4	93
Brain	46	27	73	85	47	132
Thyroid	9	31	40	9	23	32
Lung	269	38	307	263	50	313
Esophagus	119	31	150	85	27	112
Breast	7	401	408	4	383	387
Soft Tissue And Bone	43	30	73	50	26	76
Stomach	70	31	101	94	30	124
Colon-Rectum	67	55	122	70	55	125
Male Genito-Urinary Organ	60	0	60	52	0	52
Cervix	0	233	233	0	220	220
Ovary	0	113	113	0	106	106
Other Female Genital Organs	0	55	55	0	55	55
Lymphoma	83	46	129	67	35	102
Leukaemia	45	29	74	52	34	86
Myloma	47	35	82	38	30	68
Liver And Gall Bladder	73	29	102	45	26	71
Skin	39	11	50	23	8	31
Metastasis Unknown Primary	72	23	95	57	34	91
Urinary Bladder	33	5	38	33	8	41
Miscellaneous	83	56	139	50	45	95
Non Malignant	9	4	13	24	24	48
Total	**1660**	**1429**	**3089**	**1581**	**1391**	**2972**

If we analyse the incidence of cancer according to site, out of the total cases more than half of the cases in women are in the sites of breast or genital organs (52.12% in 2000 and 54.92% in 2001). To this, breast cancer contributes more, which is 28.1% and 27.53% in 2000 and 2001 respectively. Even though there is a slight reduction in the total number of incidence in the year 2001 as seen in the above table, the contribution of these major types of cancers is showing an increasing trend of 2.8%. This shows that there are some significant changes in the patterns of distribution of cancer sites. In the case of men, most frequent types of cancers are lung cancer (16.42%) and cancers in oral cavity (16.47%). These are 3.12% and 8.12% respectively in women. Altogether, lung, oral cavity and the related sites contribute more than half if the incidences (53.07%) in men, which is only 16.70 % in women in 2000 - 2001.Thus a clear demarcation can be observed in the incidence of cancers according to the sites of disease in male and females. The higher number of lung and oral cancers in men can be attributed to the difference in lifestyle and exposure to environment especially lifestyles like smoking, chewing and alcohol consumption. Literature also relates the higher incidence of lung and oral cavity cancers to these lifestyles.

Table: 3.11 Site of the Disease-Gender Cross-tabulation of Studied Sample

Site of the disease	**No. of Cases**				**Total**	**%**
	Male	*%*	*Female*	*%*		
Brain	1	5.6	0	0.0	1	2.8
Leukaemia	0	0.0	2	11.1	2	5.6
Mouth	5	27.8	1	5.6	6	16.7
Thyroid	2	11.1	1	5.6	3	8.3
Lung	6	33.3	0	0.0	6	16.7
Breast	0	0.0	6	33.3	6	16.7
Stomach	0	0.0	2	11.1	2	5.6
Lymph/bone/spinal	2	11.1	1	5.6	3	8.3
Female genital organs	0	0.0	5	27.8	5	13.9
Others	2	11.1	0	0.0	2	5.6
Total	18		18		36	

In present study sample also, cancers of lung, breast and mouth & adjacent areas are the most recurring sites with 16.7 % of patients each. There are differences in cancer sites between males and females. Table: 3.11 explain the sitewise distribution of the patients in the studied sample. Among males, one third of the patients are with cancer in their lungs and cancer in various parts of mouth stands second with 27.8%. In the case of female respondents, breast cancer stands first followed by other genital organs with 33.3% and 27.8% contribution. Among the total respondents, there are no female patient with lung cancer and no male with stomach cancer.

Among the total twelve professionals interviewed, 66.7 % are of the opinion that a comparatively early treatment-seeking tendency is observed in cancer cases in recent times. They attribute this tendency to the betterment in understanding regarding the disease among the public through media intervention and the increased exposure of the public to the disease. They also attributed this improved treatment seeking behaviour to the "increased availability of services and the timely response from the professionals". This is analysed in detail in the coming chapters. One of the physicians had attributed this tendency to the "cancer phobia" created among the public.

Conclusion

All the patients covered in this study are receiving care in home and are in different stages of their disease. From the observation, it is understood that most of the patients receiving care for cancer disease in Medical College Hospital, Kottayam are from the lower strata of society. The family members generally share the burden of care, but the major responsibility of care is on women. It is observed that this is an additional workload on them. It is socially constructed that nursing and caring of the patient is primarily the role of women.

Medical College Hospital, Kottayam is the major service providing institution for a population of almost five districts. It creates a heavy service load on the hospital, which in turn affects the quality of the services. It faces a lot of constraints both in personnel and in infrastructure. This also negatively affects the quality of services. But the general public appreciates its efforts in the provisioning of services within its limitations.

The general public understanding on the trend in cancer cases is that the incidence rate is increasing in the state of Kerala. But in the year 2001, there is a reduction in the number of hospital registration due to various reasons like change in staff, emergence of hospitals in private sector with advanced diagnostic and treatment techniques. But the population under present study are of the unanimous opinion that the number of cancer cases is increasing.

The gender difference in cancer incidence in the population shows that the number of cancer incidence is higher among males than females. There are differences in the variety of cancer sites. Men are more prone to cancers of mouth and lungs whereas in women most common type is breast cancer. Data from the present study also supports the understanding of the association of lifestyle risk factors like tobacco use to the higher incidence of lung and oral cancers. Also the disease is more normally distributed over different age groups in the case of women, which is unfavourably distributed over old age in men. In other words women are more prone to cancer in the middle age and men are more vulnerable in old age. The trend in the age at which the incidence of disease occurs shows a tendency of reduction in the mean age of incidence. A detailed analysis of the consequences of the disease and response of the population to it is made in the next chapters.

4

Cancer and its Management: Knowledge, Experience and Perception

In this chapter, the general understanding and the prevalent picture of cancer in society are explored. The experience and knowledge of patients, their primary caregivers, healthcare professionals as well as the public are analysed, as they are important factors in the effective management of cancer disease and better quality of life of the patient. The general perception regarding cancer and the understanding of the different groups on the causes consequences and treatment of the disease are also explored, as they are mutually associated. It is explored in three levels i.e. on the physical aspects of cancer, psychological and social consequences of cancer. Since the study is focusing on family based cancer care, various dimensions of home-based cancer care are areas of discussion in this chapter. The care preference of different groups of people, reasons and dynamics of such a choice are also analysed. Towards the end of the chapter home care is discussed in detail with the help of collected data.

Patient's Knowledge About the Disease

Table: 4.1 Patient's Knowledge About the Presence of Disease

Understanding	No. of Patients		Total	Percent
	Male	*Female*		
Don't know	4	3	7	19.4
Unclear knowledge	7	4	11	30.6
Clear	7	11	18	50.0

As seen in table: 4.1, among the total patients, half of them are clearly aware of their disease. 30.6% percent of them have an unclear knowledge about their disease and the rest 19.4% do not know that they have got cancer. No significant gender difference is observed among the patients in their levels of knowledge regarding their disease. The unclear understanding or ignorance of the patients about their disease is mainly because of the nondisclosure by the relatives and physician. The reasons that the relatives give for the nondisclosure are mainly either the apprehensions on the psychological impact of the 'bad news' and the resultant consequences in the life of the patient or the patient being a child. 13.9% of the relatives who did not disclose the diagnosis to the patient believe that there is no use in explaining it to their relative. They responded, "Disclosing the diagnosis will not do any good to the patient rather it will affect the hope and mental peace of the patient. So we think it is better to hide the matter from the patient". Some of the primary caregivers think that the nondisclosure will help in better results and another section think that their relative cannot bear the fact. A few professionals especially non-physicians also believe that better results will be there if it is not disclosed as it will keep the patient more hopeful of the treatment. The diagnosis is not clear to the two child-patients, as it is not disclosed to them. The doctors reported a "pressure" from the part of some of the relatives not to disclose the diagnosis. This is a reflection of the general perception on cancer that it is a disease, which makes the life of the patient miserable and makes the patient and relatives hopeless.

Understanding of the Cause of Cancer

Table: 4.2 Gender wise Beliefs of Patients About Cause of their Disease

	Perception about reason of disease				Total
	Fate	**Lifestyle**	**Occupation**	**Don't know**	
Male	0	6 (16.7%)	2 (5.5%)	10 (27.8%)	18 (50.0%)
Female	1 (2.8%)	0	1 (2.8%)	16 (44.4%)	18 (50.0%)
Total	1 (2.8%)	6 (16.7%)	3 (8.4%)	26 (72.2%)	36 (100%)

When the patients were asked about what they think as the cause of their disease, 72.2% of them responded, "don't know". 16.7% think that their "lifestyle" is the cause of their disease and all of them are males. As seen in table: 4.2 more men related their disease to some causal factor than women. This response can be attributed to the fact that most of the male patients are smokers and they think their tobacco use as the causal component of their disease. More male patients attributed their disease to their occupation pattern than female patients. But it is mostly women who attributed their disease to their ill fate.

Among the primary care givers also, 58.3% found it difficult to attribute their relative's disease to any known factor. In the case of those who related it to something, majority of them linked it with the habits, mainly to tobacco use. Other factors, they consider, as possible causal components are pollution, use of pesticides and adulteration of food.

From the response of the professionals, it is understood that the general belief of patients regarding the cause of their disease is that their previous lifestyle is the major reason and it is to be noted that this kind of a belief is prevalent among men. Also many patients consider their disease as their fate or a punishment. Some others believe that other factors like their hard work, nature of work, injuries or some other diseases caused their present condition. According to the professionals, very few patients think that it is communicable

In the case of general public interviewed, 53.3% of them have some kind of personal experience with cancer patients and 20% have professional experience. 13.3% have other type of experience like some voluntary services in cancer care or study visits etc, while another 13.3% have no experience with cancer cases. A mixed response is there from the part of the public on the understanding of the causes of the disease. The common understanding regarding the causes of cancer is that it is a lifestyle disease and it is the most recurrent answer irrespective of the education, experience or age of the respondents. Second frequent response is pollution mainly air pollution and use of pesticides. In addition to these common understanding, those public who are in the field of health care services have better understanding of the causes that they attributed the incidence of cancer to genetic reasons and other medical reasons. Thus the general understanding regarding the cause of cancer is that it is associated with the daily life practices mainly. This notion of lifestyle mainly connotes certain habits like smoking and using tobacco and intoxicating agents and pollution, in general, air and water pollution and over use of pesticides. Some of the laymen attribute this to the use of aluminium vessels and plastic products, which to them are 'not natural' or as per literature, 'carcinogenic'. Some of the public commented on the changing food pattern of people also. This kind of a response was not there from the professionals.

In short the beliefs of the participant members of the study on the cause of cancer are not identical but some degree of commonality can be observed in their understanding on the causal association between tobacco consumption and cancer. Here it is very pertinent to understand the sources of this information. The most important source of information is the media. For those who are in the field of health care, formal education is obviously an important source of information. Experts especially physicians play an important role in educating people especially the relatives and patients. The influence of media is significant and also the health education programs targeting the public are disseminating awareness through the popular media. Its influence can be a major factor in the understanding of the public regarding cancer.

Knowledge about cancer is assessed in three levels say, knowledge about the cause of cancer, about the physical consequences and about treatment. Regarding the physical aspects of cancer, among the caregivers, there is variety of responses (see table 4.3).

Table:4.3 Knowledge of Caregivers about Cancer – Physical

Understanding of Cancer	No. of Caregivers	Percentage
An Ulcer	2	5.6
Growth	13	36.1
Swelling	12	33.3
Decay	3	8.3
Others	6	16.7
Total	36	100.0

Most of the caregivers understand that it is a growth in human body. Another similar understanding is that cancer is a form of swelling. Some think that it is decay of human body either due to aging or due to some other conditions while some others think it as an ulcer. These kinds of understandings are derived mainly from their experience with their relatives.

Problems Associated with Cancer

The very idea of cancer is intrinsically intertwined with its associated health hazards. Cancer is generally accompanied by a set of physical and psychological health hazards. They may arise out of the disease itself or from its treatment. All the patients covered by the present study reported with combinations of outcomes of the disease and treatment with a wide variety of health problems. Table 4.4 compiles the major health problems according to their occurrence in patients. The most common problem is fatigue. This can be either because of the degeneration of body due to the disease itself or from the strong medication. Second major problem reported is loss of appetite. This also can be due to the above-mentioned reasons. 72.2% of the patients reported pain as one major health problem associated with their disease. Other major problems reported by the patients are nausea, physical deformity, sleep-disturbance, hair loss, weight loss, cough and others. Among these, pain, hair loss and physical deformity are the most stigmatised consequences of the disease as they are the most related outcomes of cancer or its treatment. Loss of appetite, weight loss and fatigue are related and it may affect the nutritional status of the patient and this is a major reported problem in caring the patients in home by the relatives.

Table: 4.4 Associated Health Problems of Cancer Patients

Health Problems	% of Patients Reported
Fatigue	86.1
Loss of Appetite	75.0
Pain	72.2
Nausea	61.1
Physical Deformity	47.2
Hair loss	41.7
Sleep Disturbance	41.7
Others	36.1
Cough	25.0
Weight loss	19.4

Perception of Cancer

Regarding treatment of cancer, 88.9% of the caregivers have a moderate idea of the existing treatment modalities. 5.6% of them have no idea about the treatment for cancer while another 5.6% have a clear understanding. The general perception of the caregivers about cancer disease is again mixed. Table: 4.5 compile the perception of the caregivers on their relative's disease.

Table: 4.5 Perceptions of Caregivers on Cancer and Its Cure

Perception	No. of caregivers	Response in %
Curable	8	22.2
Painful	17	47.2
Curable but Painful	1	2.8
Not Curable/ End of life	8	22.2
End of life & Painful	2	5.6
Total	36	100.0

Even though many relatives and caregivers believe that it is curable, most of them have the perception that it is a 'painful disease'. Of the total caregivers interviewed, 27.8% do not believe that their relatives' disease will cure. Reasons they give for their pessimistic attitude are mainly; the advanced stage of the disease and the functional disability of the patient as he/she is bedridden. Age of the patient is also a factor in this hopelessness, as the patient is not responding to the treatment properly. In a few cases the physician suggested stopping medication and providing nursing care and pain management within home as the patients were found to be moving towards the end of their life. This is also a factor in this kind of an attitude from the relatives. The caregivers and relatives who believe that the disease of their relative will be cured strongly rely on the assurance given by the physician and have good faith in the treatment they are giving. The general perceptions regarding cancer among all the participant caregivers are that it is painful and the life of the patient is miserable and reported that their lives are also affected.

Public perception regarding cancer is derived from a variety of factors. The information they received on the disease, experience with patients, education etc. influence their general perception towards the disease. In the present study, the perception of the public towards cancer is studied and it is found that it is developed from the consequences of the disease. To most of the respondents, the picture of cancer is formulated by certain assumptions developed out of somebody's experience. Most of the people responded with multiple answers. 73.3% of the respondents are afraid of cancer. Irrespective of differences in gender, education and occupation, to most of them cancer means painful death. The general feeling towards cancer is fear and the reasons given are the poor success rate of medical treatment and the prolonged suffering that the patient has to undergo. Table: 4.6 compile the general perception of the public regarding cancer.

Table: 4.6 Public Perceptions on Cancer

Perception	No. of Responses	Rank
Painful Death	19	1
Fear	14	2
End of Life	11	3
No Effective Treatment	10	4
Fate / Curse	4	5
Associated with Old Age	2	6

Some of the participants believe that it is the fate of the patient and to some of them it is a curse. A few respondents believe that the incidence of cancer is associated with old age. It may be because of the general observation of higher incidence of cancer and associated suffering among the elderly.

In the case of cancer treatment, among the public, 3.3% of them have no idea about treatment modalities for cancer. But 63.3% have a moderate understanding while one third of the respondents have clear knowledge about the treatment modalities and the technical aspects of treatment of cancer and they are mainly the ones associated with health care directly as medical students, social workers etc.

Psychological Consequences of Cancer

Health is not only physical, but also psychological and social well being also. In the case of cancer, which is stigmatised in society for its wide range of consequences, the psychological impact of the disease is widely discussed area. Most of the psychosocial oncological studies have explored the various dimensions of this impact. Among these, feeling of isolation is considered as one of the most important consequence. Loneliness or isolation is a general feeling that develops gradually in chronically ill patients. The specific nature of cancer, forces the patient to limit his/her mobility, both physical and social as a result of which the patient has to undergo some form of confinement. The physical dependency created by the disease and the restrictions derived out of the treatment are important contributory factors in this isolation. As the patient has to keep him/her, to a great extent, away from the mainstream, stress comes on him/her. Result of this stress generally is manifested through depression and other negative feelings. Studies show that the extent of depression is so much that patient may develop suicidal tendency also.

Generally the disease brings considerable role changes in the life of the patient. The patient is gradually becoming a dependent in most of the cases as the disease advances. Slowly but surely the power relations and decision making also gets changed within the immediate social environment and changes in roles also take place as the patient becomes more dependent.

Gradual decline in the productivity of the patient both in economic and social terms leads to developing a feeling of 'uselessness' in the minds of the patient. Also different forms of fear develop as the disease progresses. Fear of death, deformity, future of the dependent family members etc are common among the patients.

Present study also supports many of these findings. Almost all the patients reported that loss of physical health is the most important problem they are facing from their present condition. Table 4.7 gives a detailed picture of the consequences of the disease according to the patients. Since the answers are multiple, the responses are ranked according to their frequency. Almost all the patients reported the above-discussed psychological problems.

Table: 4.7 Consequences of Cancer in the Life of the Patients

Consequences	No. of Responses	Rank
Loss of Physical Health	35	1
Reduction in Social Interaction	34	2
Limited Movement	32	3
More dependent	32	3
Financial Crisis	22	4
Depressed	22	4
Changes in Spirituality	22	4
Loss of Employment	14	5
Changes in Family Relationships	5	6
Children's Education is Affected	4	7
Own Education is Affected	2	9
Others	3	8

When asked about the first feeling on the diagnosis of cancer to their relatives, 55.6% of the primary caregivers/family members reported that they were "afraid" or "shocked". Fear is a common emotion to both the patient and the family. 27.8% responded that they were shocked, 8.3% were disappointed and a small percentage of the patients were felt helpless. At the time of interview, 72.2% of the caregivers expressed optimism about their relative's health while 27.8% are not hopeful (see table: 4.5).

The data collected from the public also used to crosscheck these responses and it found supportive to the above findings. The most frequent response from the public on the psychological impact of cancer on the patient is that majority of them experience stress and depression. This stress and feeling of loss are derived out of the helplessness of both the patient and the family. Second major problem, they observe, is the fear of death followed by feeling of isolation and dependency. The following table compiles public perception on the psychological impacts of cancer on patients.

Table: 4.8 Public Perceptions on the Psychological Impacts on Cancer Patients

Knowledge	No. of Response	Rank
Depression & Stress	30	1
Fear of Death	14	2
Dependency Feeling and isolation	13	3
Problems in Accepting	7	4
No Idea	1	5

Data collected from the health care professionals also support these findings (See table: 4.9). There also depression is the most observed consequence of the disease among patients. One important observation that the professionals had made is the tendency to end one's life not only among some patients but also some of the primary relatives especially among young wives.

Table: 4.9 Perceptions of Professionals on the Psychological Problems of Cancer Patients

Psychological consequence	Rank
Depression	1
Anxiety	2
Fear	3
Others	4
Helplessness	4
Unwantedness	5
Aggression	6
Suicidal tendency	6

73.3% of the public participated in the study responded that they are afraid of cancer while the rest 26.7% are not afraid. The reasons they gave for their fear are compiled in table 4.10. It shows that most important reason for their fear is the poor efficiency of medical intervention and the feared ultimate result of the disease i.e. "painful death" in most of the cases. This fear and the perception of the public towards cancer are interconnected.

Table: 4.10 Reasons for the Fear of Cancer Among Public

Reasons for fear of cancer	No. of Responses	Percent
Not Afraid	8	26.7
No effective treatment & Painful death	6	20.0
Killer disease	5	16.7
Painful death	3	10.0
Prolonged Suffering & Painful death	3	10.0
No effective treatment	2	6.7
Killer disease & No effective treatment	1	3.3
Killer disease & Painful death	1	3.3
No effective treatment & Prolonged Suffering	1	3.3
Total	30	100.0

The first emotion in most of the families was fear in different forms. To be brief there are some commonality between the responses of different groups under this study on the psychological impacts of cancer on the patient and the family.

Changes in the Life of the Patient

Cancer brings notable changes in the life of the patient. These changes are physical, psychological and social. In the case of the patients under present study, the changes in their life are explored. The most important change is the loss of physical health. Rest of the consequences are stemmed out of this. 47.2% of the patients are reported bedridden due to loss of physical health and/or deformity (see table: 4.11). Analysing the behavioural changes of the patient, most of them are depressed and hopeless. Some of them especially male patients are blaming themselves for their present condition, which they think developed out of their early lifestyle. So the most important change is in their lifestyle especially in habits and diet. 44.4% of the patients have changed their diet pattern considerably. 38.9% reported that changes were occurred in their habits mainly like using tobacco products and alcohol. Behaviour modification in this direction is mainly by the advice of the physician.

Table: 4.11 Changes in Life After Disease

Changes	No. of Patients Reported	Percentage
Diet	16	44.4
Habits	14	38.9
Occupation	11	30.5
Bedridden	17	47.2
Spirituality	22	61.1
Others	12	33.3

A few patients find it very difficult to keep them away from their habits, as they are addicted to it. All those who were employed before getting diseased had to leave their job and remain unemployed due to ill health and treatment. The housewives have not responded on changes in their employment pattern, as they did not consider themselves as employed. But changes could be seen in their physical activities also as most of them are unable to engage in household activities like they had participated previously. 33.3% of the patients reported other changes in their life like changes in attitude, aspiration level and outlook, communication and behaviours. One important change that happened out of the disease in 61.1% of the patients is the changes in their spirituality. Many patients and their relatives are reported to be more religious and more spiritual as a relief from their "ill-fate". They "left it to the God whether to cure or take the life". Thus the changes in the life of both the patient and the family are in the physical, psychological, social and spiritual dimensions.

Needs of the Cancer Patients

Regarding the needs of the patients, most of the people believe that the immediate and important need of the patient is proper medical intervention. The interviewed professionals also are of the same opinion. Psychological support, according to the public, is the next immediate need of a cancer patient. At the same time professionals find nutritional support as the second major priority need of the patient. The following table gives a comparison of the views of public and professionals on the caring needs of cancer patients.

Table: 4.12 Immediate Needs of Cancer Patient

Need categories	**Rank**	
	Public	*Professionals*
Medical treatment	1	1
Psychological Support	2	3
Home care	3	3
Nutritional Support	4	2
Financial support	4	5
Social Worker's Intervention	5	5
Others	-	4

Analysing the common understanding of the public regarding the caring of cancer patients, most of them consider the most essential service needed is medical care followed by psychological support and home care. Nursing care is also considered as an essential service and in the case of hospital care it is an inevitable component. In home care it is considered as one of the major hurdle before the family.

The literature review has shown that the very diagnosis of cancer creates repercussions in both the patient and the family. It may be because of this psychological impact, people consider home care as important in cancer care. The other immediate needs of a cancer patient, as per the public, are nutritional support and financial support. The knowledge that the poor access of proper treatment and non-availability of advanced care in the locality add to the higher cost of treatment for cancer may be attributed to the response that 'financial support to cancer affected poor families' as an important service in cancer care. Cancer is a disease, which significantly affect the economic security of the family in many ways. Economic impact of the disease on the family is mainly by the changes in the employment pattern of the patient and/or the relative or caregiver. The opportunity cost of treatment and other health interventions is another issue before the cancer affected. This will be more when the hospital is far away from home. Previous studies also show that poor families are more vulnerable to the risk of cancer. This also can be a reason for such a response, which calls for a social responsibility to the economic support to poor cancer patients. Another need that expressed by professionals and the more educated public is the intervention by a trained person in dealing with psychological consequences. It is observed that there is no such professionally equipped person in the studied institution. Other needs, according to the participants of the study, of the cancer patients are rest, rehabilitation and support from the part of society.

Care for Cancer Patients

Comparison of the care preference of different categories of respondents say professionals, public and primary care givers, shows that there are considerable differences in choice of mode of care provision. Table: 4.13 show the gender-wise care preference of different groups of respondents.

Table: 4.13 Gender wise Care Preference

Category	**Hospitalisation**		**Home care**		**Both**		**Total**
	Male	*Female*	*Male*	*Female*	*Male*	*Female*	
Public	11 *36.8%*	4 *13.3%*	4 *13.3%*	3 *10%*	4 *13.3%*	4 *13.3%*	30 *100%*
Professionals	2 *16.7%*	3 *25%*	1 *8.2%*	2 *16.7%*	2 *16.7%*	2 *16.7%*	12 *100%*
Care givers	4 *11.1%*	6 *16.7%*	9 *25%*	17 *47.2%*	0 *0%*	0 *0%*	36 *100%*

In the case of primary care givers 72.2% prefer home care. Of the total women care givers, 74% prefer home care and it is 69.2% in the case of men. Among the total public interviewed, half of them opined that hospitalisation is more effective in cancer care. 23.3% opted home care over hospitalisation while 26.7% are of with the opinion that both hospitalisation and home care are essential in the best management of cancer cases. This implies that majority of the public prefer institutionalised care than home care.

This is contradictory to the general assumption that the burden of care, which is more on the women in the case of home care force women to prefer hospitalised care. Analysis of the reasons given by each group for their care preference shows that the most expressed reason is the provision for homely atmosphere. In the case of caregivers, financial constraints are another major problem for their preference of home care. The expensive treatment is not affordable to most of the studied families. Distance to hospital is another reason for caring in home. Preference by the patient to be in the home is another important reason for the choice of home care. Caring the patient in the hospital and managing the family simultaneously is a heavy burden on some of the caregivers especially women. In some of the nuclear families where the husband is diseased and the children are not grown up to manage themselves, the burden on the wives is more. Other family matters and household chores are also limiting the women in general to remain in home and these factors are decisive in caring the patient in home.

Observation shows that in some of the cases the doctor also suggests taking the patient home as the treatment can be taken from home through regular hospital visits. The infrastructure facilities in the hospital are also not sufficient to accommodate patients properly. Another tendency that observed by the researcher is that more male patients prefer not to be hospitalised as it restricts their mobility. In hospitals caring is more impersonal while in home it is very much personalised and the individual needs of the patient can be taken care of. Another important reason for preferring home care is the provision of psychological support from the family and the community. Gender wise preference of the mode of caring shows that, among the total participants from the categories of caregivers, professionals and public, more males (47.2%) than females (31.7%) prefer hospitalised care over home care.

As shown in table 4.14, the reasons that the public gave for their preference of care modality are vivid and multi-factorial. In the case of the public all the respondents who prefer home care is of the opinion that the provision of homely atmosphere is the major reason for their preference. Also family support and reduced expense of care are reasons behind this choice.

Table: 4.14 Reason for Preference of Home care by Relatives

Reasons	Frequency	Rank
Homely atmosphere	23	1
Financial problems	14	2
Distance to hospital	10	3
Patient's preference	9	4
Burden of By standing	5	5
Others	10	3

A few respondents prefer home care because of the distance to the medical college hospital, which is the only institution providing care to cancer patients in public sector in their district. The cultural orientation of care giving within the family and health development of its members as one of the primary function of family also can be attributed to the increased importance that the participants gave to home care.

Those who prefer hospitalisation, gave the reasons of better treatment facilities and nursing care that are available in hospitals. This does not mean that the other category of people who prefer homecare are not aware of the better treatment facilities available in hospitals. Here the important point is the facility for nursing care. Most of those who prefer hospitalisation are with personal or professional experience with cancer patients. Their past experience can be the reason for such a selection. Another major reason for their selection of hospital care is that according to them the patient is not manageable in home. The explanation they give is the behavioural changes that happened in the patient after getting diseased makes it difficult to care the patient within home. It can be in dietary practices, in personal hygiene, or because of the terminal illness of the patient who cannot manage his/her routine functions without external assistance. Some of the caregivers responded that the patient's food habit, personal hygiene, and the behaviour within the family were changed considerably and the patient is not caring or not cooperating with the nursing services that the family members are intended to offer to improve the quality of life of their relative. Since there is an option before the patient in home to postpone these activities according to his will and the family members find it difficult to pursue the patient in doing these activities. A typical example for this is the case of taking food and taking bath. Usually as a result of the treatment and its side effects, the patient experiences loss of appetite as a result of which he/she refuses to take food in time saying that "not feeling hunger and will take later". This postponement is a problem for most of the family members, as they cannot force them. Similar things may happen in the case of taking bath. At this point, the caregivers find it better to hospitalise the patient were he/she would be forced by the nurses and other staff to take food and keep oneself clean. Here the lack of experience of the caregivers in assisting the patient can be a reason for such a choice. Thus the facility for better nursing care in hospital is an important factor in choosing hospital care in many cases.

Role of Family in Caring for Cancer Patient

It is a fact accepted by everybody that the most important caring institution of an individual at the time of ill health is family. In the case of chronic illnesses, role of family is very important. Role of family in preventive, curative and rehabilitative dimensions of cancer is widely researched and accepted.

In the present study also, the role of the family is explored and the study itself is centred on home care in cancer. All categories of participants of the study admit the primary role of family in cancer care. All the patients expect physical and emotional support from their family. They rely primarily on family in recovering their health. All the health care professionals participated in the study are of the opinion that the most important role of family is in providing emotional support to the patient which they think will improve the quality of life of the patient. 41.7% of the professionals believe that family is more important than hospital in the case of cancer care. However, they are not denying the role of medical institution in providing treatment to the disease. One third of the professionals think that home care is more important in the terminal stages as family can pay more personalised care and attention in that stage than the hospital.

The participant public also report the primary role of family in supporting the patient psychologically. 75% of them consider it as the first and principal function of family. Other roles of family, they consider, are physical assistance to the patient, financial support for treatment and other needs, nutritional support, nursing care especially to bedridden patients and facilitating coping with the disease.

Within the family there are changes in communication and behaviour of members after their relative getting diseased. 72.2% of the caregivers reported that the family members are paying special consideration to the patient. More concern and sympathetic attitude are practiced towards the patient and the communication pattern also changed according to the behaviour of the patient. In the case of primary caregivers they spend more time with the patient, more concerned of the needs of the patient and paying special attention to their relative like feeding, nursing and like. Also in the case of response from other relatives also there are changes. In the case of 22.2% of the patients, their relatives or neighbours are visiting them regularly while 66.7% of the patients reported that the frequency of visit by their relatives is increased but it is not regular. 11.1% observes no particular change in the visits by their relatives. In short there is often a change in the pattern of support by family and immediate social environment being the primary health caring mechanism.

However there are problems and shortcomings in home care too. It is observed that caring the patient for a long term is a burden on the family especially when the patient is fully bedridden and dysfunctional. The response from the caregivers was mixed and multiple. Table 4.15 shows the difficulties that the caregivers are facing in providing home care to their relative.

Table: 4.15 Difficulties in Home Care: Response of Care Givers

Response	No. of Caregivers	Percentage
Pain management	16	44.4
Nursing care	9	25.0
Ignorance	8	22.2
Employment is affected	6	16.7
Patient is not manageable	4	11.1
Caring is a burden	2	5.6
Others	7	19.4
No difficulty	8	22.2

The most responded difficulty in home care is managing pain of the patient. Pain being the most feared consequence of cancer, most of the caregivers and family members find it very difficult to help their relative in alleviating pain. This inefficiency in pain management is a major motive for preferring hospital care in most of the cases. Some other difficulties they face in caring the patient in home are their ignorance about the complications of the disease and its management; difficulty in nursing care and the employment of the caregiver is affected by home care. For 5.6% of the caregivers, caring the patient in home is a real burden. Another problem that some of the families are facing is the behavioural changes of the patient due to which they cannot mange the patient in home.

The Case of Mary

Mary is an eighty-four old widow having eight children. Her husband died twenty-four years back. She is staying with her younger son Mathew, who is married and having three children. His wife Jolly is a housewife and the children are students. Mathew is unemployed and engages in agriculture works in his own land holding. The family belongs to lower middle class. The family is having a good amount of debt. They have road connectivity, electric connection and water supply.

Mary is a reputed grand old lady in her locality and enjoyed a very good social network. Her elder son is staying two kilometers away from her home and the daughters are married off. Mary used to visit her children at least once in a month and was a regular participant of the religious activities. Many of her in-laws and other relatives are staying in the same locality and thus she had a very good interaction with them. Though she was suffering from minor illnesses like back pain she was active in household activities. She was reported very particular of personal hygiene.

For the last few years she had problems in sitting and walking and had joint pain. She considered them as related to ageing and one-year back she had reported with abdominal pain and problems during sitting and toilet activities. In December 2000, she had severe abdominal pain, which she used to complain about. Usually nobody accompanies her while visiting a doctor for minor illnesses. This time Mathew, her younger son accompanied her to a private hospital nearby. There the doctor referred them to Medical College Hospital, Kottayam (MCK). But they took some medicine and came back. As the pain continued, they finally visited MCK in February 2001. There the urologist diagnosed it as cancer in urinary bladder and referred to the department of radiotherapy where it is confirmed. At this stage the disease was diagnosed as in the advanced stage. The doctor disclosed the diagnosis to the son who did not disclose it to her. According to her children, "*she doesn't know the disease and we think that it is better not to disclose for the sake of her mental peace*". The doctor prescribed twenty radiations and asked them to visit next week. By that the time the patient became very weak.

They took her to the MCK, which is 40 km away from their place on the next week. On their first visit Mary could not undergo radiation therapy as the doctor was on leave. On the next week she had undergone the therapy but the health of the patient deteriorated very fast. On the next week the doctor suggested not to take radiation therapy, as he find no use in it. According to Mathew "*the doctor told us that there is no use in radiation, and asked us to take care of her in home and prescribed some medicine for pain. We also found it better as the health of mother is becoming worse and we considered the distance to hospital, difficulty in transportation and expense of the useless treatment and so we took her back to home*". Pain, sleeplessness, fatigue, loss of appetite etc. were the physical consequences. "*We are totally disturbed and afraid* Mathew explained their feelings. "*Mother was totally ill and was very much depressed*". The response from the locality was very sympathetic and a lot of neighbours and relatives started visiting her regularly. "*Every day we have at least two – three visitors who are coming to see mother*". The news spread in the locality and the general idea among the people was "*the doctors in the medical college gave her up and there is no hope. We were also afraid of the disease*".

By May 2001, Mary was fully bedridden and Jolly, the daughter in-law was the primary caregiver, who used to nurse her and feed her and taking care of all her needs. In December 2001, they came to know about a Hospice Centre run by

Christian nuns and Mary was admitted there for three weeks. Her eldest daughter accompanied her in the hospital. Again she was taken to home and the burden of care came on the shoulders of the daughter-in-law. "*I have no daughters to help me and I have a lot of work to do within the family. I have to take care of my studying children, mange the kitchen,………and caring mother is an extra burden on me. In addition to these I have to receive her visitors and have to serve them with tea and snacks*" Jolly, explained. Slowly the quality of care was affected and the clashes between the two daughters in-law and the daughters became severe on the matter of caring the patient. This made the patient more depressed and she became totally silent on her bed. "*It is their mother also and they have a responsibility to take care of*", Jolly was a bit furious on the married off daughters. Gradually the frequency of visits by the relatives and neighbours reduced and to the family the priority to the disease of their mother also changed.

The first visit to Mary by the researcher was in first week of October 2002 and last visit was in the third week of January 2003. Within this period, several visits were made and information was collected from both the patients and the relatives. During the month of November, the state of Mary became worse and according to the elders in the locality "*there are symptoms of death, it will not prolong more than the fasting- Christmas- and pray to God for a death with dignity*". Gradually the priority of the family changed to the health of their mother and the family again became 'cancer-centred' and the entire family was "*waiting the departure of (their) mother as it is better to die than suffering this condition*". This waiting prolonged for months. Her elder son, who is staying three kilometres away from her, had been visiting her daily in the afternoon and spending time with her for hours. The importance of this visit was that it was a great relief for the mother and she used to expect him everyday as a routine. She was cleaned once in several days and the quality of nursing care was affected as a result of which she had developed bedsores and smelling. Her married off daughters started taking turns weekly in nursing her. She was totally malnourished that she became a skeleton covered by skin only as the only food she consume reduced to half a glass of tea. So the administration of painkillers also became difficult. The elder daughter in law said, " *if they (the sons) take her to some hospital, I can accompany her there as I cannot fully manage the nursing care alone. In hospital they will give glucose and it is a fact that starving patients will not die soon".* According to the sons, *"there is no hope in treatment and taking her to hospital only adds to the burden".* Here they refer primarily the financial burden of hospitalisation.

The waiting for her death continued till the end the fieldwork of the researcher and he came to know that she had died two days after his last visit to her. The case of Mary is a typical example of the burden of care for the cancer patients on their family. It shows that not only the socio-economic and psychological consequences comprise this burden, rather the cultural roles and power relations are also associated with this burden.

Summary

In this chapter an attempt has been made to understand the experiences, knowledge and perceptions of different groups participated in the study i.e. patients, caregivers, health professionals and general public on various aspects of cancer. It has been observed that a higher degree of association in responses of different participant groups on the aspects of cancer and its care covered in this study. Majority of the studied sample have some kind of experience with cancer and cancer patients. In addition to their experience, media and contact with experts helped them to develop their understanding of cancer. It is based on these understandings that their perceptions on cancer and its victims are formulated. Most of the respondents have good understanding of the causal associations of cancer and their observations of the consequences are also similar. Regarding the consequences of cancer, the most stigmatised one is pain, which generally people find difficult to bear and manage. Depression, stress, financial crises and increased social isolation due to limited mobility are the other major consequences that are observed by the participants.

The general reaction to cancer is fear and most of the population in this study, irrespective of education, age or other differences fear is the most reported response to cancer and the explanation for this kind of response is the poor control of modern medicine over cancer. Considerable portion of the population is considering the disease as painful end to life with a lot of sufferings. This is the common picture in the minds of people. They do not find any easy escape route in the case of cancer.

Caring the patient is an important area where majority of the study participants find institutionalised care as more effective while they admit the fact that family based care is significantly helpful in bettering the quality of life of the patient. The role of the family in health care is culturally conditioned. Psychological support is one of the indispensable needs of the patients. In supporting the patient emotionally and in providing more personalised care, the role of the family and immediate social environment is very important. But certain limitations or constraints are there in home care also as many of the family members consider themselves as ill equipped to cater adequate nursing care to the patient and managing pain. However it is well accepted that home care and family support are essential components in better quality of life of cancer patients. This kind of a general understanding and perceptions are influencing factors in the general health behaviour of public especially in seeking treatment for cancer.

5

Treatment Seeking Behaviour, Coping and Quality of Life in Cancer

Introduction

This chapter discusses the treatment seeking behaviour, coping pattern and quality of life of cancer patients. Treatment seeking behaviour is a part of the general health behaviour and influenced by various factors. Delay in seeking treatment for the symptoms is analysed in detail in this chapter, as one major problem in cancer management is the delay in diagnosis of the disease. The general assumptions on treatment seeking behaviour and delay are verified through the analysis of the primary data collected through the present study. Similarly coping with cancer is an important concept in cancer care. It derived from the pathological specialities and the limitations of medical intervention in curing the disease. In the field of cancer care, coping is a widely discussed area. The coping pattern of the participant patients and their families are explored in the second section of the chapter. Quality of life of the patient is the ultimate objective of every mode of health intervention. This concept is subjective and it is linked with a multiplicity of factors. These factors and their dynamics are discussed and the suggestions from different participant groups to improve the quality of life of the patient are also discussed. One case study is used in the discussion of these concepts.

Treatment Seeking Behaviour

Admission in Medical College Hospital

The patients for study were selected so that they are registered in the hospital within last one year for their treatment. Among the studied population, majority of the patients belong to poor strata and most of them seek treatment in advanced stage. Among the total patients covered by this study, 69.4% had been admitted in Medical College Hospital, Kottayam at least once in the course of their disease, while 30.6% did not receive in-patient care. Inpatient care can be either for diagnosis or for treatment or for both. Generally patients from far away places prefer in patient care, as it is very difficult to travel frequently. Patients from nearby places do not prefer inpatient care. The inadequacy of facilities in the hospital and the expense of inpatient care under different heads are the major reasons for this kind of a reduced preference. The inadequate infrastructure in the hospital, do not allow the professionals to refer all their patients for inpatient care also. The reference for inpatient care is depending upon the stage of the disease, type of treatment, distance from hospital, frequency of therapy, patient's preference etc.

Regarding the duration of hospitalisation of the patients, 33.3% of them had received inpatient care for less than one month while another one third of the sample population were admitted for one to two months. Frequency of visits to the physician also varied according to the stage of disease and treatment modality. Those who are in the initial stages and who are responding positively to the treatment are more frequent in hospital visits. In more advanced cases and terminal stage patients the visits are less frequent and terminal stage patients and some of the aged patients are seeking terminal care especially pain management services only.

Action Over Symptoms

Table 5.1 compiles the actions taken by the patents over their identified symptoms.

Table: 5.1 Action Over Symptoms by the Patients

Action	No. of patients	Percentage
Visited a Physician immediately	18	50.0
Hide from others	8	22.2
Waited for some time	5	13.9
Did not pay attention	4	11.1
Self Medication	1	2.8

Symptoms of cancer vary according to the site, and stage of the disease. Actions over the symptoms are also varied. They can be classified as, not paid adequate attention, waited for sometime for cure, self-medication, hide from others and sought medical treatment immediately. Half of the patients covered by the study responded that they visited a physician immediately after the identification of the symptoms. The meaning of "immediacy" is varied according to the individual. In the sample of patients it was observed that 22.5% of the total sample hide their symptoms initially from others. Even though this kind of a response is mainly from women, we cannot attribute it to any kind of gender differences in the absence of male genital cancers and their response to the symptoms. But it is widely accepted that the cultural conditioning attached with sexuality and related subjects are more unfavourable for women in seeking health. Those who hide their symptoms from others are generally the ones who have symptoms in their secret parts of their body especially genital organs. This can be attributed either to their ignorance or to their shame in disclosing it. The culture, which conditions individuals not to disclose matters related to their genitalia or sexuality, can be the base for this kind of a response.

There were responses of "waited for some time to cure naturally" also. Few patients went ahead with self-medication also. In the case of mouth ulcers, headache, stomach pain, and other common symptoms, some patients went for self-medication using herbal medicine or other traditional techniques. These patients were less worried about the symptoms in the beginning. In other words, these patients did not relate their symptoms with cancer.

Another initial response to the symptom was "did not care". It is mainly men, who initially neglected the presence of their symptoms. Mainly symptoms like coughing, chest pain and fevering were the ones neglected. This can be attributed to the common occurrence of these symptoms, socio-economic situation, gender, family situation and personality of the patient. Those who are in the lower strata of the work force are generally insecure in their work and are forced to neglect the initial symptoms due to the nature of their work. Data from the present study also supports this assumption. Generally the cultural conditioning of men as hard, tough, strong and healthy is also an influencing factor. In addition to these determinant factors, the opportunity cost of visiting a hospital can be the major factor, as no patient seems to be less worried about the presence of the symptoms, even though the degree of worry varies.

This shows the variety of health seeking behaviour of the patients. These actions are not discrete rather the patients responded to the symptoms they identified in themselves, in a combination of the above-mentioned actions.

Delay in Seeking Treatment for Cancer

Delay in diagnosing cancer is the major hurdle before the healthcare workers in checking the consequences of the disease. Almost all the studies in the field of cancer are of the finding that late detection of cancer is the major problem in cancer management. Most of the cancer cases are reported or diagnosed at an advanced stage at which the medical intervention has limits to control the spreading of the disease. The very nature of cancer itself is one of the main reasons for late diagnosis in most of the cases. As studies show, the site of disease – internal/ external-, gender, age, personality, general health seeking behaviour, and the prevalent health culture etc. are important factors in the stage at which the disease is detected. Apart from these factors the availability of adequate facilities for diagnosis and the socio-economic factors of the patient also influence the general health seeking behaviour of the individual.

Socio-economic disadvantages are very much linked with one's general health behaviour and studies in this direction show that the cancer risk behaviours like smoking, chewing tobacco, alcohol abuse, occupational exposures to hazardous situations and materials, pollution, and other infections are more to those who belong to lower socio-economic strata.

In present study, it was found that the general assumption of late diagnosis of cancer is true in the case of the participant patients also. The delay in diagnosis is defined, in the present study, as the time gap between the identification of the symptoms by the patient and the diagnosis of cancer by the physician. Between these the patient might have sought treatment from some physician who either treated the symptom without diagnosing cancer or referred to some other hospital (here Medical College Hospital, Kottayam) for detailed diagnostic tests being doubtful of the symptoms.

In the case of the patients studied, the delay in diagnosis ranges between two weeks to two years. Table 5.2 shows the details of the delay in diagnosis.

Table: 5.2 Calculated Delay in Diagnosis

Delay	No. of patients	Percent
2 weeks	3	8.3
1 month	7	19.4
2 months	6	16.7
2-3 months	5	13.9
4-6 months	4	11.1
6 months -1 year	5	13.9
More than 1year	6	16.7
Total	36	100.0

The average delay in diagnosis is calculated as seven months. To the direct question of delay in diagnosis, few patients responded "no delay", but it was calculated by the researcher on the basis of their answers on time of symptom identification and the reporting to hospital or time of diagnosis that in the case of all the patients there was delay in diagnosis. Here an important thing to be noted is that the understanding of the public on delay as the definition of 'delay in seeking treatment' is more individual specific. Most of them do not think that they delayed in seeking treatment, as it is a normal thing to them to wait for a few days or weeks or even for a few months to get the symptoms cured naturally. This is more applicable in the case of common symptoms like cough, fever, headache, stomach pain and minor ulcers. Once the symptoms become severe, then only they seek treatment seriously. There are many reasons for this kind of a health seeking behaviour. It cannot be attributed to any single causal factor.

No significant gender difference is observed in the case of those who got diagnosed within six months. But more males are there in the group who delayed between six months to one-year period and more female in the group of more than one year. Even though a generalisation is not possible, the site wise analysis of delay may give some explanation for this kind of a gender difference in delay. Among those who delayed more than one year, there are two breast cancer cases, one cervical cancer patient and one woman with urinary bladder cancer. A brain cancer case and a lung cancer case are also there who are males. Thus among those who delayed more than one year, there are four female and two male patients. For all these women, the cancer-affected sites are their genital/ reproductory organs. The explanation by the patients or relatives for this delay show that in two cases the patients with urinary bladder and cervical cancers hide their symptoms from others in the beginning stages due to their shyness. Others were ignorant of the seriousness of the symptoms. The breast cancer patients also had a tendency to hide the lump on their breast from others and they thought that it is an ordinary growth, which shows their ignorance of the seriousness of the symptoms. In the case of the brain cancer patient, the identified symptom i.e. headache was ignored in the initial stages considering it as an ordinary pain and the failure of the physician in the first contact point in identifying the disease also contributed to the delay in diagnosis.

The least delayed cancers are observed as cancers of mouth/oral cavity, which are easier to identify and diagnose. The symptoms are clearer also. Besides, the general perception of the people about cancer, which many of them immediately associate with smoking and mouth cancers, may give more understanding of these symptoms and its importance. Thus there is an increased possibility for seeking treatment for this type of cancers comparatively earlier than cancers of other sites. Those who did not pay adequate attention to the symptoms were more delayed in getting diagnosed. Patients with cancers in their secret body parts are the ones who hide their symptoms from others in the beginning and more delayed. Some other patients, though they were aware of the presence of the symptoms, waited for some time to allow the symptoms "to cure naturally" since they did not find the need for immediate medical intervention and the circumstances of them also played in this kind of a response. These persons can be categorised as those in the second stage of Suchman's illness behaviour model as they had interpreted the symptoms as something gone wrong but did not approach the professional for treatment.

In the case of lymphoma and bone cancer, there is a delay of more than three months. This can be attributed to the reduced clarity of the symptoms to the patients and their poor understanding of such type of cancers. Also there is a possible error in diagnosis of this type of cancers since it is not common and the diagnosis is more complex.

Many patients ignored or neglected the presence of their initial symptoms like cough, fever, minor ulcers, fatigue, and weight-loss as they being very common in nature and symptoms of other diseases also. Symptoms like recurrent giddiness and bleeding were treated with more attention by the patients, as they are not so common and more easily attributable to the presence of some serious health problems. Also people normally do not relate the symptoms they observed to the 'deadly disease' i.e. cancer. They approach a medical practitioner only when these symptoms become more severe or more disturbing. No patient under this study reported of sought preventive health check-up or screening in connection with cancer. All of them took curative measure. In other words the public, normally do not believe themselves vulnerable to cancer. This can be of because of the health culture prevalent in which routine health check-ups are not common and the poor access of majority to advanced health care practices and techniques.

Socio-economic disadvantage of the patient and family is a major component in health seeking. Access to health care services and the process of decision making in health care are very much linked with the socio-economic factors of the patient and family. Education of the patient and family is one of such factors that associated with health seeking. Even though a clear association is not found, the general tendency observed in the case of the patients is that those who are in the lower levels of education has a tendency for seeking treatment comparatively late. This relationship is not properly proved in this study.

Employment is another important factor that influence treatment seeking behaviour. In present study, most of the women are housewives who are considered as unemployed and most of the men are in unorganised work settings. Those men who are in the daily wages works and coolie works are found to be delayed in seeking medical assistance. The nature of their work is a major factor in this. In all possible way, there is a tendency among these workers to postpone the visit to a doctor and wait for a suitable time for it, which may prolong till the symptoms, become severe. Also in the case of those who sought treatment from a physician, the follow up also observed very poor. Physicians also reported poor follow up by a considerable portion of patients. Here the nature of the work, security of job, income and the responsibilities associated with the work are significant factors.

Failure of the physician in the first contact point in diagnosing the disease properly is another important component in delay. Since the patients under this study visited Medical College Hospital on referral, their first contact point is very significant and there the inferences that the physician makes bring changes in the process of medical intervention and the treatment seeking behaviour of the patient. The time gap between the first contact to a physician and actual diagnosis also observed significantly longer in many of the cases. This gap is not only because of the failure of the doctor in making the referral in time but because of the financial crises of the patient and the distance to the Medical College also. The opportunity cost of visit also significantly plays in the decision making process of visiting the Medical College Hospital for advanced treatment.

In the case of the patients studied, most of them approached nearby hospital for the first intervention. The response from there was mixed. Table: 5.3 shows the place at which the patients contacted first time for medical intervention and table: 5.4 show the response from the first contact point.

Table: 5.3 First place of Treatment

First Contact Point	Frequency	Percent
Homoeopathy	2	5.6
Nearby Private hospital	23	63.9
Nearby Govt. hospital	9	25.0
MCH	2	5.6
Total	36	100.0

As seen in table: 5.3, the first contact point for treatment is an important factor in delay. Two patients (5.6%) visited nearby Homoeopathic hospital for the treatment of their symptoms. But later they had to turn to allopathic medicine. For 69.9% of the patients, first contact point was nearby private hospital and 25% of the patients visited nearby government hospital for the treatment of their illness. Two of the patients directly visited Medical College Hospital and it is found that these patients are staying nearby the hospital. But for them also the first contact point was not the department of radiotherapy. All the patients visited the department of radiotherapy at Medical College Hospital (MCH), either for diagnosis or for treatment in a later stage. This is mainly through referral by the physician at the first contact point. A few patients visited MCH on their own decision for "better treatment". The poor and inadequate facility in the first contact point for diagnosis and treatment was a factor in this referral. MCH, Kottayam is the only institution that provides advanced treatment for cancer in public sector in the district with a large catchment area from adjacent districts also. There are a few private hospitals also but their services are limited to a very few. The less expensive treatment and the credibility of the MCH are the reasons for selecting it for advanced cancer care by a large section of the people. The shifting from first contact point to MCH is a significant factor in the delay in treatment and this can be considered as a utilisation delay.

Table: 5.4 Response from First Doctor

Response	No. of patients	Percent
Diagnosed properly	6	16.7
Did not diagnosed	15	41.7
Referred to MCH	15	41.7
Total	36	100.0

In the first contact point also, responses from the doctors were varied. In 16.7% of the cases, the disease was diagnosed properly and started the initial steps of treatment in the first contact point itself. But in 41.7% cases, the physician did not diagnose the disease properly. This improper diagnosis was a major factor in delay. In the case of another 41.7%, the patients were directly referred to MCH. This was a factor in the delay in diagnosis.

In precise, delay in seeking treatment by the patients is influenced by site of the symptom, type of the symptom, general socio-economic disadvantages, which are linked with the individual's capacity for decision making and access to health care services, and the availability of proper health care services. In present study, it is found that the delay between the symptom identification and diagnosis of the cancer is associated with combination of the above-mentioned factors.

These responses can be analysed using the classification of delay by DiMatteo and Martin. They divided the total delay in treatment seeking into three stages; Appraisal time, Illness delay and utilization delay (DiMatteo & Martin, 2002). Those who did not care their symptoms were in the first phase of appraisal time delay which means the time taken for recognise the presence of the symptom as a state of illness and to understand that something is wrong in them. During this phase the patient feels quite normal and least worried about the symptoms. Those who responded that they "did not care" were the ones who did not realise that these symptoms were serious and they were affected by some serious health problem. Those who waited for some time for natural cure and those who started self-medication were in the second stage of delay. Illness delay – the second stage – is the time taken for realising that they need some kind of medical intervention to check the health problem that happened in them. At this stage the patient starts worrying over the symptoms but not think that they need the service of a medical person. It is because of this thought they started treating the symptoms by themselves or waited for some time to cure it gradually.

Table: 5.5 Delay Between Diagnosis and Treatment

Delay	No. of patients	Percentage
Nil	19	52.8
One week	7	19.4
1 - 2 weeks	5	13.9
2 - 4 weeks	4	11.1
1 - 2 months	1	2.8
Total	36	100.0

As seen in table: 5.5, in the case of delay between diagnosis and treatment, 52.8% of the patients were reported that there was no delay. But in the rest of 47.2% of the patients the delay in treatment ranged between one week to two months due to financial reasons, access to services, distance to MCH and other factors.

This can be classified as the utilization delay in DiMatteo and Martin's model, which means the time taken for receiving actual medical care after realising the need for it. At this stage various constraints may come up in getting treated. These constraints can be clubbed under the problems in access to medical care. Accessibility is determined by number factors like availability of the services at a reachable distance and affordable price, other related expenses or the opportunity cost of hospital visit etc. The socio-economic status of the patient and the expertise of the physician also factors in the utilisation delay. In Medical College Hospital also there was a chance of utilisation delay due to the inadequacies of both infrastructure and personnel in the department of radiotherapy. In short, the delay in getting diagnosed is a combination of the appraisal delay, illness delay and utilisation delay in the case of the population covered under present study also.

Table: 5.6 Reasons for Delay: Response from Patients, Relatives and Professionals

Reason	**Rank**		
	Patients	*Relatives*	*Professionals*
Not aware of the seriousness	1	1	1
Thought it will cure gradually	3	2	*
Work related	7	*	*
Financial	6	*	4
Doctor's failure in the first contact point	4	4	3
Availability of services in the first contact point	2	*	2
Non disclosure by the patient	*	3	*
Health culture	*	*	5
Others	5	5	6

* *Not given as a reason*

The comparison of the reasons given by the participants of the study (table: 5.6) shows congruence in some points. To all of them "Not aware of the seriousness" was the most important reason. Here the patients and the relatives were not aware of the seriousness of thc presence of the symptoms and they could not relate their symptoms to cancer. The patients responded that financial and work related reasons are less important and availability of services is more important factors in seeking treatment. This shows that if the services are available, they think that they could have received better care. However, the opportunity cost of visiting the hospital is also an important factor in the delay in diagnosis and treatment. Few professional referred 'health culture' as a reason for delay. Here health culture, to them, is mainly the preventive health behaviour. But it is determined by various micro as well as macro factors like socio-economic status of the patient, accessibility and availability of services and nobody from this category mentioned it.

From the above analysis, it is found that there was considerable delay in diagnosis in many cases. The average delay in diagnosis was seven months and the delay in treatment after getting diagnosed ranges from one week to two months. The factors in delay were patient specific, familial and social. It ranges from patient's personality factors to the general health culture prevailing in the community. The factors in delay spread over the individual level to social structure and administrative levels. So it is very significant to have an understanding of these factors and their interactions with the individual's health seeking and very much helpful in the planning and formulations of health care programs especially in the field of cancer care.

Coping with Cancer

It is a widely accepted fact that cancer is not a disease which affects an individual only rather its consequences are borne by the entire family also. The impact of cancer is not only physical but emotional and social also. And these impacts on relatives and even on the community or neighbourhood are very much evident. The perception of the public on cancer is stigmatised and it is synonymously used as suffering and painful death. Unfortunately the medical intervention, more specifically curative intervention, is not found much effective and has its own side effects. The very optimistic professional also calculate the survival rate of cancer in terms of a period of five years. This itself influence the attitude towards cancer. The attitude and perception towards cancer are evident from the expressed idea of the participants of the study that cancer is painful, which most people vigorously trying to avoid. This very assumption and the sensation of pain are creating fear in not only the patient but in family members and community. Coping with cancer is very much significant in the quality of life of the patient. In the present study, major thrust is given to the coping pattern of the patient with disease. Coping is a concept that encompasses the understanding of the stressful life events (here the disease), acceptance to the reality and behavioural as well as emotional adaptations to the stressor for reducing the consequences of it. There are a variety of coping strategies, which ranges from the denial of the reality to becoming a part of the stressor.

Behavioural scientists in the field of cancer put forward the important concept of 'coping' in cancer care and management. This concept and its importance are derived from the above-discussed perception of the public. Since the fear of cancer is deep rooted in society, it is very important to help the patient and family to cope with the disease and it need knowledge, expertise and skill to help the patient in adjusting with the reality. The coping strategy should be planned properly and this planning must be initiated by the physician, as he is the one who come to know the reality first. The very breaking of the bad news itself is an important part in the coping strategy. As analysed in the previous chapter, almost all the patients experience a "shock" when the diagnosis is first conveyed to them. Like health belief model says, generally people do not prefer to hear the bad news and like to believe strongly that they are not vulnerable the unfavourable condition and it will happen only to others but not to them. It is a kind of defence mechanism, which is a form of denial. This is a coping mechanism that the individual takes up to defend his/ her ego. It is generally very difficult to work on this defence and the physician is an important factor in the coping strategy. He must learn to help the patient to develop his own coping strategy after studying the personality and other behavioural factors of the patient. This is based upon the skill of the physician in identifying the patient as an individual and not as a mere 'case'.

Literature says that the initial period of disbelief of the patient is followed by anger, depression, anxiety, fear and a variety of emotions and psychological stages. Finally in most of the cases, the patient gradually accepts the reality. The professionals and key informants participated in this study also are of the same opinion. Dr.Gupta of Cansupport, a Delhi based NGO supporting cancer patients and family observes:

> "The psychological changes the cancer patient undergoes is very complex and depend upon the individual patient. In the initial stage when the news is broken, the general feeling is a shock. Then most of the patients develop a mind block. Many patients develop denial of the reality, which is usually negative. If it is positive that shows the will power of the patient and is helpful in coping. Some others develop anger and its manifestations to oneself, family and even to the society. Some others develop deep grief, which destroy the patient faster. The final stage is the acceptance. But before that he/ she undergoes, a range of psychological changes like helplessness, worry, panic, depression etc. the sooner the patient accepts the reality the better the quality of his/her life".

Coping by the family with the disease and the state of health of their relative is also significant in cancer care and management. According to Dr. Gupta,

> "The family also undergoes such kind of psychological dilemma. Many factors like personality, social beliefs and interaction, economic factors, age, education, family constitution etc. plays their important role in these developments".

The participant professionals of the study also mentioned the coping pattern of the patients. 8.3% of the professionals consider ignorance of the disease is helpful in coping with the disease. This is an expressed reason for some of the relatives to hide the news from the patient. Rest of the health professionals believe that the patients are forced to accept the reality or consciously accept the disease at a later stage. 25% of the professionals believe that spirituality is helpful in coping with the disease.

More than half of the patients (61.1%) reported that after getting diseased, their spirituality has been changed. Many of the patients cope with the disease by relying on prayers and spiritual activities. To a majority of the patients, spiritual activities are a great relief from their suffering. For most of them especially to the aged patients it is an engagement also. Many family members also responded that they "left it to the God", as they consider that the cure of the disease is beyond their control.

Family is the primary agency for health care provisioning in society. It is one of the primary functions of family to provide safety, security and well being to its members. The dynamics within the family influence the coping pattern of the patient very much. The family dynamics of the participant patient are observed and it is found that there are a variety of factors influencing the coping of the patient, which are within family dynamics. Since all the patients studied here are receiving care in their home and they all are with the opinion that their families are supporting them in all possible ways. This support is an important component in accepting the reality. But in some cases, especially in the case of bedridden patients, they are very much dependent and that makes them more depressed. There is a change in the support from children and other dear ones. The visit frequency of relatives is increased in many cases, which help them in feeling that they are more considered. But a few patients do not prefer visit by others as it is creating a disturbance in them by considering them as terminally ill. These patients do not like to "be labelled as ill". This is a form of manifestation of their frustration and it shows that they did not accept their condition properly.

The pressure of disease on family is so much that in nuclear families, the members find it very difficult to adjust with their relative's disease. The reported suicide of the young wife of a cancer patient by jumping down from the terrace of the hospital when she came to know the diagnosis of her husband shows the degree of stress on family. Family structure and relationships are very significant in assisting the patient to cope with the disease. All the participants of the study are of the opinion that the primary role of family in cancer care is to provide psychological support and assisting the patient to cope with the disease.

Professional assistance in coping is also suggested by the participants. 16.7% of the public and 50% of the professionals are of the opinion that the intervention of professionally trained social workers will do better in developing coping capacity among patients and family. But a few professionals do not find any reason for the intervention of a social worker. They think that the physician can assist them to adjust with the disease. It is true to a great extent also. But observations by the researcher in the hospital on the doctor-patient relationship found that inadequacy of staff puts pressure on the physicians and at an average they get less than five minutes to spend with each patient in one visit. During this visit, it is very difficult to assist the patient in a more empathetic way. Also the doctor-patient relationship is not healthy enough to develop a platform for a desired psychological intervention. As one of the professional opined, "the very orientation of current medical education is not in favour of the patient. It does not consider the social conditions of the patient". The biomedical orientation of the physicians, in general, complemented by the workload limit them from a more comprehensive approach to cancer care. It is observed that it is the nurses and paramedical staffs are spending more time with the patients than doctors. Observation show that these nurses and paramedical staff were not received any special training in dealing with cancer patients, apart from their basic training. This shows the need for a specially trained person's intervention in assisting the patient and family to cope with the disease.

Family members and patients also expect more empathetic communication from the health care professionals. It is observed that this demand is more among the in-patients. The support that outpatients are getting from the family within their own homely atmosphere and the provision for better social interaction compared to the inpatients are factors in better coping of the patients in homecare. The doctor-patient relationship is observed as inadequate and the physicians reported constraints in developing a constructive doctor-patient relationship. One of the interviewed physician observed, "generally (cancer) patients and their families are pessimistic and they must be made positive to the treatment. Patients can be made positive to the treatment through healthy communication". According to a nurse "a mere touch by the doctor is a great relief for the paining patient". The experiences of a social worker in one of the hospice centre also support the observation that the patients and their family expect care with more personal touch from the professionals. In the case of homecare, modified communication between patients and family members as well as the assurance and empathetic care from the professionals catalyse their coping with the disease.

Thus, the above analysis shows that coping with cancer is an important factor in the quality of life of the patient and family. The time taken for accepting the reality and the mode of that acceptance are significant in the life of the patient after getting diseased. Coping pattern varies according to the individual's personality and social factors. It is also found that patients and family need some kind of external assistance in coping and health care professionals like physician, nurse and social workers can facilitate the process of coping by developing a healthy and productive rapport with the patient and family.

The Case of Alice

Alice, fifty-two years old widow is a high school educated, Christian housewife. She is the mother of three children of whom two daughters are married off and the twenty-eight years old son in running a petty shop. She is staying with her son in her small house. Her husband committed suicide eight years back. Alice was a hard working coolie worker who used to engage in agricultural works and other petty work along with her household chores. She was highly active and known for her outgoing and energetic nature in the locality.

One year after the death of her husband (i.e. seven years back), she noticed a small lump, which she narrates as "*like a pepper*" on her right breast. She ignored it in the beginning but disclosed this to her friend and co-worker who is her neighbour. The friend advised her to visit a doctor. After a few months she had pain on the breast and visited a private doctor who send her back giving some tablets. She continued her coolie works. In between she managed to marry her daughter off.

After a few more months she had severe pain on her right side and especially shoulder and gradually it developed to the neck backside of her right shoulder. The pain was very severe while she works in the field and used to get her right side massaged by her friend. She did not doubt of any serious health problem rather she thought it as from her hard work.

One day she got a chance to visit somebody in the nearby government hospital and decided to consult the physician there. After a detailed examination the lady physician asked her to go immediately to Medical College Hospital, if possible on the same day and told her that she will follow up that whether she obeyed her or not. But she visited the MCH a few days later due to her engagements in home and work. In MCH she was confirmed of having breast cancer. "*I was* *guided to the department, which I recognised as cancer ward and I found the shock on the face of my sister who accompanied me. But I was not at all bothered of it*".

On 1st August 1996 she had undergone mastectomy. The boldness shown by her to take the decision to remove the right breast completely was "*a surprise to the doctors*". "*The motivation for me to take such a bold decision was my experiences with an old lady in my neighbourhood who had suffered the ill fate of having breast cancer and died with that severe pain. The assurances from my physician also helped me*".

She was not aware of the consequences of the surgery fully. She spent fourteen days in MCH where the after care was very pathetic that her son and sisters were asked to purchase medicine from outside and the dressing of the wound was not proper that it turned to a wound with pus and even maggots. In between she took heavy doses of chemotherapy and radiotherapy. After two weeks she went back to a nearby government hospital. There she managed to get a bed on the expense of hundred rupees to the doctor. The doctor removed the pus and dressed the wound. She spent two weeks there also and returned home. "*During the stay at the local hospital I used to take bath daily, which helped me to regain my health soon*"

The major consequence of the surgery was the contraction of the muscles and the severe pain while moving or lifting right hand. "*I used to lift my right hand by dragging it up over the wall suffering the severe pain and gradually the pain started reducing and not I can do all the activities with it easily*", she proudly explained waving her hand. Now she is fully back to her normal health but not going out for work.

Regarding the side effects of treatment she said that only slight fatigue and slight hair loss at the time of intense medication. "*Now I am perfectly OK*". She stopped taking medicine in November 2002, on the advice of the doctor.

Regarding her attitudinal change, "*I felt nothing special at the time of diagnosis and now also I am not at all afraid. Many of the patients who underwent*

> *surgery along with me had died of their disease and I found many of them were weeping and not taking food during their disease episode. My children were very much afraid and there was a rumour that I was going to die, in my locality, when I left Medical College Hospital. My children are very serious about my health and keen on my activities. Just because of my disease, my son, quit using tobacco. The response from my in-laws was not satisfactory.*" The behavioural change in her after disease was mainly spiritual. " *The disease increased my faith in God and it is His grace that I could survive. Now every morning I attend the service in the church which is two kilometres away from my home*" she stopped working outside, but continues in all her household activities. "*Both my daughters are married off and they have children also. Now I am satisfied and not at all worried of my death*".

The case of Alice is an example for delay in diagnosis yet remission. The work related and financial factors, her ignorance of the seriousness of the symptoms were the major factors in the delay. Also this is a case of coping with cancer. The acceptance of the disease and the determination she shows and the channelisation of her feelings is notable. This case is an example for the effective coping and thereby improved quality of life of cancer patients.

Quality of Life in Cancer

Quality of life is a very subjective idea. It is very much abstract and difficult to quantify. It encompasses the perception of the individual on his/ her satisfaction with the physical, emotional and social well being. "Physical health, psychological well being, independence, social relationships, the familial and social environment and natural environment are important components in the quality of life of an individual" (Kishore, 2002). Since it is a subjective perception, it is individual specific. It is very difficult to set a universal standard for assessing quality of life of the patient as it is very much related to the individual's value orientations, belief system, motivations, knowledge etc.

In the present study quality of life of the patient is assessed in terms of the physical disability, stage of illness, response to treatment, and in terms of the reported consequences of the disease to the patient. Based on the observation by the researcher on the dynamics within the family of the patients and the responses of both relatives and patients, the quality of life of the patient is ranked. The variables considered are the stage of disease, degree of disability in terms of dependency, feelings and attitude of the patient towards the present health condition, patient's coping with the disease, family support in terms of nursing care, and financial status of the family.

These variables were assessed on a five-point scale and the total point of each patient is calculated (see table 6.9). Stage of the disease is divided into five stages: *terminal stage*, *advanced but not terminal*, *curing or recovering*, *recovered but under treatment*, and *survived fully* from cancer. Degree of disability also categorised into five levels say *fully dependent/ bedridden*, *dependent but not bedridden*, *surgical deformities*, *weakness*, and *normal*. In the case of current feelings of the patient, the five divisions are *totally depressed*, *disappointed*, *not disappointed but afraid*, *hopeful* and *confident of cure*.

Coping of the patient is assessed in five levels. First, the patient *not at all accepted* the reality i.e. fully depressed and afraid of death and suffering or aggressive etc. Second, *poorly adjusted* in terms of denying the reality or negating the treatment and disappointed. Third, *moderately coping* with the disease situation in terms of accepting the reality and changing the lifestyles and falling in line with the treatment. Fourth level is *good* characterised by understanding the disease situation and positively approaching the disease situation. Fifth level is the ideal stage where the patient is proactive to the disease, which is categorised as *coping very well*.

In the case of support from the family, it is also divided into five levels. In the first level the patient is fully abandoned and this is categorised as '*very poor*'. The second level is '*poor*' family support, which is characterised by poor communication, poor nursing support etc. from the part of the family members. In the '*moderate*' level the family is supporting the patient with concern and offering possible services in a normal way. '*Good*' and '*very good*' levels of family support are characterised by the varying degrees of special concern from the caregivers and the family members, special nutritional support, good nursing care, good communication, psychological support and physical assistance, assistance in conformity with the treatment and spiritual assistance.

Financial status of the family is also divided into five categories ranging from '*very poor*' to '*very good*' in terms of the family income, employment of patient and family members, assets etc. The total points are classified into four classes as '*poor*', '*moderate*', '*good*' and '*very good*' as shown in table: 5.7.

Table: 5.7 Classification of the Quality of Life of the Patients In Terms of Assessed Points

Quality of Life	**Range**
Poor	6 to12
Moderate	13-18
Good	19-24
Very Good	25-30

As shown in table 5.8, it is calculated that out of the studied total of thirty-six, 47.2% of the patients were at the terminal stage of their life and 25% were at an advanced but not terminal stage.19.4% of the total patients were in the curing stage from their disease while two patients (5.6%) were recovered but continuing with treatment. One participant is reported as survived fully from the disease.

In the case of disability, all the terminally ill patients (47.2%) were fully dependent of their family, while 16.7% are dependent but not bedridden and 30.5% of the patients have surgical deformities. 5.6% of the patients reported only mild deformities or weakness.

Among the total patients, 16.7% are hopeful that their disease will cure and a same number of patients are categorised as not depressed but afraid of their disease. Two third of the patients reported either disappointed or totally depressed. Not a single patient is fully confident of the cure of their disease.

Table: 5.8 Distribution of Patients According to the Variables of Quality of Life

Stage of the disease		Disability		Current feelings	
Terminal	17 (47.2%)	Fully dependent/ Bedridden	17 (47.2%)	Totally Depressed	20 (55.5%)
Advanced but not terminal	9 (25%)	Dependent but not bedridden	6 (16.7%)	Disappointed	4 (11.1%)
Curing / Recovering	7 (19.4%)	Surgical deformities	11 (30.5%)	Not disappointed but afraid	6 (16.7%)
Recovered but under treatment	2 (5.6%)	Weakness	2 (5.6 %)	Hopeful	6 (16.7%)
Survived fully	1 (2.8%)	Normal	0	Confident of cure	0
Coping		**Family support**		**Financial status of family**	
Not at all accepted	6 (16.6%)	Very poor (Abandoned)	0	Very poor	2 (5.5%)
Poorly adjusted	13 (36.1%)	Poor	2 (5.6%)	Poor	11 (30.6%)
Moderately adjusting	11 (30.6%)	Moderate	9 (25%)	Moderate	12 (33.3%)
Good	5 (13.9%)	Good	21 (58.3%)	Good	11 (30.6%)
Coping very well	1 (2.8%)	Very good	4 (11.1%)	Very good	0

Out of the total thirty-six patients, only one patient (2.8%) is found to be very well coping with the disease. Five patients (13.9%) are assessed as good in their coping whereas eleven (30.6%) were moderate in their coping patterns. More than one third of the studied patients (36.1%) are poorly adjusted while six of them (16.6%) are very poor in coping with their disease characterised by total depression and hopelessness and this adds to the misery of their life.

Majority of the patients (58.3%) enjoy good family support in terms of nursing care, special attention and better communication from the primary care givers in particular and from other family members in general, while 11.1% is reported as enjoying very good support from their family. Nine patients (25%) were reported receiving moderate support from their family and in the case of two patients the support from their family was observed as very poor and their family members consider the caring for their relative as a burden. The financial status of the families also assessed and it is found that the families are almost equally distributed over the three categories of good, moderate and poor. Two families are belongs to extremely lower economic status and those patients are the ones lower in their quality of life as their economically disadvantaged position is a major barrier in access to cancer treatment as well as other essential services.

Considering all these factors, the quality of life of the patients is assessed and it is divided into very good, good, moderate and poor. The following table show the distribution of the patients in different categories of quality of life.

Table: 5.9 Quality of Life of the Patients

Quality of Life	No. of Patients	Percentage
Poor	15	41.7
Moderate	12	33.3
Good	8	22.2
Very Good	1	2.8

In the case of eight patients (22.2%) the overall quality of life is assessed as good. For one third of the total patients (33.3%), it is assessed as moderate and fifteen (41.7%) patients are disadvantaged in terms of the above-analysed factors and their quality of life is graded as poor. One of the survived patients, who is enjoying very good support from family and very well coped with the disease is categorised as very good in quality of life. Physical independence and absence of any major disability and positive attitude towards life are factors in her quality of life.

All the families responded positively to the question of the conscious steps taken by them for improving the quality of life of the patient. The families are offering "all types of support" to their relative. This includes, the provision of best possible treatment, physical and emotional assistance, special attention for the nutritional well being, nursing care, spending more time with the patient, healthy communication and others based on the needs of the patient.

Suggestions for Better Cancer Care

The participants of the study, responded with a variety of suggestions to improve the quality of cancer care services. Table: 5.10 compiles the suggestions given by the caregivers from their experience with cancer. Among these, the most expressed one is the provision for free medicine as the treatment for cancer is expensive and there is an inadequate provision for low cost medicine for poor patients even in public hospitals, it is the primary need of the cancer affected especially poor patients. The financial burden is an added one to the psychological and social consequences of cancer on the affected. So another related suggestion from the caregivers is financial assistance as the relative's disease affected the financial security of those families. Almost half of the caregivers responded on the inadequate facilities in the Medical College Hospital (MCH). Inadequate infrastructure facilities and personnel are the two major problems that the hospital is facing. Both the professionals and public also suggested better facilities in MCH. One important suggestion came up from the caregivers is the provision of cancer care services in regional hospitals. Patients from far away places have to travel long distance to reach MCH for treatment and follow up. Provisioning of essential treatment services and after care in secondary hospital will help the patients and families in better access to these services. Also in the case of terminally ill patients, nursing services at a reachable distance will improve the quality of life of the patient. Better information regarding cancer is another suggestion as the disease is still a least informed area among the public. Better dissemination of information will help in coping with the disease and in developing a positive approach to the disease.

Table: 5.10 Suggestions of the Caregivers for Better Cancer Care

Suggestions	No. of Responses	Rank
Free medicine	31	1
Better facilities in MCH	16	2
Health education	13	3
More facilities in regional hospitals	9	4
Financial assistance	7	5

Suggestions from the professionals and public are also covering all these areas. Apart from the above suggestions, the professionals suggested counselling services to patients and families and a multidisciplinary team approach to cancer. Some of the professionals suggested holistic medicine that can incorporate yoga, meditation and spirituality. All the categories of the participants suggested spirituality as a channelisation and relief for patients. Private participation in cancer care and provision of more specialised cancer service centres are also suggested by the public. Most of these suggestions are keeping in mind the fact that the services in cancer care are inadequate in its existing for to meet the emerging needs of health of the people.

Summary

This chapter analysed the three important concepts in cancer care- treatment seeking behaviour of the patients, coping pattern and quality of life. It is found that significant delay, which is calculated as an average of seven months, is there in diagnosing cancer after the identification of the symptoms. This is a long period especially in cancer and very significant as the cancer gets metastasised. This is a major problem in the curative intervention of the disease. The factors that play in this delay are individual specific and social structural. These factors are not considered as discrete or independent rather they are interlinked. It is observed that after diagnosis, the health seeking behaviour of the patient shows a sudden improvement and it is evident from the reduced delay in getting treatment. Similarly coping with cancer also explored in the case of the studied sample. Since coping is a process that begins with the identification of the symptoms by the patients and others, the dynamics within the process of coping must be analysed in connection with the health seeking behaviour of the patient. It is found that, in general, the coping pattern of the patients with their disease is poor as more than half of them were 'poor' or 'very poor' in coping and the assistance from the professionals in this direction is limited. The institution under the study also lacks adequate mechanism for assisting the patients in developing effective coping strategy.

Good health and the coping strategies are determinant factors in the quality of life of the patient, which is the final objective of every intervention. Variety of factors influence the quality of life of the patient and it is analysed in terms of the present stage of disease, coping with it and the support from the family. It is found that to almost half of the patients the quality of life is poor and to another considerable portion it is only in a moderate level. Though this is very subjective in nature and a generalisation is not possible with this kind of an analysis, it is worthwhile to explore the various dimensions of the life quality of cancer patients. Suggestions from the relatives and professionals for the better quality of cancer care show that availability of adequate services at a reachable distance and at an affordable price is primary. Since majority of the patient are from the lower strata of society, financial assistance mainly in the form of subsidised medicine is an expressed and felt need of the patients. Here the role of public sector is significant. The implications of the findings of the study are discussed in the next chapter.

6

Summary and Conclusion

The present study was an attempt to explore the various dimensions of life of the cancer-affected patients. It focused on three main areas i.e. coping with the cancer disease, treatment seeking behaviour of the affected and quality of life of the patient. The perceptions and attitude of the patients, relatives, health care professionals, and public were explored to complete the picture of cancer care and management. Kerala state was selected for the study due to the dominance of non-communicable and chronic diseases in the midst of its better health status in terms of health indicators. Among the major causes of death, in Kerala, cancer stands second to heart diseases and cerebral thrombosis. In such a background, an understanding of the meaning of cancer and how it is dealt by various sections of the affected people was aimed through the present study. The population under the study is the people receiving services from the department of radiotherapy in the Medical College Hospital, Kottayam, Kerala. All the patients under the study are receiving home care and registered in the Medical College Hospital within one-year period of the study.

A review of studies on cancer disease and its management is done in the first chapter. It is found that globally a health transition is happening in favour of non-communicable diseases. The stage and pace of this transition are varied across regions and countries. In the case of cancer, in the developed world, it is already established as one of the top killer diseases. In developing world also cancer incidents are slowly increasing. Thus it has developed as a global health problem. Studies show that there are geographical and cultural differences in the pattern of the incidence and distribution of cancer. In India it is found that the rate of cancer incidence is increasing over time. Even though communicable diseases continue to be the major health problems of the country, studies show that the reduction in the rates of communicable diseases, in some way, are balanced by the increasing rates of non-communicable diseases. In some of its states like Kerala, the incidence of cancer is higher than the national average.

Researches in the field of cancer are generally concentrated in the biomedical aspects of the disease. This can be because of the inadequate knowledge regarding the causal associations of the disease and the lack of effective treatment for cancer. The interests of market led funding agencies, which are financially assisting these studies are also significant influences these researches. Thus the political economy of cancer research shows that it is dominated by market forces. Most of these researches lack an epidemiological frame of analysis that can research the question of health of the people in a broader and more comprehensive perspective. The causal associations of cancer disease, according this frame of analysis, cannot be reduced only to biomedical factors like genetic reasons, exposure to carcinogens, infections and lifestyles, rather these are the intermediary variables between the real causal factors and the disease. In the transformist view of health, the socio-economic disadvantages of the people are manifested through the above mentioned intermediary variables and ultimately lead to vulnerability to cancer. But the dominating frames of references do not go further beyond these intermediary variables. The obsession with tangibility and empiricism is an important factor in this kind of approach. Present study calls for a paradigm shift in cancer research as the disease causation and its consequences in the health of the people must be analysed in a broader socio-economic, political and cultural frame.

The basic research question explored through this study is the process of coping of the affected with cancer disease and the dynamics of psychosocial factors in deciding the quality of life of the affected. Coping is conceptualised as the response of the affected in minimising the distress originated from cancer. It is a fundamental psychological process based on which people develop certain skills of adjustment. Coping is an ongoing process, which encompasses the meaning of the disease to the affected, perception of them regarding the various dimensions of the problem and the resultant response to minimise the impact of the problem. In present study coping is operationalised as an umbrella concept and linked with health behaviour and quality of life of the affected. Coping with cancer is analysed in the context of home care. A number of studies emphasise the role of family atmosphere in helping the patient to cope with the disease. Therefore, it is also important to look at the coping pattern of the family with their relative's ill health.

Analysis of the socio-demographic profile of the patients show that majority of the patients receiving care from the medical college hospital are from the lower strata of society. The medical college hospital, Kottayam is the only tertiary care hospital in public sector in the district and the provisioning of low cost, advanced health care services makes it the most important service provider for cancer patients. It covers a population spread over five adjacent districts.

The general perception regarding cancer is that it is painful suffering, end of life, incurable and unrecoverable. This kind of perception is derived out of the previous experience of most of the participant members of the study with cancer disease. The study also shows that the dissemination of information regarding cancer among the public is an important determinant factor in the perception of the people. Most of the information they received is from mainstream mass media, which also influenced by the dominant paradigm of biomedical orientation. The general tendency to reduce the causal associations of cancer disease to lifestyle factors, and within lifestyle factors limiting them to smoking and tobacco consumption is an important factor in the perception of the public, who easily associate cancer with smoking.

Patients who suffer from cancer generally come to know the disease only in the advanced stage after which curative intervention is difficult. Pain is one of the most feared and common after effect of cancer and it is the most stigmatised outcome of the disease. The prolonged suffering and the degeneration that is caused by the disease create a pessimist attitude among the public as well as the affected. The first impression that comes to the mind of the general public when they hear the word cancer is pain, suffering and death. Thus coping with cancer, in other words, is coping with pain and death.

Both the reviewed studies and present study find that cancer cases in India and especially in Kerala are increasing. The distribution of disease occurrence over age groups shows a tendency to cluster towards the later years of age. Both the literature and present study support this observation. Though there are differences in the matter of gender-wise vulnerability to cancer among various studies, present study find an increased vulnerability of men to cancer over women. It is observed that in middle age, women are more prone to cancer and the most observed type is breast cancer. The hospital records show that cancer incidence in the population is more among men. It is found that the female specific cancers (cancer of breast, cervix, ovary and other female genital organs) are comparably equal in number with cancers of lungs and mouth related sites among men. This shows that a clear gender difference is there in the pattern of cancer occurrence.

Consequences of cancer are at the individual, family and community levels. At individual level it causes ill health in terms of physical malfunctioning, deformity, dependency and psychological as well as social distress. However, many studies argue, cancer is a disease that affects family as the consequences of the disease are borne by the entire family. These consequences range from psychological distress to social, financial, and physical problems of the family members. They are generally manifested through depression, disappointment, limited social interaction and mobility, financial insecurity, changes in employment pattern, and even ill health of the caregivers. The consequences of the disease are more on families from the lower strata of society due to their socially and economically disadvantaged positions. As the individual and family cannot be separated from the community, consequences of cancer are influencing the response from the community also. This is reflected through the response of the community, which expressed a fear towards cancer and suggested collective responsibility in improving the quality of life of the cancer affected. The need for a broader frame of understanding of health is justified by the fact that health is very much associated with the general culture of the community. The definition and meaning of health and disease as well as the response of the people to health problems are derived out of cultural complex existing in the community. As literature shows there are cultural variations in health development over societies. In a society where health care is a collective responsibility and family is the primary institution in health development, biomedical approach is inadequate in understanding health of the people.

Present study had explored the consequences of the disease among the cancer affected in a multidimensional way. Physical deformity, pain and side effects of the treatment are the most reported physical consequences while depression, hopelessness, loneliness, fear of death and loss of independence are the common psychological problems that the patients are suffering from. Among the family members, the most reported problems are depression, feeling of insecurity and different forms of fear. Socially, the disease restricts the mobility and interactions of the patient and to a certain extend the caregivers. The stigmatised perception that cancer is a warrant of painful suffering and death is common among the public and their attitude towards the affected is with more sympathy and concern.

The prolonged suffering of the disease influence the priority of the family over time. In the beginning the family along with the patient is more cancer-centred and gradually as the disease prolongs, the family goes back to its original functioning. In most of the case the family again becomes cancer-centred at the terminal stage of the patient. This is a part of the process of coping of the family with the disease of their relative. Even between these priority changes, in the study, it is found a common agreement on the importance of home care among the various sections of the participants of the study. Most of the participants consider the role of family in providing psychological support and more personalised care, which are considered as crucial in the coping process, equally important as medical intervention. In the terminal stage when medical intervention fails to help the patient to recover from the gradual decay of health, importance of home care is more. Emphasis of these roles of family is rooted in the cultural practices and values related to health and family in society.

There are lot of constraints that the family has to face both in home care and hospital care. To most of the families, nursing care is a major hurdle in caring for the cancer patient within family. The disease brings changes in the lifestyle, diet pattern, physical functioning, communication and behaviour of the patient. It is important to adapt with these changes in caring for the patient. In hospital care also these factors are important but the nursing care is excluded from the family members to a great extent and there the primary caregivers are the professionals. But in hospital care, there is the extra burden on the family of accompanying the patient. It is observed that the burden of care for the patient is more on women. As one researcher observes, family is a code word for women especially in the case of health care. Caring for the patient is an additional responsibility of women apart from the usual household chores. One important observation made in the study is that it was women who preferred home care to the cancer affected. The reason can be the extra burden of accompanying the patient in the hospital.

Physical access to the hospital is an important factor in the mode-of-care preference. This is also a factor in the delay in seeking care for the disease. The distance to the hospital is an important factor in the follow-up of the treatment and compliance with the treatment modalities, which in turn influence the quality of life of the patient. Thus, the preference of the mode-of-care is determined by provision for nursing care and treatment, access to services, provision for family support, facilities in the hospital, family structure, employment of caregivers, doctor's decision, stage of disease etc.

A review of different models in health behaviour is made in the study. Health Belief Model argues that the perceived threat or benefit derived from the symptoms the individual identified acts as an intermediary variable in health seeking behaviour. This model is based on the notion of good health as a positive value. Kasl and Cobb also consider perception of the individual regarding the value of the action he/ she takes as an intermediary variable between the socio-economic, demographic, psychological and biological factors and illness behaviour. Theory of reasoned action explain health behaviour as a rational choice of the individual derived from his/ her subjective norms regarding responsible actions for being healthy in society. Anderson and others classify the factors in health behaviour as predisposing, enabling and need factors. Socio demographic factors and belief system act as predisposing factors, while factors relating to accessibility and availability are enabling the actions for health development, which the individual consider as a need for being functional in society. Mechanic's explanation and classification of the determinants of health behaviour is also symptom-centred and argues that the cognitive, cultural and socio-economic factors contribute to the health behaviour of the individual. Different from these explanations, Suchman describes the process of health behaviour. He divided it into five different stages. These stages are not discrete rather there is a continuum or overlapping between these stages. One's health behaviour can be considered as a manifestation of his/her adjustment with the disturbance created out of the health problem. In other words, it is a part of coping.

In the reviewed models, some of them are dealing with the factors of health behaviour whereas some others are explaining the process. While some approaches explain health behaviour in a social psychological dimension, some others are incorporating the importance of socio-economic and cultural factors in determining the health seeking behaviour of the individual. It is found that a wide range of factors influence the treatment seeking behaviour of the cancer affected. It is determined by the nature and type of the symptoms the patient had identified, site of the disease, age and gender of the patient, employment, family structure, education of the patient and the family members, economic background, previous experience with cancer disease, availability and accessibility of health care services and the general health culture.

Delay in seeking treatment was specifically explored and it is found that factors like the site of the disease, type of symptoms, access to health care system, quality of health care, financial status, and opportunity cost of treatment were found significantly influence the time gap between symptom identification and diagnosis. Unavailability of adequate diagnostic and treatment facilities in the first contact point and the professional competence of the first physician contacted are important factors in determining the delay in diagnosis of cancer in the studied population. Most of the patients failed to relate the identified symptoms to cancer as their understanding of cancer were not adequate. In the case of oral cancers, there is a difference in this aspect as the mainstream media disseminate information regarding the relation between tobacco consumption and mouth as well as lung cancers. This influence is evident from the response of the participants of the study as most of them relate cancer to smoking. The site and type of the symptoms are also found significantly influenced the delay in seeking treatment as many patients initially did not pay adequate attention to the 'common symptoms' they identified. Also some of the female patients who have cancers in their genital organs hide their symptoms in the initial stages that resulted a considerable delay in diagnosis.

Coping with cancer is an important area in cancer care and management. As the consequences of cancer is not limited to the individual patient alone rather it affect the family and the community in various levels, coping with cancer is not confined to the patient only. It is a subjective process characterised by certain physical and psychological responses. Acceptance of the reality and adapting to that by modifying the responses accordingly is broadly considered as coping. Literature shows certain important factors in the process of coping. One among them is the communication between the participant members. The power of words is an established one in reducing the impact of psychological disturbance. In the case of cancer care, the communication within family as well as between the patient and the professionals are significant factors in facilitating coping. Similarly the interpersonal relations are also influence the coping of both family and the patient with the disease.

Coping with cancer starts from the identification of the symptoms. But the diagnosis of the disease is the turning point in the life of the patient and the family. Because of this reason, the role of health care professionals is significantly important in facilitating the coping process. This can be through the proper dissemination of information, effective communication, empathetic assurance and provisioning of quality care. The coping strategy is determined by the socio-economic, demographic and cultural environment as well as the personality of the patient. External intervention in the form of manipulation of the above-mentioned environment and behaviour modification of the affected through professional assistance are helpful in coping with the disease. In the case of the studied patients and families more than a half of them are poorly coping with the disease. Spirituality is an important coping strategy in the case of chronic illness. In the present study also, a considerable portion of the patients and families cope with their problem through spirituality.

All the forms of care giving and medical interventions are aimed at improving the quality of life of the individual. Quality of life is synonymously used for well being in many studies. In the studied population, quality of life of the cancer affected was assessed in terms of six variables: the degree of disability, stage of the disease, coping with the disease, current feelings of the patients, support from the family and financial status of the family. It is found that the quality of life of almost half of the patients is poor while one third of the participants are enjoying a moderate quality of life after getting diseased. Those who are in the incurable stages of their disease are the ones with very poor quality of life. Among the above six factors, support from family is found to be very important in the better quality of life. Hence, in a culture where the primary institution in healthcare of the individual is family, home care is significantly important in chronic illnesses and this is more important in cancer for the curative intervention is limited due to the limitations of modern medicine and its consequences are prolonged. However, the limitations of medical intervention in cancer cure should not be used to justify the inadequacies in health care service system, as it is an integral part in ensuring better quality of life of the patient.

Implications of The Study

The understanding from the present study implies certain conscious interventions in the area of health of the people. Primarily, there is an urgent need for strengthening the existing health care service system through the adequate allocation of manpower, finance as well as infrastructure facilities according to the emerging health needs of the people. As understood through the study, there should be provision for cancer care and management in regional level. Currently this care is limited to the tertiary care hospitals in public sector and highly sophisticated multi-speciality or super-speciality hospitals in the private sector. This limits the access of the affected poor to adequate health care. Provision of cancer care diagnosis, essential treatment and aftercare facilities in the secondary hospitals will ensure better access and compliance with the treatment which in turn contribute to the quality of life of the patient. Availability of services at a reachable distance will improve the help seeking behaviour of the people thereby increase the effectiveness of cancer treatment.

Cancer affects the financial security of the family. Provisioning of subsidised medicine and treatment in public sector is an expressed as well as felt need of the affected people. Coping with the disease can be facilitated by professionally equipped persons. A multidisciplinary team consisting of physician, nurse, radiographer, medical social worker and other paramedical staff will help in better provisioning of cancer care and such an intervention will in assist the patient and family in coping with the disease. The doctor-patient relationship must be constructively used as a platform for better cancer care services. A holistic approach to the disease and its consequences, which encompasses medical, psychological, social, cultural and spiritual dimensions of health of the affected, can be formulated as home-based cancer rehabilitation. Towards this, basic training to primary caregivers and the family in essential nursing care and effective communication is an important area to be developed. The dissemination of information regarding cancer is significantly important in developing a positive and optimistic attitude towards the disease among the public. Collaboration between public health agencies, professionals from related fields, media, genuinely interested non-government organisations and the public, which is complemented by adequate policy support from the government, is helpful in these areas especially in the context of increasing dominance of chronic and non-communicable diseases. Finally a broader understanding of cancer in a macro perspective, which covers socio-economic, socio-political and cultural dimensions of health will help in effective care and management of cancer.

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Appendix -I

Coping with Cancer

Interview Schedule for Patients

Schedule No.....

General Information

1. Name :
2. Address :
3. Age :
4. Sex (1)Male (2)Female
5. Religion (1)Christian (2) Hindu (3) Muslim (4) Others
6. Marital status (1)Married (2)Widowed (3)Separated (4)Unmarried
7. Education (1)Illiterate (2)Primary school (3)HighSchool
   (4)Higher Education (5) Others (specify).........
8. Occupation Previous ....Current..................

Family background

9. Living environment: (1) own home (2)children's home (3) others
10. Type of family (1)Joint family (2) Extended (3) Nuclear family
11. Details of family

Name	Relation	Sex	Age	Edu. Status	Marital status	Employment	Remarks

12. Have you ever been admitted in MCH? Yes / No
    If 'yes', when? .... How long?
13. How often are you getting services from MCH?
    (1)Daily (2) Twice a week (3) Weekly (4) Monthly (5) Others
14. Who is the primary care giver in your home?
15. Do your children / relatives visit you regularly? Yes / No
    If 'yes' how often?

Disease details

16. What is your knowledge about your disease
17. What type of cancer is affected?
18. What was the first symptom of your disease?
19. When did you notice it first?

20. What did you do then?
21. When did you first approach a doctor for treatment?
22. Who accompanied you in your first visit?
23. What was the first response from the doctor?
24. When was your disease diagnosed?
25. How much delay was there between
    (a) Symptom identification and diagnosis
    (b) Diagnosis and treatment
26. Why was this delay?
27. Where did you first seek treatment? Then what happened (a brief narration of the history of treatment seeking)
28. If the first contact point was other than MCH, why did you leave that place?
29. How did the doctor disclose your disease to you?
30. What was your first emotion when you heard the news?
31. What do you feel now?
32. What was the response from the family?
33. What do they feel now?
34. What are the major health problems you are suffering from the treatment of your disease?
35. What do you think as the reason for your disease?
36. Explain your lifestyle
37. What changes happened in your lifestyle after getting diseased?
38. What kind of services are you getting from MCH?
39. What kind of services are you expecting from:
    - Family
    - Relatives
    - Society
40. What kind of services are you getting from:
    - Family
    - Relatives
    - Society
41. How is your family managing the expenses of your treatment?
42. What kind of changes happened in your life after getting this disease? (Social, Economic, Spiritual, Psychological, Familial ,Physical- narration)

Appendix -II

Coping with Cancer

Interview Schedule for Relatives / Family Members

Schedule No......

General Information

1. Name :
2. Age :
3. Sex (1)Male (2)Female
4. Religion (1)Christian (2) Hindu (3) Muslim (4) Others
5. Marital status (1)Married (2)Widowed (3)Separated (4)Unmarried
6. Education (1)Illiterate (2)Primary school (3)High school (4)Higher Education (5) Others (specify)
7. Occupation :
8. Relationship with the patient
9. How long have the patient been diseased?
10. When was the disease diagnosed?
11. Was there any delay between symptom identification and first visit to a doctor? *Yes / No*
12. If 'Yes', why?
13. Was there delay between diagnosis and treatment? *Yes / No*
14. If yes, why ?
15. Where did you first visit for treatment?
16. Why did you seek treatment in MCH?
17. What is the information that the doctor had given you?
18. How did he break the news?
19. Are you satisfied with the way the news was broken? *Yes / No*
20. If '*No*' why and how do you expect it to be broken?
21. What do you know about Cancer? Specify the source of information?
22. What do you think as the reason for your relative's disease? (Biological and non-biological if any)
23. Does the patient know that he/she is a cancer patient? *Yes / No*
24. If '*Yes*', who disclosed it? *Doctor / Nurse / You / Others*
    If '*No*', why it is not disclosed?
25. What did you feel when the news was broken?
26. What were the feelings of the patient at that time?

27. What emotional changes have you been undergone? (Narration)

28. What changes happened in the patient after the diagnosis?
29. Explain the attitudinal and behavioural changes happened in you and your family members after the patient got the disease
30. What are the disturbing factors arouse out of the disease of your relative? (Social, economic, psychological and others)
31. How often the patient visit MCH?
32. Who accompanies him/her?
33. What are the changes in communication between you/ family and the patient after getting the disease?
34. What do you think better for the improvement of health of the patient? *Hospitalisation / Home care*
35. Why?
36. What are the services you are getting from the MCH?
37. Is there any short comings in these services ? *Yes /No*
38. If '*Yes*' explain
39. What are the difficulties you face in giving care in the home?
40. How far the MCH is from your home?
41. Do you think this disease will cure? *Yes /No*
42. Why?
43. What conscious steps are you taking in improving the quality of life of the patient?
44. Your suggestions

Appendix -III

Coping with Cancer

Interview Guide for Professionals

Schedule No......

1. Name :
2. Qualification :
3. Specialization (if any) :
4. Did you get any aspecial training in cancer care? *Yes / No*
   If '*Yes*', specify
5. Nature of work
6. Work experience with cancer patients
7. Explain the time trend of cancer in your institution (changes in number, type, age, treatment seeking behaviour etc. of patients)
8. What are the essential services needed for a cancer patient
9. What are the services your institution provides
10. What are the areas to be improved
11. What are the problems that MCH is facing in health care provisioning to cancer patients

Disease specific

12. Major symptoms of cancer?
13. What kind of treatment is effective for cancer?
14. Related health problems?
15. Causes of cancer?

Patient related

16. The psychological problems that the patients generally face
17. Explain the stigma attached to cancer
18. The beliefs that the patients have regarding their disease?
19. What is the general attitude of the patient to treatment and providers?
20. The general demands the patients generally make from the providers

Communication

21. To whom do you prefer to break the bad news of cancer?
22. Why?
23. How do you explain the diagnosis to the patient?
24. Do you think that the present way of breaking the news is proper? *Yes / No*

25. If '*No*' why?
26. Do you think that the present training is adequate in communicating with cancer patients? *Yes / No*
27. If '*No*' why?
28. How much time usually you spent with the patient in one session-
29. Do you think that this kind of communication is enough? *Yes / No*
    If '*No*'why?
30. Do you think special training is needed in communicating with the patient? Why?
31. What kind of conversation the patients generally prefer?
32. Do you have to face any other problem in dealing with the patient? *Yes / No*
    If '*yes*' explain
33. Explain the way in which the patients generally cope with their disease
34. In what stage they generally seek treatment
35. Is there any delay in seeking treatment? *Yes / No*
36. If 'yes' what do you think as its reason?
37. Explain the role of family in the management of cancer
38. Which is more effective in cancer care? *Hospital care / Home care* & Why?
39. Role of hospices in the management of cancer?
40. Suggestions in improving the quality of life of cancer patients?
41. Explain your idea of ideal cancer management

Appendix -IV

Coping with Cancer

Interview Schedule/Questionnaire for General Public

Schedule No......

1. Name
2. Age
3. Sex
4. Education
5. Occupation
6. Work experience
7. Do you have any experience with cancer patients ? Yes / No
8. If 'yes' , what kind of experience ?
9. Is / were there any relative / friend of you having cancer? Yes / No

   If 'yes', what type:..........................Present status:..................
10. What do know about cancer?
    - Causes of cancer
    - Treatment
    - Care for patients
    - Public perception
    - Others
11. From where you got this information? Formal education / Media / Parents / Experts / Others (specify)
12. Are you afraid of cancer? Yes / No
13. If 'yes' why?
14. What is your attitude towards cancer patients?
15. Which is your nearest hospital providing cancer care?
16. How far it is from your residence?
17. What is your knowledge about the problems faced by cancer patients;

    Physical
    Psychological
    Social
    Financial
18. What do you think as the immediate needs of patients with cancer?
19. Which one do you think effective in cancer care - *Hospital care / Home care*

20. Why?
21. In your opinion, what is the role of family in the care of cancer patients?
22. In your opinion, what special considerations should be given to cancer patients?
23. What do you think of the services provided through the medical college
24. What role private sector can play in cancer management
25. Explain your idea of effective cancer management (prevention, treatment and rehabilitation)
26. Your suggestions to improve the quality of life of cancer patients.