Chapter I

FRAME OF REFERENCE
INTRODUCTION:

Chronic diseases such as cancer and other non-communicable diseases are fast replacing communicable diseases in India and other developing countries (N.S. Murthy, 2004). Cancer is group of diseases with similar characteristics. Cancer can occur in all living cells in the body and different cancer types have different natural history. Epidemiological studies have shown that 70-90 percent of all cancers are environmental. Lifestyle related factors are the most important and preventable among the environmental exposures (Cherian Varghese, 2009). The term cancer refers to a group of diseases which share similar characteristics. Cancer can affect all living cells in the body, at all ages and in both genders. The causation is multifactorial and the disease process differs at different sites. Tobacco is the single most important identified risk factor for cancer. A host of other environmental exposures, certain infections as well as genetic predisposition play an important role in carcinogenesis. It is now known that over one-third of cancers are preventable, and one-third potentially curable provided they are diagnosed early in their course. The quality of life of patients with incurable disease can be improved with palliative care (M. Krishnan Nair, 2005).

Cancer is a major public health problem, with significant associated death and disability. It is the second leading cause of death in developed countries and is one of the three leading causes of death for adults in developing countries. There are over 200 different types of cancer but four cancers: lung cancer, breast cancer, prostate cancer and large bowel cancer account for more than half of all cases. Of the 12.4 million new cancer cases in 2008, the most common cancers in terms of incidence were lung (1.52 million), breast (1.29 million) and colorectal (1.15 million). The types of cancer vary around the world and there is significant variation in the risk of different...
cancers by geographic area. Most of this global variation is due to exposure to known or suspected risk factors related to lifestyle or environment and provides a clear challenge to prevention. In developed countries, almost as many cancer cases are attributable to an unhealthy diet and inactive lifestyle as to smoking. Although a third of all cancer deaths are linked to cigarette smoking, obesity is associated with colon, breast, uterine, oesophageal and kidney cancer (Boehringer Ingelheim GmbH, 2009).

Cancer is a leading cause of death worldwide. The disease accounted for 7.9 million deaths (13 percent of all deaths worldwide) in 2007. In addition, despite advances in treatment, deaths from cancer are projected to rise, with an estimated 17 million deaths in 2030. Cancer predominantly affects the elderly population with approximately 65 percent of cancers diagnosed in patients over 65 years. Of the 12.4 million new cancer cases in 2008, the most common cancers in terms of incidence were lung (1.52 million), breast (1.29 million) and colorectal (1.15 million) (Boehringer Ingelheim GmbH, 2009). Urbanization, industrialization, changes in lifestyles, population growth and ageing all have contributed for epidemiological transition in the country. The absolute number of new cancer cases is increasing rapidly, due to growth in size of the population, and increase in the proportion of elderly persons as a result of improved life expectancy following control of communicable diseases. In India, the life expectancy at birth has steadily risen from 45 years in 1971 to 62 years in 1991, indicating a shift in demographic profile. It is estimated that life expectancy of Indian population will increase to 70 years by 2021–25. Such changes in the age structure would automatically alter the disease pattern associated with ageing and increase the burden of problems such as cancer, cardiovascular and other non-communicable diseases in the society.
Cancer has become an important Public Health Problem with over 800,000 new cases occurring every year, and is one of the ten leading causes of death in India. At any point of time, it is estimated that there are nearly 2.5 million cases in the country with nearly 400,000 deaths occurring due to cancer. Cancer incidence in India is estimated to be around 70-90 per 100,000 population. From the population based registries in India covering 28-30 million population from different parts of the country, the age adjusted incidence rates vary from 44-122 per 100,000 population in males, and 52-128 per 100,000 females. Cancer registries have also highlighted that more than 80 percent of cancer in females occur in the age group of 35-64, and 3.5 percent to 4.5 percent in childhood, thereby suggesting the impact of cancer as a major public health problem in the most productive age group. Nearly 1,500,000 people require facilities for diagnosis, treatment and follow-up at a given time (K. Uma Devi, 2009).

Breast and cervical cancer are the two most important cancer types and account for one-third of all cases diagnosed in women of the developing world (Dinshaw AK, 2004). The incidence of breast cancer is rising and is the most common cancer among urban women (Chopra R., 2003). Presently 75,000 new cases occur in Indian women every year. There an estimated annual global incidence of 500,000 cancers, India contributes 100,000 i.e. one-fifth of the world burden. In 1996, breast cancer was the leading cancer in women globally, accounting for 376,000 deaths, followed by cancers of the stomach (290,000 deaths) and the colon rectum (252,000 deaths). Cervical cancer ranked fourth and accounted for 247,000 deaths in women. Twenty percent of all female deaths from cancer, in India, in 1990 were from cervical cancer, amounting to an estimated 61,000 deaths. The number of cervical cancer deaths in women in India is projected to increase to 79,000 by the year 2010. In the same year, an estimated 59,000 deaths in Indian women would be caused by breast cancer and 53,000 deaths by oral cancer. In Southern India carcinoma of the uterine cervix is the most common
form of cancer in females (Shanta V., 2003). A total of 4304 cervical cancer cases were registered during 1982-89 in the Chennai registry, India (Gajalakshmi V, Rajaraman S, Shanta V., 2000) (Radhika Bobba, 2003).

Nearly 70 percent of India’s population lives in rural areas where the measures of health and living standards are low. Rural women are vulnerable to most of the risk factors for cervical cancer such as early marriage, early childbirth, multiparity, poor genital hygiene, and chronic infection with sexually transmitted disease. India, a country of more than one billion people, lacks organized Pap smear programs, and screening has not reached the vast majority of women in need. Pap smear screening is not feasible due to lack of infrastructure, cost and necessity of follow-up visits. Meta analysis of the publications on Pap screening indicates that the sensitivity of a single Pap smear is 50 percent and not 80 percent. As a result of these difficulties, many Indian women seek care only when the cancer is advanced and not amenable to curative treatment. There are 27 regional cancer centers, and many specialty hospitals are equipped with comprehensive cancer care facilities. However, very few centers have a gynecologic oncology division served by gynecologists trained in gynecological oncology (proportionately infrastructure vs. trained gynecological oncology is lacking). In our regional cancer center, more than 16,000 new cases have been registered, of which 8,000 cases are diagnosed with cancer annually and, of which 1,500 to 2,000 will be gynecologic cancers.

However more than 50 percent were compliant to treatment protocol, and less than 30 percent default during the adjuvant therapy and 20 percent default after the preliminary investigations. Overall, 30 percent complete follow-up for three years in regional cancer centers and 70-80 percent in comprehensive care centers. Recently, many corporate private hospitals in urban India are provided with most of the high tech facilities for diagnosis and treatment, where the complaints to treatment and follow up has
much improved as most of women who have insurance coverage belong to the upper middle class. However, this constitutes less than 10 percent of the population coverage. India launched its National Cancer Control Program in 1975-1976 in response to the incidence of various cancers affecting women and men. The program goals include the primary prevention of cancers through health education, secondary prevention through early detection and diagnosis, strengthening of cancer treatment facilities and patient care for patients with advanced cancer. In 1990-91 & 1998-99, the national government established a District Cancer Control Program (DCCP) and subsequently modified the District Cancer Control Program in an effort to extend prevention and early detection services to rural communities. However, the program was not focused on cervical cancer and very little impact was observed. There was no provision for follow-up or treatment of cancer patients once diagnosed in the screening program (K. Uma Devi, 2009).

**CONCEPTUAL FRAME:**

The occurrence of cancer within a population can be studied at many different levels, including forms of social organization, the individual, a particular organ system, or a particular molecule. The causes of cancer can also be studied at these different levels, including socioeconomic factors, lifestyle, the organ burden of a carcinogen, or DNA adducts. Clearly, there are advantages in understanding disease causation at all of the different levels at which it operates. Although cancer risk factors such as tobacco smoke may appear to operate at the individual level, exposure may occur due to a wide range of political, economic and social factors; conversely, tobacco smoke ultimately also has effects at the cellular and molecular levels, including the production of mutations in DNA. Of course, it is important to gain information, and take action, at all possible levels, but the history of public health shows that changes at the population level are usually more fundamental and effective than changes at the individual level, even when a
single risk factor accounts for most cases of disease. In this sense, a risk factor such as smoking can be regarded as a secondary symptom of deeper underlying features of the social and economic structure of society. Thus, just as a variety of health effects in various organ systems (for example, various types of cancer) may have a common contributing cause (for example, tobacco smoking) at the level of the individual, a variety of individual exposures (for example, smoking and diet) may have common socioeconomic causes at the population level. In many instances there is clear evidence that cancer is related to socioeconomic factors, but this does not appear to be fully explained by known risk factors. More importantly, there is little evidence as to which socioeconomic factors are of most importance, or whether it is the overall 'package' of social inequality that is responsible for the differences in cancer risk (N. Pearce, 1997).

The primary goal of public health is the prevention of disease in human populations, and socioeconomic factors are of major importance in this context. There are now major social class differences in incidence and mortality from cancer and other chronic diseases, and that social class differences in mortality are increasing and are greater now (in relative terms) than they were in the nineteenth century (Marmot & McDowell, 1986; Pappas et al., 1993). In most industrialized countries, studies have repeatedly found strong associations between social class and cancer (Logan, 1982), with a nearly twofold relative risk for cancer when comparing the most disadvantaged group with the most advantaged group (although there are some specific cancer types for which the differential is in the opposite direction)(N. Pearce, 1997).

Some social scientists and epidemiologists emphasize that the major improvements in health status have come from social and economic changes and their influence on factors such as housing, income and nutrition (McKeown, 1979; Szreter, 1988). These various pathways to understanding the disease process fall into two main approaches, which mirror wider scientific debates in recent centuries. The 'bottom-up' approach variants of which include
reductionism, positivism, or the downstream approach (McKinlay, 1993) focuses on understanding the individual components of a process at the lowest possible level and using this information as the 'building blocks' to gain knowledge about higher levels of organization. One current example is molecular epidemiology, which attempts to understand disease at the molecular level and then (ultimately) to use this knowledge in public health policy (for example, by screening populations for susceptibility to specific carcinogens). This approach stems from the clinical tradition and is typified by an emphasis on specific risk factors and the use of the randomized clinical trial as a paradigm. It certainly yields useful information about the level under study (for example, the molecular level), but it is debatable whether it is an effective and efficient long-term strategy for gaining knowledge or preventing disease at the population level. As Smith (1985) notes, this approach lacks distinctive theory regarding the occurrence of disease at the population level, and its products can be likened to 'a vast stockpile of almost surgically clean data untouched by human thought' (Anonymous, 1994). Although it has an air of scientific purity, this approach is in fact rarely used in other sciences or related disciplines; for example, nobody would attempt to predict the weather or the motion of the planets from measurements of individual molecules. Such an approach is not only impossible in practice (because of the infinitely large amount of information required), but recent work in chaos theory has shown that such an approach is also impossible in theory because small inaccuracies can produce huge effects in non-linear systems (Firth, 1991).

In contrast, the 'top-down' approach [variants of which include the structural approach (Tesh, 1988), the dialectical approach (Levins & Lewontin, 1985), and the upstream approach (McKinlay, 1993) starts at the population level so as to ascertain the main factors that influence health status within the population. Studying disease at the population level usually requires a greater emphasis on observational (epidemiological) studies rather than experimental studies, and may also involve a greater use of 'ecological' studies
of 'sick populations' rather than 'analytical' epidemiological studies of 'sick individuals' (Rose, 1992). Thus, the 'top down' approach stems from the demographic/social science tradition (rather than the clinical trial paradigm). The study of socioeconomic differences in cancer primarily belongs to this tradition, which has been supported in a recent editorial in The Lancet (1994) that argued for the 'need to move away from the almost exclusive focus of research on individual risk, toward the social structures and processes within which ill-health originates, and which will be more amenable to modification' (McKinlay, 1993).

REVIEW OF LITERATURE:

In most of the population of the world there has been a large increase in the incidence of breast, corpus uteri and ovarian cancer and a decrease in cervical cancer. Change in the age at the first birth of the first child has been correlated with the increase in the breast cancer incidence among Mumbai population. The decrease in the cervical cancer incidence rates that has been observed in Mumbai is due to increase in mean age at marriage (Balakrishna Bhika Yeole, 2002).

In India more than 60 percent of cancers belong to breast, cervix, endometrium and ovary. In conclusion it may be pointed out that breast cancer in urban India and cervical cancer in rural India have become priority health problems. Socio-demographic transition i.e. taking place would result in increase in female cancer load and particularly of breast cancer. Economic constraints together with higher education levels compelled many women to seek employment, which are different from that of earlier generation. This leads to late age at marriage and first delivery and less number of children becomes common. Such compelling need based social cultural practices are difficult to change in a preventing oncology program. The present female patient attendance in the hospitals indicate that less than 10 percent attend for
treatment in stage-I disease. The necessity for early detection of female cancer, when cure rate can be about 80 percent, need to be propagated in view of the fact that at present there are no known powerful modifiable lifestyle factors. The need is thus for early detection and follow strict treatment protocols developed and tested in Indian conditions. From the available estimates it may be seen that there would have been four million female cancer incidence cases (Breast – 80,000, Cervix – 100,000 and Ovary – 20,000) annually in the country. The prevalence rate if considered three times the incidence rate indicates the approximate requirements for major curative and rehabilitative services (Balkrishna Bhika Yeole, 2002).

The Unique Needs of the Cancer Patient: Supportive needs often fall into five main categories: informational; psychological (needs related to emotions and coping); social (communicating with people); practical and financial; and spiritual (relating to belief and the need for hope) (Zabora J, BrintzenhofeSzoc K, 2001).

Informational Needs: One goal of psychosocial support is to make sure that individuals and families have access to accurate information to answer whatever questions they have. Counsellors can recommend good information sources and advise on how to evaluate and use available information, including:

- Weighing the benefits and side-effects of treatment before you make decisions
- Getting information about your illness and managing side effects, and learning about things you can do to help healing. Pointing to other resources that may help you cope complementary therapies and other types of support that may be available and useful to you and your family, such as peer support groups, community resources, palliative care, etc. (Zabora J, BrintzenhofeSzoc K, 2001).
Breast Cancer is “a malignant growth that begins in the tissues of the breast. Over the course of a lifetime, one in eight women will be diagnosed with breast cancer” (Medline Plus Medical Dictionary, 2004). Several types of breast cancer exist. In addition, breast cancers are diagnosed at various stages in their development. The type of breast cancer and how advanced the cancer is influence the prognosis. More advanced breast cancers are often defined by how far they have spread to the tissue surrounding the breast or the lymph nodes. The type of breast cancer also influences which treatment regimens tend to be most suitable (Naomi Louise Reyes, 2005). Breast cancer is emerging as the leading cancer in women. A large number of factors are identified as risk factors for breast cancer. Late age at first pregnancy (greater than 30 years), single child, late age at menopause etc are some of them. A high fat diet is also identified as a risk factor. Physical activity is found to be protective for breast cancer. The sudden changes towards affluent life styles have reduced the physical activities to a minimum and increased the consumption of diets rich in fat. High fat diets during the pubertal age and obesity in the post menopausal age are risk factors for breast cancer. Regular breast self examination by women themselves is a very good way of detecting breast cancer in early stages. Detecting a cancer when it is in the very early stage can improve the cure rate from breast cancer (Cherian Varghese, 2009).

Cancer of the cervix is now thought to be a sexually transmitted disease. Its association with early sexual activity and sexual promiscuity in particular, has been well established in a number of epidemiological studies in the West and in Asian populations. It has been suggested that cervical cancer might be caused by sexual transmission of an infectious agent. The human papilloma virus (HPV) has been identified as the leading candidate for the sexually transmitted aetiological factor in cervical cancer. Despite a very high incidence of cervical cancer in India, the role of sexual promiscuity has not been well addressed in Indian populations, where the rate of promiscuity among women is known to be very low. A recent case-control study in India
found male promiscuity responsible for increased risk of cervical cancer. The present study was undertaken to examine the role of sexual risk factors in this cancer among women living in and around a South Bengal district in India, where society is more conservative and marital infidelity an uncommon event (Litan Naha Biswas, 1997).

Cancer of the cervix has been the most important cancer in women in India over the past two decades. All the urban population based cancer registries (PBCR) at Bangalore, Bhopal, Chennai, Delhi and Mumbai have shown a statistically significant decrease in the AARs of this site of cancer. This decline is despite the absence of any organized screening programme. The decline in the AAR varies from 42.3 (in 1982-83) to 22.3 (in 2004-05) per 100,000 in Chennai to a marginal decline in Barshi from 23.5 (in 1988-89) to 22.8 (in 2004-05). Cancer of the cervix accounted for 16 percent of all cancers in women in the urban registries in 2005. However, it constitutes 37 percent of the cancers in females in Barshi. The highest age specific incidence rate of 98.2 per 100,000 for cancer cervix was seen in the 60-64 yr age group. Since over 70 percent of the Indian population resides in the rural areas, cancer cervix still constitutes the number one cancer in either sex. Based on the data of the PBCRs, the estimated number of new cancers during 2007 in India was 90,708. The relative five year survival reported some time earlier averaged 48.7 percent (A.Nandakumar, 2009).

Cancer of the uterine cervix is still the most common cancer among women in India. Improvements in living standards and access to health care have reduced the rate of occurrence of cervical cancer in certain States like Kerala. However the changing sexual behaviour in young adults might lead to another wave of cervical cancers. Early age at first intercourse, multiple sexual partners, poor sexual hygiene, repeated child birth etc are some of the reproductive risk factors for cervical cancer. Improvements in the living
standards of women have resulted in a reduction in the incidence of cervical cancer. Regular cervical cytology examination (pap smear) by all women who have initiated sexual activity can prevent the occurrence of cervical cancer. This has been successfully achieved in many European countries. However there are many limitations for cytology based cervical cancer screening in India. The States in India are in various levels of health care delivery and health infrastructure and it is possible that there are certain areas in which screening programmes could be initiated. The system for screening, with facilities for call back and proper referral are very important, irrespective of the screening strategy (Cherian Varghese, 2009).

Some items, known as risk factors, increase the likelihood that a woman will develop or die of breast cancer. Others, known as preventive measures, decrease this likelihood. Known risk factors include increased age, personal or family history of breast cancer, early menarche, late menopause, having a first child late in life or never having children, smoking, and heavy alcohol use. Preventive measures include getting regular mammograms, performing breast self-exams, breastfeeding, exercising regularly, and eating a healthful diet. The commonly cited statistic that one in eight women will develop breast cancer refers to a woman’s lifetime risk of developing the disease. A woman’s risk of developing breast cancer increases with age. Between ages 30 and 40, the risk is one in 252; between 40 and 50, it is one in 68; between 50 and 60, it is one in 35; and between 60 and 70, it is one in 27 (Ries et al., 2003). The incidence of and death rates from breast cancer vary by race and ethnicity. Before age 40, the incidence rate is higher among African American women than among white women; after age 40, the reverse is true. However, at all ages African American women are at a greater risk of dying from breast cancer. From 1992 to 2000 the incidence of breast cancer increased in Asian and Pacific Islander, Hispanic, and white women. During the same time period it decreased in American Indian and Alaska Natives and remained stable in African American women (Naomi Louise Reyes, 2005).
Psychosocial cancer care: Cancer is now being recognized as a chronic disease in countries with advanced health care. Cancer as a chronic disease in developed countries with adequate screening programmes and good access to timely treatment cancer survival rates are improving. Cancer is now being recognized as a chronic disease in countries with advanced health care. This extended survival profile brings with it a range of physical, emotional and social challenges in the longer term, including:

- role changes in the household, especially in terms of parenting functions
- social isolation and difficulty re-integrating into social or community circles
- impact on decisions made around family size for patients of child-bearing age
- questions about potential genetic links in the case of a particular cancer
- adjustment to changed appearance, possibly with body image issues
- altered body functioning that may affect intimate relationships, mobility or elimination
- uncertainty about resuming employment (fatigue, workload)
- disruption or interruption of career path
- potential prejudice when returning to the workplace, particularly when seeking new employment
- potential long-term loss or reduction of income
- financial depletion due to treatments, possible environmental modifications or equipment required
- regular encounters with social stigma
- possible psychological disorder, e.g. depression and/or anxiety.
- uncertainty about personal life expectancy, which can make future planning difficult.
- Emotional exhaustion and/or emotional withdrawal by carers, family and friends who find it difficult to sustain high levels of compassion for prolonged periods of time (Clare Manicom, 2010).
This list is not exhaustive, but hints at the profound impact that even a ‘curable cancer’ can have on the life of a patient and family. It is understandable, therefore, that several more developed countries are now offering active rehabilitation programmes for people moving out of the active treatment phase of their cancer, typically including physical activity alongside emotional, social and economic reintegration with appropriate professional support during this ‘phase’ of cancer management (Clare Manicom, 2010).

Cancer as a family concern: With awareness of the impact of cancer beyond the patient, it is evident that entire family units may be affected by the diagnosis and its implications or by the course of the illness. Family members as carers have also been identified as being at risk of manifesting physical exhaustion and/or emotional stress and burnout. The literature focuses on the importance of supporting partners, children and parents of adults facing cancer. Running parallel to the concern about the emotional needs and responses of family members to cancer is an increasing interest in education, information, and access to relevant information with regard to diagnosis, treatment, and side-effects (Clare Manicom, 2010).

Stages in the cancer Journey: Because of the uniqueness of individual social contexts, the journey through cancer treatment and beyond presents a logistic, an organizational and, primarily, a physical challenge. In spite of medical and treatment advances and increasingly researched psychological interventions, people with cancer still face uncertainty and a sense of not being in control of their lives. If the medical team working with the patient has insight into some of the potential concerns that may arise, they can access and provide supportive care. There are several stages in the journey through cancer where a heightened sense of anxiety and stress can be expected from the patient and his/her immediate supporters. Anxiety, depression and distress have been major features in recent psycho-oncology research. It is not uncommon for
these symptoms to require a multi-disciplinary approach to manage them well enough for the patient to continue functioning optimally. It is vital to remember that throughout the abovementioned stages patients and families frequently deal with economic stresses and uncertainties that can become substantial burdens and influence decisions about treatments, continuation of employment, and type of care available should the patient become frail. There are also two less discussed concerns that our patients face at any stage in their cancer journey. Both demand open-mindedness and support from the health care professional. These are the issues of sexuality and intimate relationships, and spiritual or existential concerns (Clare Manicom, 2010).

Potential losses associated with cancer: As with many other chronic medical conditions, the diagnosis of cancer requires some adjustments that may relate to physical functioning or appearance, be linked to capacity for economic activity, or lead patients to reviewing their world view and values. At the very least and even for a brief while a member of society is subjected to medical scrutiny and investigation and is faced with the label ‘patient’. In sociological terms, this label carries with it certain roles and expectations from wider society and medical staff who generally require certain behaviours from their patients (Clare Manicom, 2010). Even though not every person with every cancer will encounter these losses, the different levels at which a sense of loss may be encountered are summarized below:

- Relationship losses
- Role changes – adjusting to being a patient, parenting, social availability, intimate relationships, potential mental/intellectual capacity
- Social isolation – fewer or discontinued employment/studies/activities, abandonment, stigma and rejection
- Emotional distance from loved ones
- Difficulty in having conversations, caregiver fatigue/burnout, blaming, guilt about past behaviours or actions
• Disruption of sex life – may be linked to physical, attitudinal or relationship factors.
• Practical losses
• Loss of physical independence – mobility, hygiene, self-care, driving a car, declining fitness levels
• Economic losses
• Material changes – altered living conditions, financial hardship.
• Emotional and/or spiritual losses
• Lack of self-confidence and self-belief, uncertainty
• Body image concerns and reservations
• May impact on intimate relationships
• Loss of dreams and aspirations – family dreams and hopes (possible infertility, not seeing children grow up, etc.), career or personal ambitions unfulfilled
• Existential uncertainty – spiritual beliefs challenged sense of punishment or guilt, feelings of abandonment, alienation or remoteness from faith.
• Loss of future – need to acknowledge and mourn the future that will not be experienced or shared (Clare Manicom, 2010).

**Quality of life:** Outcomes research is the study of the net effects of the healthcare process on the health and wellbeing of individuals and populations and has a broad scope, including research on satisfaction with care and measurement of patient preferences and quality of life. The quality of life of patients during and after disease and treatment is an important outcome of breast cancer care and an extensively studied subject. The first instruments to measure cancer patients’ performance status and quality of life were physician rated; quality of life studies based on patient questionnaires did not emerge until the late 1980s and early 1990s. In the last decades a great variety of survey instruments have been developed for the assessment of health-related quality of life in breast cancer a recent literature review identified over 100
different quality of life instruments used in breast cancer; although only a few of these have become extensively validated and established over time. Due to the complexity of breast cancer care and the heterogeneity in patient populations, one single instrument may not be sufficiently comprehensive and sensitive to determine clinically meaningful changes in outcomes across all phases of care. Generally, health domains considered in a quality of life assessments are: 1) somatic concerns, such as pain and symptoms; 2) functional ability; 3) family wellbeing; 4) emotional wellbeing; 5) spirituality; 6) treatment satisfaction, including financial impact of illness; 7) future orientation; 8) sexuality, intimacy, and body image; 9) social functioning; 10) occupational functioning; and 11) preferences. Published quality of life studies have encompassed the major stages of breast cancer care: screening, local treatment, adjuvant treatment, treatment of metastatic disease, and survivorship and surveillance.

Women and Social Support: Cancer causes long-term stress which can affect interpersonal relationships. Social support has been shown to be effective in the psychosocial adjustment and coping processes associated with the diagnosis and treatment of cancer. Support groups have shown to be an effective intervention. Young adults with cancer also benefit from support groups with peers as they have different needs than older cancer patients. Cancer research needs to address psychosocial issues for women, given that the quality of life for women is as important as disease treatment. There is little research on cervical cancer that integrates social and psychological issues with prevention and treatment of cancer. One researcher has found links between early family ties and women who are at high risk for cancer. The level of support in current relationships prior to cancer also can determine the level of support a person with cancer will receive. Caregivers often have a difficult time dealing with support needs of patients. One study has found family and caregivers have different definitions of support. Communication of support needs is important. Interventions also need to consider women’s ethnic backgrounds (Martha L. Weber, 1998).
Women living with cancer: Christine Dunkel-Schetter (1984) describes cancer as a stress process that can extend over months or years, where treatment can be painful, and where an ambiguity over recurrence exists. She lists several possible interpersonal changes as the prognosis worsens, including a decrease in social interaction, declining provision and satisfaction of support, and more prevalent problems with family and communication. A positive relationship has been found between social support and psycho-social adjustment and coping with diagnosis and treatment of cancer. Dealing with cancer can alter a person's social relationships, their values, beliefs, meaning of life, and expectations for the future. Cancer patients can be seen as victims who have no control over the event. Social support appears to be beneficial for isolated patients and can mediate how an individual copes with stress related to the process. After treatment, there can be subtle, long-term residual effects as the patient returns to everyday life.

Future research needs to deal with the ambiguity of the treatment outcome and how the individual will cope with this uncertainty. Specifically for cervical cancer, Lambley (1993) notes key physiological vulnerability factors for women. These include how they are supported both socially and interpersonally, and how they cope with stress. He mentions early family ties can play a role (for example, adolescents with unsupportive parents may engage in high-risk behaviour to satisfy emotional and psychological needs). He found that women who have been found to be at high risk for cancer often have histories of early family problems. Not only do they engage in high-risk behaviour such as sex at an early age and sex with multiple partners, many have left home early and are not equipped with social skills to develop and maintain strong social ties in the future. In addition, they may have unsatisfying relationships and lack the emotional energy to develop new, supportive relationships, which increases their risk. This is similar to research results on alcoholic women who also reported less social support during adolescence than non-alcoholic peers. For cervical cancer, Lambley concludes
that there are many factors that interplay simultaneously for dysplasia to progress to malignancy, and all of these factors need to be taken into account (Martha L. Weber, 1998).

Lambley (1993) also states there is little in the research literature that integrates social and psychological considerations with medical treatment, or that deals with the prevention and treatment of cervical cancer. There is little support or psychological advice given to women who have been treated for cervical cancer and what information is given pays scant attention to the interpersonal issues involved. He adds that in addition to treatment, there also is the stress of cancer diagnosis that can affect treatment outcome. He believes this is an area that needs consideration for the prevention of recurrence of the disease. One counsellor agrees, stating “not all patients need or want professional counselling, but all of them need to be listened to, as their search for meaning may be a very important part of the healing process.” One study conducted in the United Kingdom points out barriers in communication between patients being screened for cervical cancer and health professionals. It appears that health professionals are concerned with control and surveillance, while women are generally seeking insurance and reassurance. In another study, Blanchard et al (1995) compared the definition of support by parents of children with cancer and the definition held by health professionals. Parents defined support as compassion, skill in listening, and caring. Health workers described support in terms of being available, being consistent with the family, showing oneself as supportive, understanding and supporting the parental role, and assisting with needed resources (Martha L. Weber, 1998).

McKie (1993) suggests that community health workers can play a large role in reducing fear and anxiety by providing emotional support and informational support that increases knowledge of screening, causation and treatment. Johnson and Meischke (1991) found that people with cancer are
active information-seekers. They state there are two cancer information needs: They note other studies have found other needs regarding cancer, including personal and social integrative needs, and tension release or escape. In their own study, the authors found that once diagnosed with cancer, people turn to authoritative channels, such as doctors, for their information. Dunkei-Schetter (1984) agrees. She found that informational support given from family and friends was often unhelpful and even bothersome. Johnson and Meischke (1991) point out that in general, health care professionals have a difficult time handling the information and personal needs of patients. Thus, individuals often turn to their interpersonal network for emotional support. Dunkei-Schetter (1984) recommends educating doctors on the importance of providing at least small amounts of emotional support, in addition to giving patients information. She describes team approaches where nurses and social workers are incorporated as emotional and information specialists. However, she notes they may not completely substitute for physician care. Last, Johnson and Meischke (1991) state the more barriers an individual encounters in trying to obtain information, the less likely she or he will seek out information actively (Martha L. Weber, 1998).

Spiegel (1992) reports a study that measured the effects of a psycho-social intervention for women with cancer using a support group. The support group enhanced the quality of life for patients, and increased their feelings of control. It helped the women to gain control over strong emotions, and to make use of available social support. Patients frequently feel isolated as family, friends and health care workers often have a difficult time dealing with strong emotions. These feelings of isolation often leave a patient feeling removed from the mainstream of life, as if they are already dead. The author notes that social isolation is linked to greater mortality participation in support groups may alter the risks associated with isolation. Young adults with cancer have different needs than older people with cancer. Roberts et al (1997) state that developing cancer at an early age disrupts normal developmental tasks.
such as establishing independence from parents, starting a career, finding a partner, and having children. They point out that young adults also are faced with the issue of their own mortality, something not usually dealt with until the sixth decade of life or later. The authors state this last issue can result in isolation from healthy peers who do not want to deal with the issue themselves. These patients may not feel they have anything in common with older cancer patients. In a study by the authors on support groups for young adults with cancer, individuals stated they sometimes received too much support and not enough private time. Other members said that family members and friends withdrew or had trouble communicating after the diagnosis of cancer. All members stated they did not get enough information from their doctors, and the group process included giving informational support. Patients also discussed feeling disfigured or physically affected as a result of treatment. Welisch (1993) points out that group experience does not always appear to be beneficial. For example, a study comparing white and Asian women with cancer found cultural differences.

Groups that focus on talking appear to be less relevant to Asian women who might be better served by groups that teach psychically-focused skills such as meditation, relaxation and massage. She notes that while many groups are short-term, there is a growing recognition for groups to continue for years throughout the disease process. In addition, patients' partners experience increased vulnerability to illness upon the death of the patient, indicating that support groups also would be helpful to the partner for the prevention of future disease. She reminds readers that staff who treat patients also need support. Studies indicating that happier staff served patients who adapted and coped better than patients who had less happy staff (Martha L. Weber, 1998).
Dunkel-Schetter (1984) acknowledges the issue of support and cancer is complex. She states "stresses such as cancer have several simultaneous effects that take place over time and that are interwoven". She notes, for example, that the stress placed on a person with cancer's family and friends can influence the quality and quantity of support. In a study of parents of children with cancer, Chesler and Barbarin (1984) describe five core difficulties that parents and friends face with regard to giving/receiving social support: The authors report that friends' compassion and desire to help is complicated by their own emotional distress. In addition, good cues from parents about what kind of support is helpful not only made it easier to give support, it also made friends feel appreciated. Another variable that can influence support is the prior communal relationship between the patient and supporter. Williamson and Schulz (1995) found supporters who had been caring and responsive to the individual's needs prior to onset of cancer had less depression and feelings of being burdened than caregivers who reported little prior communal behaviour. The authors suggest that the new care-taking role may be taken on out of obligation rather than concern for another's welfare, or out of interest in maintaining the relationship. The authors conclude that with regard to caregiver support, the perception of the burden is important because early identification of supporters who are at high-risk of becoming distressed as a result of the caregiver role is important (Martha L. Weber, 1998).

According to Payne et al (1996) there are several factors that interplay and determine an individual's response to cancer: Exterior influences are medical parameters of the disease such as state at diagnosis, available treatments, and complications of treatment. Future research can explore the nature of the communication of support and longitudinal studies to inspect the impact of disease stage on support interactions. Analysis of the use of coping strategies, and more scrutiny on the impact of changes in the patient's social network would be useful. One doctor asks, "Why do four women with an identical diagnosis have such different outcomes? We need to look more
intensively at the woman, and less at the tumour." Another doctor notes that early detection is not prevention and that more research is needed on the psycho-social issues arguing that women want better support systems and attention paid to their quality of life, not just a postponement of death (Martha L. Weber, 1998).

**Human resource generation:** Cancer control programmes need a large number of trained personnel in various specialties. These include Epidemiology and Statistics, Cancer Registry Operations, Cytotechnicians and Cytotechnologists, Nurses trained in Palliative Care and in care of cancer patients on Chemotherapy and radiotherapy, medical personnel in all aspects of cancer treatment, Physiotherapists and Occupational Therapists, Counsellors and various other specialists. Once the programme is initiated the services of all the above categories of personnel are needed and the Regional cancer Centres should take this as a priority and start training programmes (Cherian Varghese, 2009).

**Rural women and health care seeking behaviour:** The majority of the women with cervical cancer present with advanced stage, where surgery may not be suitable. However, cervical precancerous lesions were treated according to the age and with concern to fertility issues. Early invasive cervical cancer of stage-la is treated with hysterectomy, stage-la without lymphovascular space invasion is subjected to extended type-II radical hysterectomy with pelvic lymphadenectomy, and stage-Ib to stage-Ila (selected cases) are subjected to radical hysterectomy (RH type-III) with retroperitoneal pelvic lymphadenectomy with or without salpingooophorectomy. Depending upon the surgico-pathological prognostic risk factors, postoperative adjuvant radiotherapy or chemo radiation is recommended. Low risk patients are kept on regular follow up, intermediate risk patients are subjected to adjuvant brachytherapy with or without pelvic radiation, and in patients high risk prognostication, chemo radiation is recommended. Cervical cancer stage IIb to
stage IIIb and selected stage I b-lla chemo radiation is recommended. Few patients who partially responded to chemo radiation or external pelvic radiotherapy, and not suitable for intracavitary brachytherapy were subjected to surgery when the parametrium clinically appeared free of disease with residual disease confined to the cervix (K. Uma Devi, 2009).

However, those women with advanced disease, not affordable for chemotherapy, radiation therapy is recommended. Some women with bulky early disease are subjected to neoadjuvant chemotherapy for 2-3 cycles, followed by surgery at 2-3 week intervals. Clinically proved stage-IV disease with good performance status, either with distant metastases or locally invasive will be subjected to diversion colostomy followed by palliative chemo radiation or palliative chemotherapy (K. Uma Devi, 2009).

Figure – 1.1

Barriers to Quality Care

Model of access to cancer care. KAB: knowledge, attitudes, and (health) behaviors; QOL: quality of life.
Women's perceptions of cancer: Although breast cancer has been one of the most publicized women's health topics, women still have misconceptions about the disease. Despite what many believe, breast cancer is not the number one killer of women in the United States. In 2000, heart disease claimed the lives of 366,000 American women, compared with 42,000 lives taken by breast cancer. Heart disease or stroke kills one of every two women in the United States, and heart disease itself has a mortality rate almost nine times that of breast cancer. However, recent research indicates that women fear breast cancer more than heart disease and other more common diseases (Mosca et al., 2000; Covello & Peters, 2002; Naomi Louise Reyes, 2005).

A study of 1,000 women found that 61 percent of women aged 45 to 64 years old identified breast cancer as the condition they most feared, whereas nine percent said they most feared heart disease. Fifty-eight percent of the respondents said they believed they were as likely, if not more likely, to die of breast cancer than heart disease (Mosca et al., 2000). A survey published in 2002 found similar results. In addition to finding that breast cancer was the condition the women most feared; the researchers found that a third of the women surveyed said they believed that breast cancer was the disease with the greatest impact on a woman’s quality of life, more so than Alzheimer’s disease and heart disease (Covello & Peters, 2002). Similarly, an American Heart Association survey and a New York Times/CBS News survey indicated that most women consider breast cancer the greatest threat to their health (Naomi Louise Reyes, 2005).

In addition to overestimating the relative likelihood of developing breast cancer, many women have misconceptions about breast cancer itself. In a study of African American women, the respondents said they believed that breast cancer was predominantly a hereditary disease and greatly underestimated the impact of other factors on breast cancer incidence. The
participants indicated that they felt that if someone in their family had breast cancer, they were destined to develop the disease, too. The study indicated that this belief diminished women's desire to seek information about breast cancer and kept many women from engaging in preventive measures such as mammography (Duncan, 2001). In a poll of 1,045 women in Great Britain, 58 percent of the respondents indicated that they believed that breast cancer was more likely the result of genetics rather environmental, lifestyle, or behavioral factors (Spittle, 1999). The reality is that genetics plays a predominant role in only about 10 percent of breast cancers diagnosed each year (Naomi Louise Reyes, 2005).

Many of the women would prefer to be treated in their local or regional area, rather than having to travel to a metropolitan centre. The cost of opting for local treatment is that choices may be limited. Most women, apart from those in remote areas, will have reasonable access to a surgeon who can operate on the primary cancer, remove it and stage the disease. Increasingly, some general surgeons in rural areas have undertaken the considerable effort required to develop a special interest in breast cancer surgery. All surgeons who elect to manage women with breast cancer should keep themselves and their colleagues up to date with the current knowledge and treatment of all aspects of the disease, including current clinical trials. An audit of patient treatments and outcomes should also be maintained. Particularly in rural and remote areas, General Physicians play a key role in the initial diagnosis of women with breast cancer. They also have an ongoing and important role in palliative care where that proves necessary. With the exception of a few major towns, radiotherapy is not available outside capital cities, and resident medical oncologists are not usually available. Given that radiotherapy usually requires six weeks away from home, this influences some women to opt for mastectomy instead of breast conservation plus radiotherapy. This decision is often made for pragmatic, financial, work, family and social reasons.
Cancer communication and health: Cancer communications is the study and application of the use of strategically designed messages delivered through selected media, to convey relevant health information to targeted audiences (of health care consumers, cancer survivors, health care providers, researchers, patients, at-risk populations and others) to promote cancer prevention and control, encourage cancer screening and early detection activities, reduce cancer morbidity and mortality, and enhance the quality of life (Kreps & Viswanath, 2001). This is a very exciting and potentially propitious new area of research and intervention. Consequently, a major investment in cancer communications research proposed by the National Cancer Institute is timely. Communications can raise awareness of health problems and recommended actions, and give people the information they need to make informed cancer-related decisions. Moreover, effective communications can influence people to engage in behaviours that will improve their health, such as stopping smoking or undergoing screening for certain types of cancer. Although use of media alone can produce behavioural change, the effect is increased when its use is supplemented by other community-based educational efforts (Farquhar et al., 1977; Puska et al., 1985; Flay, 1987). The theoretical basis of this of this effect is that increased knowledge and understanding alone do not motivate a person to change. Other factors, such as self-efficacy, skills to implement the change, convenience, and social and cultural mores all influence the decision to change (Maibach & Cotton, 1995).

A larger body of health communication literature has demonstrated the powerful influences of communication interventions on a broad range of health behaviours and health outcomes. For example, Kreps and O'Hair (1995) report a series of studies showing the influences of intrapersonal, interpersonal, group, organizational, and societal communications on health knowledge, behaviour and outcomes. Culturally Sensitive Health Communication Strategies It is important to develop culturally sensitive health communication programs and policies, especially in limited-
resource countries. Culture frames the social norms, beliefs, values, and languages that healthcare consumers use to respond to and communicate about breast cancer. Any single set of health communication practices is not likely to work equally well in different countries. For example, health communication programs that are appropriate and effective in the US may be ineffective and inappropriate if used in Brazil, Cambodia, or Indonesia. Interventions need to be guided by indepth analyses of the unique culturally based communication features of each country or target population and should have a measurable evaluation component when possible. An example is seen in the Prashanti Cancer Care Mission program developed in Pune, India. The target audience was segmented into key homogenous groups based on religion; literacy and education; financial status; castes; status as urban, semi-urban, or rural; language of communication; and relevancy. Culture-specific visual images for posters were gathered from classical Indian art forms to present culturally acceptable images of women, breasts, and torsos using tree spirits and deities from sculptures. Using these art forms to present the breast as integral to a woman’s feminine, maternal, sexual, biologic, physical, emotional, and spiritual reality provides a grounding in the cultural ethos of the community and hence mitigates aversion and uncomfortable reactions (Gary L. Kreps, Rama Sivaram, 2008).

Communication and Social Support: The provision of social support has been shown to be an effective communication strategy for moderating many negative psychological reactions to breast cancer, and helps promote psychosocial adaptation, such as reducing cancer-related pain and suffering, encouraging participation in cancer prevention and control activities, and coping with end-of-life concerns. Social support can be provided to cancer patients by healthcare providers, family members, friends, and peers who experience similar healthcare challenges. The ability to provide meaningful social support depends on the communicators’ abilities to engage in sensitive and empathetic interpersonal communication. Research suggests that peers
who share similar experiences with breast cancer (often in online support groups) are particularly rich sources for social support. In limited-resource countries it is particularly important to develop programs that facilitate access to relevant sources of social support to promote adaptation to the stresses of breast cancer. Strategic health communication programs that promote effective breast cancer survivorship should provide opportunities for participation in social support networks (Gary L. Kreps, Rama Sivaram, 2008).

**Communication Channels:** Patient-provider communication. Interpersonal interaction between patients and healthcare providers is a primary channel for health information regarding breast cancer. Both healthcare providers and consumers need to share relevant health information. Providers depend on gathering full and accurate information from their patients about symptoms, health behaviors, and psychosocial responses to cancer. Patients need the most accurate and up-to-date information concerning breast cancer diagnosis, treatment, survivorship, palliative care, and end-of-life issues. In general, patients consider their physicians to be preferred sources for such information. Effective patient-provider communication can encourage patient cooperation (compliance) with treatment recommendations. Sensitive and culturally competent communication strategies are needed to ameliorate the significant differences in cultural backgrounds (such as age, education, socioeconomic status, sex, and national origin) that often exist between patients and providers. Similarly, competent interpersonal communication among interdependent healthcare providers (physicians, nurses, therapists, pharmacists, and other professionals) who are part of the breast cancer treatment team is essential for coordinating effective breast cancer care (Gary L. Kreps, Rama Sivaram, 2008).

**Family/social network communication:** The family is a primary cultural unit for health education across most countries despite the level of economic development, and helps establish culturally engrained beliefs about health and
Family members and friends are significant sources for health information that can influence cancer prevention, control, and care activities. Family members, especially in many limited-resource countries, often provide needed home care to spouses, parents, and children with cancer. Strategic health communication efforts in limited-resource countries must include educating key family members and friends about ways they can serve as advocates to help support the health information needs of those with breast cancer (Gary L. Kreps, Rama Sivaram, 2008).

The social networks that healthcare consumers have within their local communities are very powerful influences on health beliefs and health behaviors. Local opinion leaders have high credibility and are often ideal sources for delivering and reinforcing breast health messages. For example, in Malaysia, local folk healers known as “bomos” are potentially important health information sources for many women, if bomos are educated regarding the latest relevant breast health information. However, health promoters have found that significant time and resources are often needed to identify and develop relationships with key community leaders within at-risk communities in limited-resource countries. To maintain changes in health behavior over time, it is important to develop broad community support. For example, although it is good to encourage women to engage in recommended mammography screening, it is even better to build local social policies and programs within the communities where these women live to support mammography services (Gary L. Kreps, Rama Sivaram, 2008).

However, it is not productive to encourage women to seek early detection, diagnosis, and treatment of cancer when they have limited access to care, which is a reality in many developing countries. Community engagement in breast cancer awareness and prevention in low-income countries is needed and should be part of an overall strategic health communication strategy to
enhance breast cancer prevention, early detection, and access to care. Communication Campaign Interventions Strategic communication campaigns help influence health behaviors at the group, community, and population levels. They have been used to decrease the prevalence of smoking, to increase consumption of fruits and vegetables, and to increase adherence with recommended cancer screening recommendations (Gary L. Kreps, Rama Sivaram, 2008).

Cervical cancer is unquestionably a success story in the history of cancer control. Since cervical cancer screening programs using the Papanicolaou test (Pap test/Pap smear) were introduced more than 50 years ago, age-adjusted mortality from cervical cancer overall has declined three-fold. Because of the Pap test, which is inexpensive, easily administered, and effective, and because proven treatment for precancerous cervical lesions and localized invasive cancers is available, virtually all cervical cancer deaths should be avoidable. Pap tests find precancerous lesions that are easily and effectively treated with colposcopy or simply watched, since not all precancerous lesions become cancer. When cervical cancer is detected before it has spread, it is one of the most successfully treated cancers, though patients may suffer adverse consequences from treatment, including infertility and late effects of radiation and/or chemotherapy. Recent research discoveries, including liquid-based cytology, a combined Pap test and test for the human papillomavirus (HPV) that causes most cervical cancers, and the development and testing of HPV vaccines promise to improve even further our ability to prevent or identify abnormalities of the uterine cervix long before they become cancerous. Still, in 2004 an estimated 3,900 women died from cervical cancer (Harold P. Freeman, 2005).

Despite the consistent decline in cervical cancer mortality overall, an entrenched geographic pattern of deaths from this disease has persisted for
decades. This ongoing disparity in mortality from a wholly preventable disease drew the interest of the National Cancer Institute (NCI) and led the NCI Center to Reduce Cancer Health Disparities to lead the inquiry into underlying factors that may contribute to the disparity. The NCI explored the hypothesis that in addition to being a cause of concern, endemic elevated cervical cancer mortality may be a marker or an indicator of weaknesses in the health care system infrastructure, particularly with respect to medical care access, cultural issues, and health communication and education issues that disproportionately affect poor and other underserved women. Most women living in areas with high rates of cervical cancer mortality rely on publicly funded programs for their health care. Poverty, in turn, is a human condition marked by substandard housing, lower educational attainment, subsistence-level employment, high unemployment, greater exposure to environmental toxins, and reduced access to health care. These conditions, occurring in a variety of urban and rural settings, also may affect health status significantly (Harold P. Freeman, 2005).

It is known that delay in treatment can affect health outcome and that patient delay in presenting to a General Physician is the main factor contributing to these outcomes (Anderson and Cacioppo 1995, Ristvedt and Trinkaus 2005). The value of public education programmes promoting symptom awareness is therefore dependent upon their ability to prompt the individual to self-refer earlier than they might otherwise and within the ‘time window’ when the cancer can be cured (Bloom 1994). There is also a growing body of evidence which indicates that those living in disadvantaged circumstances are more reluctant to engage in help-seeking behaviour (Douglas Eadie and Susan MacAskill, 2007).

Perceptions and Attitudes to Cancer: Cancer was regarded as a common disease which could affect all sectors of Scottish society. The majority of
participants knew of at least one person in their social network, typically an elderly relative or family friend, who had cancer or who had died from the disease. A smaller number had personal experience of the disease. Despite its high incidence, participants described a general reluctance to discuss cancer which they equated with fear and medical sciences inability to find a breakthrough cure for the disease. Terms such as ‘taboo’, ‘covered-up’ and ‘pushed under the carpet’ were frequently used when describing people’s willingness to discuss the disease. Interestingly, this apparent reluctance was less evident in the discussion groups with participants keen to use the opportunity to voice their opinions and describe their experiences of the disease. There was also a widely held belief that people were more prepared to talk about the disease than had been the case in the past, with some regarding this as part of a general trend towards a greater openness about difficult social issues (Douglas Eadie and Susan MacAskill, 2007).

Perceptions and Attitudes to Early Detection: Early detection was a familiar concept, more so amongst women, many of whom were regular participants in mass screening programmes. It was also widely recognized that early detection and treatment improved chances of survival, and that the individual had the potential to affect their own health by presenting early if they experienced suspicious symptoms. Whilst self-awareness and self-examination were regarded as important pre-conditions to early detection, knowledge of cancer signs and symptoms was extremely variable. Signs commonly mentioned included ‘lumps’ (particularly in the breasts and testis), ‘bleeding or unusual discharge’ (particularly in the stool or phlegm), ‘weight loss’ and ‘tiredness and malaise’. There was also an appreciation that different cancers, or cancers located in different parts of the body were likely to present with different symptoms, although understanding of symptom specificity and of the association between symptoms and cancer stage were extremely limited.
Fear of cancer and high levels of mortality associated with the disease were a recurring theme in these discussions and had a negative impact on peoples willingness to consider self-detection strategies and to seek the opinion of a health professional or to discuss symptoms with family or friends. This pattern of response was expressed in different ways. Women were more likely to recognize and verbalize these fears: Men, on the other hand, were more inclined to deny these fears, which in some instances led them to adopt extreme and entrenched positions on the issue. So whilst the benefits of early presentation and diagnosis were widely accepted at a rational and objective level, when viewed at a personal level, the strong emotions which cancer can arouse appeared to act as a barrier to confronting the issue.

Cancer Disparities: Despite dramatic improvements in health in the United States over the last century, at no time in the history of the United States has the overall health status of racial/ethnic minority populations such as African Americans, Native Americans, Hispanics, and several Asian subgroups equaled that of white Americans. Disparities in health are receiving increased national attention, and several major federal and local initiatives have been set up to define and reduce or eliminate disparities in health. While advances in health and medical care have produced improvements in longevity and health outcomes, there remain disproportionate disease burden and poorer health outcomes, or "health disparities" in the United States (Claudia R. Baquet, 2005).

Disparities in health care access, utilization, and delivery are well established. Access to, and delivery of, quality health care and differences in cancer screening and follow-up, as well as disparities in cancer treatment, palliative care, and pain management are all factors related to racial/ethnic and geographic disparities in cancer rates. These health care factors may result in
differences in cancer prognosis, stage, survival, mortality, and recurrence for minorities and the poor. Health care delivery disparities have resulted in important national discussions as a result of a recent Institute of Medicine report. This report concludes that minorities, particularly African Americans, frequently receive lower quality of health care than whites, even when access-related factors are controlled. The sources of these disparities are complex and likely developed within the context of historic inequities, bias, clinical uncertainty, mistrust, personal behavior, and the organization and operation of the current U.S. health care system. Disparities may occur in risk factors, exposures, and access and use of quality cancer services, which may result in higher cancer morbidity or incidence rates. Disparities in access to quality cancer and health care services may produce racial/ethnic differences in cancer outcomes, such as higher mortality or lower survival rates from certain cancers. This has been well-documented for African Americans compared to whites (Claudia R. Baquet, 2005).

Data from the American Cancer Society, Centers for Disease Control and Prevention (CDC), National Cancer Institute (NCI) Surveillance Epidemiology and End Results (SEER) program, and North American Association of Central Cancer Registries document the existence of disparities in cancer incidence, mortality, and survival among different racial/ethnic groups, particularly for African Americans. Table highlights cancer disparities among blacks and whites in incidence, mortality, and survival for select cancers in the United States. Socioeconomic status (SES) is one of the major determinants of health. According to the U.S. Department of Health and Human Service’s Healthy People 2010 report, higher socioeconomic groups experienced greater health gains compared to lower socioeconomic groups. Lower socio-economic status has been associated with higher cancer risk behaviors as well as poorer cancer outcomes, particularly for cancers of the breast, colon, and prostate. Cancer mortality rates in the United States are significantly higher in the lower socioeconomic groups. Furthermore, higher educational attainment and
income among African Americans has been more positively associated with reductions in smoking among black men than white men. Contributing factors associated with lower SES may include lower educational level, culture, ethnic/cultural beliefs, and access to adequate health care. Although overall cancer mortality showed a steady decrease from 1995 to 1999 throughout the state, ethnic and racial minorities continue to demonstrate significant cancer disparities throughout Maryland. Socio-economic status as a major contributor to health status and cancer disparities must be addressed as part of a comprehensive approach to eliminate cancer disparities throughout the state (Claudia R. Baquet, 2005).

**Poverty and cancer:** Despite the attraction of certain utopias and the convincing strength of some of the social and philosophical theories underlying attempts to change the social structure and to achieve a more egalitarian society, social inequalities have not disappeared and seem even to be increasing worldwide. Inequalities in health are part of the social inequalities present in our society and one of their most convincing indices. Sanitary conditions are worse, mortality higher, survival rates of cancer patients lower, and life expectancy shorter in developing countries than in industrialized countries. Similar if not identical differences can be seen within industrialized countries between socio-economically less and more favoured population groups. In many areas of the industrialized countries social and environmental conditions comparable with those existing in the poorest countries last century have been recreated. Occupational risks are becoming a serious problem in developing countries, largely as a consequence of the transfer of hazardous industries from industrialized countries where certain industries are judged to be unacceptable. A similar double standard is applied to tobacco advertising and sales in the industrialized and developing countries. The projections of the total number of cancer cases in the next decades indicate a generalized increase, proportionally greater in developing than in industrialized countries (L. Tomatis, 1995).
Social Inequalities and Cancer: Inequalities in health reflect social inequalities in society; they provide perhaps the most convincing index of inequality. Despite attempts to change the social structure and to arrive at a more egalitarian society, social inequalities have not disappeared and seem even to be increasing worldwide. At the global level, socioeconomic differences in health are stark. They are apparent in the worse sanitary conditions, higher mortality, lower life expectancy and lower cancer survival rates of the populations of developing countries compared with those of industrialized countries. Differences in cancer risk are also seen within industrialized countries between the socio-economically less and more favoured population groups. In certain areas of industrialized countries, social and environmental conditions comparable with those existing in the poorest countries of the world have been recreated. However, social inequalities in health are not limited to those of lowest socioeconomic status but operate across the whole of society (Kogevinas, M., Pearce, N., Susser, 1997).

The occurrence of cancer within a population can be studied at many different levels, including forms of social entities, ‘the individual’, a particular organ system, or a particular molecule. The causes of cancer can also be studied at these different levels, including socioeconomic factors, lifestyle, and genetic alterations in a clone of cells. Clearly, there are advantages in understanding disease causation at all of the different levels at which it can be analyzed. Although cancer risk factors such as tobacco smoke may appear to operate mainly at the individual level, exposure may occur due to a wide range of political, economic and social factors; conversely, tobacco smoke ultimately has effects at the cellular and molecular levels, including the production of mutations in crucial genes. Of course, it is important to gain information, and take action, at all possible levels, but the history of public health shows that changes at the population level are usually more fundamental and effective than changes at the individual level, even when a
single risk factor accounts for most cases of disease. In this sense, a risk factor such as smoking can be regarded as a secondary symptom of deeper underlying features of the social and economic structure of society. Thus, just as a variety of health effects in various organ systems (for example, various types of cancer) may have a common contributing cause (for example, tobacco smoking) at the level of the individual, a variety of individual exposures (for example, smoking and diet) may have common socioeconomic causes at the population level (Kogevinas, M., Pearce, N., Susser, 1997).

Social Inequalities in Cancer with Special Reference to South Asian Countries: Data on cancer mortality by social class were first published for England and Wales in 1911 (Lynge, 1998), and it was evident even at that time that deaths due to cancer were distributed unequally in the population. In the population-based cancer registries in Mumbai (Bombay) and Chennai (Madras) data on clinical extent of the disease and survival of common cancers in women have been analyzed in relation to socioeconomic parameters like education level, marriage status and place of residence (urban or rural). While there is a lack of reliable data on economic status, the education level of the individual can be used as a pointer. Socio-economic status within societies has always been an issue on the political agenda but inferior survival as a result of social inequality has not received its due attention. It is the purpose of this paper to present key data on socioeconomic differences in cancer incidence and mortality in South Asian countries. An adequate infrastructure for registration of cancer in India is now available as a result of the national cancer registry program, although coverage is less comprehensive in other countries (Arun P Kurkure, Balkrishna B Yeole, 2006).

Historical perspective: Socio-economic differences in the frequency of cancer may be attributable to differences in the circumstances of life of different sections of society. Societies are not homogenous, and variations between people of different social classes in many aspects of lifestyle, culture and
behavior have clear repercussions with regard to health. In most studies of socio-economic differences and cancer occurrence, measures have been used that are constructed on the basis of occupation, education, income and wealth or area of residence (Liberatos et al 1988). Classifications involving such measures have been criticized as providing imprecise definitions and having an uncertain relation to sociological concepts. However, they persist in epidemiological research because data on morbidity and mortality and on health behavior reveal clear social divisions (Arun P Kurkure, Balkrishna B Yeole, 2006).

**Fighting Inequalities:** Empowerment is defined as a multidimensional social process that helps people to gain control over their own lives and thereby overcome the vicious cycle portrayed. Poverty and lack of education together leads to the lack of empowerment which leads to delay in diagnosis, inability to access health care facilities to complete treatments and have adequate follow up. Role of socio-economic status and reproductive factors in breast cancer in India is studied by Reddy 2005. According to existing status in the country the education levels have been categorized into four groups i.e. illiterates (no schooling at all), primary (up to 6 yrs of schooling), secondary (7-10 yrs of schooling), and college (11-15 yrs of schooling). Income level has been categorized into three levels. Lower income (below Rs1,500/- p.m.), Middle income (Rs.1501-4500/- p.m.) and higher income (Rs.4500/- p.m.). Area of living has been classified into two groups namely urban and rural as per census definitions (Arun P Kurkure, Balkrishna B Yeole, 2006).

As far as diagnosis is concerned there is no difference in staging low socio-economic group patients. While 75 percent of breast cancer patients have been diagnosed in high socioeconomic group in early stage. As far as treatment outcome is concerned 89 percent of breast cancer patients have received adequate treatment in high socio-economic group as against only 44
percent in low socio-economic group. Patients belonging to the high socio-economic groups have more than three times better 10 year survival as compared to the patients belonging to low socio-economic group. The link between oral cancer with low-income level, poor oral hygiene and habits like use of alcohol, tobacco and pan were demonstrated by Dhar et al (2000).

Social isolation as a barrier to good health: Social isolation emerged as a major barrier to health and as a significant health concern that was connected to feelings of exclusion and invisibility. Isolation was a reaction to stigmatizing institutions and unjust professional practices, a consequence of mothering responsibilities and material deprivation, and both a cause and outcome of psychosocial health problems, functional impairment, and disability. According to the women, their social isolation significantly influenced their psychosocial health and self-reported health status. Social exclusion is a process by which people are denied the opportunity to participate in civil society; denied an acceptable supply of goods and services; are unable to contribute to society, and are unable to acquire the normal commodities expected of citizens. All of these elements occur in tandem with the material deprivation, excessive psychosocial stress, and adoption of health threatening behaviours shown to be related to the onset of, and death from, illness and disease (Raphael, 2001). The barriers faced by the women and their consequent social isolation led them to feel that they were not a part of the community, had no voice, and were invisible (Colleen Reid, Pain Panic, 2002).

Changing lifestyles, increasing lifespan and chronic infection lie at the root of the global growth in cancer. As more and more countries urbanize, changes in diet, insufficient exercise, smoking, drinking and obesity combine to increase cancer risk. Individual risk of cancer also increases dramatically with age, and populations are aging more rapidly in low- and middle-income countries than in the richer world. It took more than a century for the
proportion of people over age 65 in France to double, from 7 percent to 14 percent, in 1980. In Singapore, this same phenomenon is expected to take just 19 years, with people over 65 representing 14 percent of the population by 2019. And in China the proportion of people over 65 is projected to triple from 8 percent in 2006 to 24 percent in 2050. In parts of Eastern Europe, too, the aging of the population is dramatic, with the proportion of people over 65 in Poland projected to rise from 13 percent in 2005 to 21 percent in 2025, and in Slovenia from 16 percent to 24 percent in the same period. Around one in four cancers in developing countries, as opposed to only one in ten in the developed world, are linked to infection. These infections can be caused by viruses (e.g., hepatitis B for liver cancer, and human papillomavirus (HPV) for cervical cancer), bacteria (Helicobacter pylori for stomach cancer), or parasites (schistosomiasis for bladder cancer). Because so many human cancer cases are lifestyle-, behavior- or infection-related, however, they are also potentially preventable. Estimates suggest that about half of new cancer cases and cancer deaths could be prevented. The knowledge and tools to make a major impact on these diseases exist today. Making the commitment to reduce significantly breast and cervical cancer in low and middle income countries will, however, require important changes in the way health services are managed and delivered. This will make them not only better able to address growing cancer rates in low-resource settings, but also better equipped to respond to a broad range of chronic diseases, including diabetes and cardiovascular problems, that are an ever increasing burden on the poorer countries of the world (FCCO, 2009).

India is a sub-continent with wide ethnic, cultural, religious, and economic diversity and variation in the health care infrastructure. The health care facility pattern is heterogeneous, with numerous regions where the benefits of the awareness, early diagnosis, and multidisciplinary treatment programs have not reached. With rising incidence and awareness, breast cancer is the commonest cancer in urban Indian females, and the second commonest...
in the rural Indian women. The numerous myths and ignorance that prevail in the Indian society result in an unrealistic fear of the disease. Cancer awareness programs are more concentrated in the cities and have not reached the remote and rural parts of the country. Women often do not present for medical care early enough due to various reasons such as illiteracy, lack of awareness, and financial constrains. It is hardly surprising that the majority of breast cancer patients in India are still treated at locally advanced and metastatic stages. Lack of an organized breast cancer screening program, paucity of diagnostic aids, and general indifference towards the health of females in the predominantly patriarchal Indian society do not help early diagnosis of breast cancer.

A multidisciplinary approach to breast cancer treatment that is so vital is available only at a few select regional centers. This review aims at providing an overview of the available data and views on breast cancer care in India. Data from the various cancer registries, publications/presentations from individual institutions, and the data from SGPGIMS Lucknow – a major tertiary care teaching hospital of North India – have been used. The data available on various issues relating breast cancer care in India is scant and heterogenous. There is no central cancer registry to provide comprehensive nationwide data. The only credible data on a large proportion of population is available from the population-based cancer registries (PBCRs) – both urban and rural – and the various hospital-based cancer registries which work under the national cancer registries program of the Indian Council of Medical Research (ICMR). There are numerous other non-ICMR cancer registries organized and run by hospitals and institutions. One major hindrance in collation of data from these diverse registries is the lack of uniform methods of data collection and storage. This makes any meaningful interpretation of nationwide data an arduous task, and any efforts at this are often viewed with suspicion (Gaurav Agarwal Pooja Ramakant, 2008). The incidence rates for breast cancer are varied, and the highest rates are in the developed world and the lowest rates are in East Asian
countries (IARC). A retrospective study of women with breast cancer in a London hospital showed that the predominantly younger population of black women were more likely to present with aggressive triple negative tumours, not fuelled by hormones. Black women in the study presented on average, 21 years younger than white women (Bowen et al, 2008).

A study in South East England found that South Asian women appear to have a lower risk of breast cancer compared to non-South Asian women. South Asian women who develop breast cancer may also have a higher survival compared to non-South Asian women (Dos Santos Silva et al, 2003). Yet other research indicates that the incidence of breast cancer is rising faster in South Asians than in other ethnic groups in the UK (McCormack et al, 2004). The Thames Cancer Registry looked at breast cancer in ethnic groups in South East England and found Black African women had a significantly worse overall survival rate than other ethnic groups (Jack et al, 2009). This echoes the findings of other US studies, where white American women have the highest incidence rate but black African American women are more likely to die from the disease. African American women with a family history of breast cancer were found to be less likely to undergo genetic counseling compared to white women with a family history of breast or ovarian cancer (Armstrong et al, 2005). It is unclear what factors influence the incidence of breast cancer and subsequent survival rates and this is clearly an area where more research is needed to enable better strategies to be developed for the detection and treatment of the disease in black women (Chlebowski et al, 2005; Pesquera et al, 2006).
STATEMENT OF THE PROBLEM:

Cancers of the female reproductive tract and breast has a high incidence amongst Indian women. Cancer registries have also highlighted that more than 70 percent of cancers in females occur in the age group of 35-64, and that these cancers exercise an adverse influence on the productive role of women in our society. Over 70 percent of patients report for diagnostic and treatment services at an advanced stage of disease, resulting in poor survival and high mortality rates. More than 50 percent were compliant to treatment protocol, less than 30 percent default during adjuvant therapy and 20 percent default after the preliminary investigation. More than 70,000 new cases of cervical uteri and over 75,000 of breast cancers are reported in India every year (K Umadevi, 2009).

India's National Cancer Control Program emphasizes the importance of early detection and treatment. But there is no organized screening program and the majority of Indian women lack both awareness about the disease and access to prevention and treatment facilities. Although cancer screening programs are presently available in all the regional cancer centers and comprehensive cancer care specialty hospitals, which include Pap smears, as well as colposcopy, it is restricted to limited population coverage. In addition, nearly 75,000 Indian women die annually from cervical cancer disease (58 percent). Nearly 70 percent of India's population lives in rural areas where the measure of health and living standards are low. Rural women are vulnerable to most of the risk factors for cervical cancer such as early marriage, early childbirth, multiparity, poor genital hygiene, and chronic infection with sexually transmitted disease.). The health and family planning services in India have not been adequately sensitive to the health of women, more particularly their reproductive health. Women are less empowered to take care of their own reproductive health (K Umadevi, 2009).
There is no central cancer registry to provide comprehensive nationwide data. The only credible data on large proportion of population is available from the population-based cancer registries (PBCRs) – both urban and rural – and the various hospital-based cancer registries which work under the national cancer registries program of the Indian Council of Medical Research (ICMR). Widespread inaccessibility of preventive, early detection and treatment services for large segments of the population in India due to the geographical and financial constraints contribute to poor health outcomes (Parkin DM, Bray F, Ferlay J, et al. (2005). Diagnostic infrastructure in the country is limited. There are many districts in the country which do not have a pathologist and pathology/cytology services, which are crucial for diagnosing cancer. Financial and geographic constraints and lack of manpower have contributed to the urban concentration of facilities. An un-estimated number of cancers diagnosed in the population are not treated. Untreated patients are likely to demand more resources from society (ICMR, 2002).

There is no uniform cancer prevention strategy for the entire country. Awareness programmes have been undertaken in a few places, but there is no uniform standardized information, education and communication (IEC) strategy for cancer prevention. There is no education on risk factors, early warning signals and their management. Cancer screening is not practiced in an organized fashion in any part of India. There are sporadic attempts at opportunistic interventions and small-scale research studies for field interventions (Krishna Nair, 2003). Even after detecting an abnormality such as a lump, the visit to a doctor for diagnosis and treatment is postponed substantially, as the initial manifestations – limps, etc. – are not associated with pain or other troublesome symptoms. Inadequate diagnostic facilities at the peripheral/community health centers close to a woman’s home act as a deterrent from seeking specialist advice. That may mean traveling and professional fees (Gaurav Agarwal, Pooja Ramakanth, 2008).
Treatment facilities are also mostly limited to urban areas of the country. In India the availability and affordability of cancer treatment shows wide disparities. The majority of patients with cancer present to a cancer treatment centre in late stages of the disease (80 percent are advanced) and this adds to the already high morbidity, mortality and expenditure. Treatment results are about 20 percent less than what is observed for similar conditions in more developed countries, mostly due to late diagnosis and inappropriate treatment. Oral morphine is the mainstay for cancer pain relief and is still not widely available in the country. There is a serious limitation of manpower for providing palliative care. Finances The funds for the cancer programme are mainly from the Government and needs to be augmented. Private initiatives are few and are unlikely to cater to a large population across different socioeconomic strata, as it is often not a financially viable venture (Cherian Varghese, 2003). A large proportion of Indian patients are treated with inadequate/inappropriate initial surgical procedures before they are seen and managed by specialists (Gaurav Agarwal, Pooja Ramakanth, 2008).

The review of the literature points out the paucity of literature on rural women who are affected with cancer, their healthcare seeking behaviour, perception of the disease, knowledge of risk factors and the cancer healthcare communication. Paucity of such literature is a limiting factor for effective care of the cancer patients and the control of cancer. Hence, an attempt is made to examine these issues in the context of a drought prone, backward district namely, Anantapur district.
METHOD OF THE STUDY:

Objectives of the study: The present study aims at understanding the Cancer Care and Communication among the Rural Women who affected with Cancer of the Breast and Cervix. The following objectives are framed to determine the scope of the study and to facilitate a scientific study.

The study objectives are:

a. To study the socio-economic status of the Cancer patients;
b. To examine the reproductive health status of the selected communities;
c. To examine the Healthcare seeking behaviour with reference to stages of seeking cancer care among rural women;
d. To understand the perception and knowledge levels towards cancer among the rural women;
e. To study the effect of health communication on cervical and breast cancer control in terms of stage presentation and access to treatment facilities.

Universe: The women belong to the weaker section villages, which covered by the Rural Development Trust (RDT) network. The RDT Hospital is situated in Bathalapalli was commissioned in December 2000 as 50-bedded Hospital and now it has upgraded to 250-bedded specialty Hospital. Bathalapalli, which is 27 kms away from the district headquarter Anantapur of State of Andhra Pradesh. It is strategically located with easy access for about 500-600 villages around Dharmavaram, Kadiri, Tadipatri, Anantapur etc Thaluks. The population of all these villages would be around 7 lakhs. The Breast and Cervical Cancer patients attended to RDT Hospital form the universe of the study. RDT Hospital, Bathalapalli is a secondary level care rural Hospital run by voluntary organization namely Rural Development Trust (RDT) and it’s a referral hospital for other RDT Hospitals as well as Community Health programme.
Sample: A total number of 20,496 women who visited to RDT Hospital, Bathalapalli for various gynecological complaints. 2,793 patients were referred to Cancer Detection clinic for their symptoms such as reproductive tract infections, painful or painless swelling/lump of the breast during the period of January 2008 to December 2008. Among these 2,793 referrals, 102 women were diagnosed to have Cancer of the Breast (45) and Cervix (57) respectively. These 102 cases are only frank cancers formed as our study sample. The precancer cases were not considered for the study. The incidence of cancer cervix and breast cancer are most common among women and hence, all our respondents are women.

Tools of Data collection: To elicit primary data a structured interview schedule was administered. The schedule covers the following broad areas:

- Socio-economic back ground
- Reproductive Health status
- Healthcare seeking Behaviour
- Access to early detection and treatment facilities
- Women perception and knowledge towards cancer
- Communication towards Cancer Care

In addition to the primary data, secondary data from the official records/publications were collected.

Data Analysis: The primary data was analyzed by processing through computer. The standard SPSS package will be used for data analysis. The independent variables considered for the purpose of analysis are Caste and Age. The dependent variables considered as reproductive health practice indicators, healthcare seeking behaviour and access to cancer care communication indicators. Wherever necessary the statistical tools like percentages, ratios, averages were employed.
Chapterization:

The present study is presented in eight chapters.

The first chapter provides introduction, conceptual frame, the review of literature, the statement of the problem and the method of study.

The second chapter presents the overview of Breast and Cervical cancer and setting of the study.

The third chapter presents the socio-economic profile of the respondents.

The fourth chapter presents the reproductive health status of the respondents.

The fifth chapter explains about the rural women's perception and knowledge towards cancer disease.

The sixth chapter explains the healthcare seeking behaviour of the rural women with reference to cervical cancer and Breast cancer. Stage presentation, symptom experience, evaluation and action with regard to seeking medical care are documented.

The seventh chapter explains the Cancer Health Communication among women in rural areas of India under reference.

The eighth chapter is concluding chapter and provides a summary of the findings and discussions of the study.
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