PERCEPTION OF BREAST CANCER RELATED STIGMA AMONG THE WOMEN

- **BINDU K S**

INDEX

DEDICATION

This thesis is dedicated to my family and friends who have nonetheless support my love and interest for all things. Heart fully dedicated to all Breast cancer survivors.

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I am thankful to **DR. BRINDHA SEETARAM** for her guide and support to complete theses. I am thankful to **DR. KALPANA KUMARA** for bearing with me and teaching me the significance and statistical significance, and for re-explaining it to me when you made free yourself.

A STUDY ON BREAST CANCER STIGMA AMONG WOMEN

- **BINDU.K S**

Background:

Major depression and depressive symptoms, misconception and social stigma although commonly encountered in patients with medical illnesses, are frequently under diagnosed and undertreated in women with breast cancer. Depression, social stigma and its associated symptoms diminish quality of life, adversely affect compliance with medical therapies, and reduce survival. Treatment of depression in women with breast cancer improves their dysphonic and other depressive symptoms, enhances quality of life, and may increase longevity.

Breast cancer is the most common cancer among women worldwide. A very important factor in the timely treatment and prevention of progression is high breast cancer awareness. Rural women are at risk of latter stage breast cancer due to poor education, lack of awareness and lack of access to medical facilities. Majority of the patient who are attending CA breast support group (STHRI) are stigmatized by myths and misconception about their diagnoses. However Breast Cancer related myths and stigma among the women are important problems that must be addressed.

Abstract:

The aim of this study:

The present study has been undertaken to evaluate behavioral and psychosocial impacts and the level of awareness and stigma due to misconception and myths before and after treatment of women with breast cancer. The main aim of the study is to assess breast cancer knowledge, beliefs, and practices among rural women and assess the quality of life in breast cancer survivors who have undergone mastectomy and lumpectomy and also to prepare and validate the information booklet to improve their knowledge and reduce their misconceptions. Along with these to find out how best to support other women in the future in ongoing breast cancer support group in the hospital.

The ultimate goal of the work was to inform development of effective breast cancer educational resources for women aimed at removing barriers to evidence-based prevention and early detection interventions.

Materials and Methods: This cross-sectional-descriptive study was conducted on 266 women (out of 300) aged over 30 to 60 above in breast cancer supportive group called STHRI in HCG MSR cancer Hospital Bangalore India during October 2016 to September 2016. The data collection tool was a researcher-made questionnaire that measured participant knowledge and experience of breast cancer in five aspects (general awareness, risk factors, and mammography, symptoms of breast cancer and myths and stigma towards breast cancer.

Results: Out of 300 (participants, age information was available for 261. The age range was between 30 and 60 was 70%. Most participants (154, 57.9%) had an average overall awareness of breast cancer. In the general awareness dimension, most participants (130,

48.9%) had poor scores. Most (166, 62.4%) also had average awareness about risk factors and many (137, 51.5%) had good awareness about mammography. Most participants did not know that changes in breast shape (232, 88.2%), dimpling of breast skin (192, 72.3%) and nipple discharge (183, 69.6%) are the main symptoms of breast cancer. And over all (91. %) had strong misconception and leading life with social stigma.

Conclusions: This study indicated average awareness of participants about breast cancer. Since rural women have lower levels of education, it is recommended that educational courses with contents about breast cancer, its risk factors, and symptoms be held for these women.

Keywords: Awareness - rural women - breast cancer - risk factors – mammography, Diagnosis, stigma and misconceptions.

Introduction:

Stigma is a mark or sign of disgrace usually eliciting negative attitudes to its bearer. It attached to a person with a mental disorder it can lead to negative discrimination. It is sometimes but not always related to a lack of knowledge about the condition that led to stigmatization (1). Throughout history, humans have encountered and confronted depression and social stigma. Stigma can be defined as a mark of shame or an attribute that is deeply discerning within a particular social interaction. (2)

Stigma can be internal –it can affect self-perception of survivors, causing guilt, blame or shame. It can come from manifestation, lack of awareness and deeply-engrained myths. Not only have to deal with the emotional impact on diagnosis of a disease, but also with constrains of poverty, lack of care and dependency (3).

The twentieth century has often been called as the cancer century. This is because more than a hundred types of cancer have been discovered in this century, and because of

enormous medical effort were made to fight all kinds of cancers all over the world. By definition, a cancer is a disease that is characterized by "controlled growth and spread of abnormal cells, when such growth takes place the cancer cells form a tumor from which cells will invade the neighboring tissues and organs. Some of these cells may even travel through the blood or other means to attack other organs and tissues in the body (4).

In the early decades of the century cancer was considered to be a fetal, medical therapy has developed significantly over the years such that most cancers can be treated and cured. After decades of struggling with various cancers, doctors are becoming more aware of the causes of these diseases, how they can be treated and what can they be done to prevent them. Breast cancer however remains one of the major concerns in the medical field, mainly because it has many forms and happens to strike a large number of women.(4)

The breast has probably been the most overworked organ of a woman's body since time began. As marliyn yalom demonstrates in her wide-ranging survey. A history of the breast, everyone seems to have a claim on it. Men and women are aroused by it, artists represent it, poets apostrophize it, babies are nourished by it, fashion and commerce fetishize it-and disease afflicts it. All of these responses to the breast, including the last one, are condition and is a site of conflict for so many of society's values and beliefs that it often seems not to belong to a woman at all.(5)

A diagnosis of breast cancer is one of the most frightening experiences a women can have, which can make them worry and uncertainty about modern medicine as well as their future. As a result of side effect of treatment and the deep thinking of their future survivorship most of the women may develop." Cancer stigma from losing their body features like hair loss or the loss of breast and changes in their skin color. Statistics says breast cancer is the most common diagnosed malignancy in women worldwide 22% and

in India 18.5%. Increased life expectancy, urbanization, western lifestyles are known incidence of breast cancer. The burden of breast cancer is increasingly in world wide. The occurrence is above the age of 50 years in developed nation whereas in developing nations like India is above the age of 40 years (5).

The incidence of breast cancer is on the rise in India, breast cancer is the second most common malignancy in Indian women. It is estimated that 211, 2490 patients suffer from invasive breast cancer in year in the United States. These numbers represent a sharp increase over the past 30 years (6). Currently, in India the incidence of breast cancer has steadily increased over the years and as many as 100000 new patients are being detected every year(7) .The increase reported by the cancer registries id nearly 12% from 1985 to 2001, representing a 57% rise in India's cancer burden.(8)

The trend for increase in breast cancer incidence over time for most of the population in India were found to statistically significant An epidemiological assessment of increasing incidence and trends in breast cancer in Mumbai and other sites in India, during the last two decades. Trends in breast and cervix cancer in 6 population based cancer registries (Mumbai, Bangalore, and Chennai. Bhopal, Delhi and Bharshi) were evaluated over the last two decades. (9) This approach showed a decreasing trend of cancer of cervix and increasing trend for breast cancer throughout entire period of observation in most of the registries. (10)

According to the international agency for research on cancer, Sharp rise in breast cancer worldwide in 2012, 1.7 million women were diagnosed with breast cancer and there were 6.3 million women alive who had been diagnosed with Breast cancer in the previous five years. Since the 2008 estimates, breast cancer incidence has increased by more than 20%, while mortality has increased by 14%. 522000 deaths in 2012 and the most frequently

diagnosed cancer among women in 140 of 184 countries worldwide. It now represents one in four of all cancers in women (11)

Doctors have identified several kinds of breast cancer. The majority of the breast cancer almost 95% is a cancer tumor that develops in the milk ducts. Those cancers which remain inside the duct without spreading out are known as in situ cancers. On the other hand, if the cancer cells spread out and invade other areas, they are known as invasive cancer. The other types of breast cancer almost 5% are known as lobular breast cancer because they develop in the breast lobes. A very rare type of cancer occurring in only 1% of all cases is known as inflammatory breast cancer. (ACS, Online). According to the surveillance and health service research reports of the United States, most cases of BC are older than 70 years of age. (12)

The breast cancer can be caused by various factors. In most cases, it isn't clear what causes normal breast cells to become cancerous. Doctors do know that only 5% to 10% of breast cancer is inherited. Families that do have genetic defects in one of two gens, breast cancer gene1 (BRCA1) or breast cancer gene 2(BRACA2) have a much greater risk of developing breast cancer. The women treated with chest radiation therapy for lymphoma in childhood or during adolescence when breast are developing have a significantly higher incidence of breast cancer than do women not exposed to radiation. Mutations may also develop as a result of exposer to cancer causing chemicals. Some risk factors are anything that makes it more likely people gets a particular disease. But having one or even several risk factors doesn't necessary mean women develop cancer. Most women with breast cancer have no unknown risk factors other than simply being women. In fact, being female is the single greatest risk factor for breast cancer. Although men can develop the disease, it's for more common in women genetic and environmental factors are most identified cause for the breast cancer.

Detecting breast cancer is both easy and difficult. It can be easy because any previously unnoticed lump on the breast could be an indication of a breast cancer, even though it might not be so. However a clear change in a mole on the breast is usually considered a reflection of cancer growth in the breast. There are many methods for detecting breast cancer including breast self-exam (BSE), which is easy to do, does not cost anything or require any equipment and trained personnel.(13) The diagnostic power of BSE is 80-90% and can result in 50% reduction in mortality (Shiraly et al., 2010). Detecting the early signs of breast cancer in the early stages plays a key role in its early diagnosis and appropriate treatment so that if women do regular monthly breast exams, progress of 95% of cases of breast cancer to advanced stages can be prevented.(14) In addition, early diagnosis can prevent additional costs related to chemotherapy in late stages of the disease and improves patients' quality of life.(15)(Heidari et al., 2008; Abu-Helalah et al., 2014) All in all the best way of detect the breast cancer are Mammography, Magnetic Resource Imaging (MRI), Clinical Breast Examination (CBE), Breast self-awareness, Breast Ultra Sound.(16)

The treatment decisions are made by the patient and the physician after consideration of the optimal treatment available for the stage and biological characteristics of the cancer, the patents age and preference and the risk and benefits associated with each treatment protocol. Most women with breast cancer will have some type of surgery, which is often combined with other treatment such as radiation therapy, chemotherapy, hormone therapy and or targeted therapy. In many cases, the surgery requires removing a considerable part of the breast, leaving the woman with a great distress and a feeling of loss and disablement. In the past, women who underwent mastectomy suffered seriously because of the physical distortion of their bodies after the surgery. Today, however, plastic surgery has developed in such a way that it has become part of the treatment. Many insurance companies also cover plastic surgery expenses if they result from an

accident or another surgery. In many cases, women who undergo mastectomy suffer serious psychological traumas that reflect on their sexual lives. In part, this is due to the fact that many people think that cancer is contagious when in fact it is not. Cancer growth of cells is induced within the body and therefore cannot be carried from one person to another, even if an exchange of cells takes place through sexual intercourse.

Once the treatment ends, the patient may find themselves overwhelmed by emotions. This happens to a lot of people. They may have been going through so much during treatment that they could only focus getting through their treatment. The cancer journey can feel very lonely. They might think about the possibility of their own death, or the effect of their cancer on their family, friends and career. They may also begin to re-evaluate their relationship with their spouse or partner (17). Breast cancer has been the most extensively studies human tumor site not only from clinic epidemiologic, experimental, and molecular angle, but also from a psychological point of view. Because breast is an emotional symbol of women's pride and personality, including sexuality and motherhood, any threat to breast is to shake the very code of her mind and feminine orientation. (18). It is also intimately associated with women's self-image, self-esteem, femininity, and reproductive and nurturing capacity. Breast cancer in women causes extreme mental stress leading to many emotional disorders, such as anxiety, tension, depression, grief, anger, hopelessness, helplessness, and a high degree of passivity (19). Breast cancer survivors often encounter physiological and psychological problems related to their diagnosis and treatment that can influence long term prognosis (20). It is widely accepted that the quality of life is impaired by persistent depression or anxiety (21). Some studies suggest that younger women, who represent about 1 out of 4 breast cancer survivors, tend to have more problems adjusting to the stresses of breast cancer and its treatment. They may have trouble with emotional and social functioning. (22)

Culture is defined as a set of shared and socially transmitted ideas about the world that are passed down from generation to generation. Culture as a socially transmitted phenomenon carries with it the idea that people who interact on a regular basis know the same unwritten rules and criteria for social life the confer status as member of group. (23).

Some of the most common psychosocial concerns reported by women with breast cancer include: Fear of recurrence, Physical symptoms such as fatigue, trouble sleeping, or pain, Body image disruption, Sexual dysfunction, Treatment-related anxieties, Intrusive thoughts about illness/persistent anxiety, Marital/partner communication, Feelings of vulnerability, and Existential concerns regarding mortality.

Cancer related myths and stigma about cancer are important problems that must be addressed. (24). They present significant challenges to cancer control.-myths and stigma can have a silencing effect, whereby efforts to increase cancer awareness are negatively affected,- myths and stigma can affect individuals and behavior such that they are less likely to adopt cancer risk reducing behavior or seek out the support and service they need when they are diagnosed with the disease. Unfortunately stigma and myths associated with cancer are not directly addressed or challenged in many countries. (25). Myths about cancer treatment were also common. Patients are often reluctant to undergo surgery because they believe, if you cut into the cancer, it will spread immediately all over the body '. Some others perceived cancer treatment to be as bad as, or worse than, the disease itself. Cancer symptoms or body parts affected by the disease can cultivate stigma. For example, cervical cancer is high stigmatized because the cervix is part of the body you don't speak about'. Gynecological or breast cancer may present symptoms that women are reluctant to disclosure to their doctors, and may be even less willing to undergo the necessary physical exam to investigate the cause of such symptoms.

Concepts of Health-related Stigma

Stigma is defined an attribute, behavior, or reputation that is socially discrediting in a specific way that may cause an individual to mentally classified by others an undesirable, rejected stereotype, rather than in an accepted, normal one. Since the original stigma work the definition of stigma has varied considerably to include a characteristic of an individual contrary to the norm of the social unit. The meaning of norm includes a common belief that a person ought to behave in a meaning of norm includes a common belief that a person ought to behave in a certain time. More recently, the words stigma and stigmatization refer to an invisible sign of disapproval permitting insiders to draw a line around the outsiders in order 9 to distinguish group inclusion limits. The distinction permits insiders to know who is in and is out allow the group to maintain its commonality by demonstrating what happens to those who deviate from the accepted norm conduct. (Folk 2001).

Stigma and the act of stigmatization are in issues of disempowerment and social injustice. Link and Phelan (2001) described as when elements of labeling stereotyping, separation, status loss and discrimination occur together in a power situation that allows them. Stigma exists when the following interrelated components converge. The first component is that people distinguish and label human differences. Second, dominate cultural beliefs associate labeled persons to undesirable characteristic and negative stereotypes. Third, distinct categories label person in order to achieve separation of us from them. The fourth component occurs when labeled persons experience a loss in status and discrimination lading unequal outcomes. Lastly, stigmatization is solely dependent on access to social, economic, and political power permitting the identification of differentness, creation of stereotypes, division, loss of status, and discrimination. According to these five components of stigma, the nature of labeling a person provides the impetus to separate us from them.

The person is thought to be thing that they are labeled. For example, because smoking causes lung cancer, these patients may be labeled as smokers, regardless of their actual smoking status. Another example, people who have seizures may be labeled as epileptics instead of a person with epilepsy. Labeling helps us we understand the social processes involved in how society allows one group's views to dominate what becomes a real and important consequence for another group.

Stigma is further described by socialist Gergard Falk (2001) and is categorized into two types:

1. Existential stigma
2. 2. Achieved stigma:

Existential stigma is derived from a condition that occurs without a known cause or from which there was little control. Achieved stigma is earned based on a person's conduct and or because they contributed heavily to the condition or behavior. Existential stigma often accompanies a cancer diagnosis, because there is a lack of understanding of the cause and it is often experience vulnerability, lack of control over their health and a need to protect others from embarrassment. (Lapore & Revenson, 2007; Chapple et. al., 2004).)

Diseases associated with the highest degree of stigma share common attributes: (1) a person with the disease is seen as responsible for having the illness; (2) the disease is progressive and incurable; (3) the disease is not well understood among the public; and (4) the symptoms cannot be concealed (Goffman, 1963, Falk, 2001). People often try to conceal stigmatized health conditions or avoid situations that may reveal these conditions, which often lead to delays in seeking health care and information (Link et. al. 1992, Tod, Craven, Allmark, 2007), unnecessary suffering, lost productivity, and suboptimal use of health care resources (Berger, Wagner, & Baker, 2005).

Researcher concludes that the process of stigmatizing sometime is not possible unless they lack social, economic or political power in comparison to the person being stigmatized. The powerful have greater access to resources and influence.

Stigma exists when labeling, negatively stereotyping, discriminating against, exclusion, and low status co-occur in power situations that allow them to occur (Link & Phelan, 2001). Stigma differs from prejudice, stereotype, and discrimination, although they are part of the stigma experience. Prejudice is an attitude or negative judgment toward a group and its members.

Stereotype is a belief about a group, and discrimination is an unjustified negative or harmful behavior toward members of a group.

In summary stigma is the expression negative attitude about someone or something thought to be socially unacceptable? Stigma can be a result of manifestation leading to fear and misunderstanding. As a danger of smoking became more apparent, well-intentioned efforts to restrict smoking and exposure to second hand smoke may have caused a negative reaction to smokers. Because smoking represents the primary risk for 11 lung cancer, disease is still seen by many as self – inflicted. Stigma ascribed to controllable factors such as smoking elicits a greater negative reaction than stigma ascribed to uncontrollable factors such as breast cancer. Stigma may also threaten a person's identity, social life, and economic opportunities and deeply affects families and support persons. Stigma is associate with disease is dependent on the perception of patient responsibility for the disease and whether the disease leads to a serious disability, disfigurement, lack of control, or disruption of social interactions.(26).

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Mechanisms of Stigmatization.

There are four mechanisms that directly affect the psychological wellbeing of those who are socially stigmatized: (1) Negative treatment or direct discrimination; (2) expectancy confirmation or self-fulfilling prophecy; (3) automatic stereotype activation behavior; and (4) stigma induced identity threat. Negative treatment or direct discrimination limits access to certain life domains that affect a person's social status, psychological wellbeing and physical health. For example, healthcare systems establish tobacco-free campus policies that clearly designate the boundaries where smokers are not permitted to smoke. Those who violate the policy face corrective action or reprimands. Also, in accordance with hospital credentialing, healthcare providers assess the smoking status of every patient upon admission. Smoke free policies and smoking assessment policies signal that the smoking behavior is unacceptable and can create a separation between "us" and "them". The accumulation of institutional policies and practices may work to further disadvantage those who are stigmatized even when individual prejudice or discrimination are absent. Expectancy confirmation or self-fulfilling prophecy occurs when individuals perceive negative stereotypes that influence certain behaviors toward a stigmatized person in ways that directly affect their thoughts, feelings, and behaviors (Darley and Fazio, 1980). The stigmatized person may then confirm the initial inaccurate expectations, stereotypes, or prejudicial attitudes. For example, patients with symptoms of lung cancer may delay seeking treatment as a coping mechanism to avoid being judged (Corner, et al. 2006). Contributing to this mechanism of stigmatization, when healthcare providers perceive lung cancer to be self-inflicted and hopeless, they are less likely to offer aggressive treatment options than they would to other cancer patients, especially if 15 the patient continues to smoke (Levealahti, et al. 2007). Important to note is that perceptions of situations do not always correspond to objective events. Some individuals

who are targets of objective discrimination fail to realize it and others believe they are victims of discrimination even when they are not (Major et al, 2002b). Automatic stereotype activation behavior creates an involuntary reaction in the absence of discriminatory behavior on the part of others. These automatic responses are referred to as "the power of an idea (over the body)" associated with linkages in memory between stereotypes and the behaviors they imply. These memory linkages lead to initiation of the stereotype and assimilate the stereotype behavior. Lung cancer patients who are aware of the stereotype (blame and guilt) may "automatically" behave differently (withdrawn, avoidance) regardless of whether there are observable discriminatory actions (Major and O'Brien, 2005). For example, a never smoking female lung cancer patient about to receive chemotherapy may tell people who ask when she loses her hair, that she has breast cancer because she doesn't want to be judged. Stigma as Identity Threat Stigma-induced identity threat is the model that explains how experiencing a stigmatized identity can lead to stress and stress-related health outcomes through the coping process (Major and O'Brien, 2005). A person's identity may be derived from their race, age, ethnicity, occupation, heritage etc. Social identity provides a sense of membership or connection with other people (Tajfel and Turner, 2004), and is a valuable key contributor to self-esteem and self-concept. People are motivated to protect their identities from anything that may threaten or harm their self-esteem by demeaning or devaluing their identity (Steel et al., 2002). Possessing a consensually devalued social identity (stigma) increases the potential exposure to stressful or identity threatening situations. Stigma-induced identity threat can occur as a result of discrimination or other identity related threatening situations leading to psychological, physiological, and social outcomes such as depression/anxiety, considerable stress, and limited social support (Major and O'Brien, 2005; Steele, Spencer, & Aronson, 2002). Stigma related identity threat occurs as a result of three processes that shape a persons' evaluation of being stigmatized and the significance of situations:

collective stereotypes/representations, situational cues, and individual personal characteristics (Major & O'Brien, 2005).

Measuring cancer – related Stigma

In recent years there has been an increase in research into perceptions of stigma among cancer patients, but little systematic research into perceptions of stigma among cancer patients, but little systematic research into the general public's attitudes. in a review of 38 articles exploring stigma and cancer, the majority focused on the cancer patients' experience. With only seven studies in non-patient samples, and these were mostly qualitative investigations. To our knowledge, at the time of conducting this work no scales were available for assessing cancer stigma in the non-patient population. A 2006 review of illness-related stigma identified 24 scales, but none of them assessed cancer-related stigma. (28). Although these scales have traditionally been used to indicate stigma, stigma of cancer was expected to be more subtle than with other illnesses and many of the items traditionally used are unlikely to be appropriate because of the non-contagiousness of cancer (e.g. I would share a plate with someone with *cancer*). Twenty years ago a measure of cancer attitudes was developed that included some items related to stigma (the Cancer Attitudes Inventory

Psycho-oncology Services

The psycho-oncology service specializes in emotional difficulties and mental health problems and exits to provide supportive care to patients and their families from diagnosis to life beyond breast cancer. The service is provided by a multi-disciplinary team to include a psychiatrist, a counselor, a psychotherapist and specialist nurses. Together, these specially trained staff helps patents and their families address a spectrum

of problems to include anxiety, depression, relationship difficulties and other concerns related to cancer and its treatment in short or longer term.

This cross sectional descriptive study conducted on STHRI (Support to holistically restore the individuals) support group is a nonprofit voluntary service set up for cancer survivorship in HCG MSR hospital, Bangalore. The mission is to encourage and empower the female breast cancer survivors. It focus on survivor who needs physical and psycho-social support though providing yoga therapy, physiotherapy and diet counseling once in every week. The main objectives of support group are……To provide a safe and open environment to the express of unguarded feelings which can be addressed in kind, supportive and non-judgmental manner, To offers emotional support as well as wisdom and practical information, To address each individuals psychological, physical and appearance problems through yoga therapy, physiotherapy, suggestions about prostheses, wig and diet counseling, To promote awareness among the caregivers. Participant's experiences with support groups varied, depending on how closely they identified with other members of the group. In this particular group as per the participant's discussion many misconceptions exist about breast cancer, and there is something of a community taboo surrounding the disease. The patients themselves were blamed for somehow bringing it on themselves, or felt that they would be shunned by the community if it were known that they had cancer. Others were afraid of the effect of the disease on their self-esteem, and on their relationships with their husbands and other family members. Few women were told by their family that the disease was "a punishment from God". Others said they had no support from their husbands after being diagnosed, and some feared abandonment. Nobody who is facing the challenge presented by cancer should have to face this sort of emotional pressure as well.

1. Review of literature

A study was conducted by clinical nursing department, faculty of nursing university of Jordan, majority of the participants among 1647 51.5%agreeed that cancer is stigmatized in Jordan. Almost 70% of the participants reported that when they think of cancer, they immediately think of death and considered it is a hopeless diagnosis. (29)

A study was conducted on perceptions of breast cancer related stigma and genetic knowledge among Latin women, none of the women showed significant gains in knowledge related to breast cancer after reviewing the educational flies. All women demonstrated significant increases in anxiety between baseline emotional status and emotional status related to either a real or hypothesis diagnoses of cancer. Unaffected participants showed higher anxiety means overall. (30)

A study reveals that in the myths and conceptions about cancer, findings from Jordan, being patients with cancer in Jordan can be stigma provoking and is associated with many misconceptions. Socio-demographic characteristics and cultural beliefs crossed lines with the participants. (31).

Chemotherapeutic treatment produces a range of relatively immediate effects, including pain, nausea, fatigue, mouth sores, depression, problems sleeping, and temporary hair loss. Women across cultures often report that hair loss is one of the more troublesome; it makes them feel unattractive and look like they are sick or dying. Further, they often feel stigmatized by others. (32)

A qualitative study examined the experience and coping strategies employed by breast cancer patients in relation to its impact on their physical, mental health, religious and family issues. Thirty breast cancer patients were interviewed. Data was analyzed

using thematic analysis. The patient experience of breast cancer focused on the range of emotions felt throughout the illness trajectory, the importance of religion and family support on coping strategies employed to manage the side effects of chemotherapy and also financial concerns. (33)

A qualitative study was conducted by professor Bonnie Braun family science departments is used phenomenology as the method for understanding how women without Partners navigate their breast cancer diagnoses, treatment, and recovery? The concept of lived experience comes from the German word erlebnis. Experience as we live through it and recognize it as a particular type of experience, phenomenology focuses on how humans explore to qualitative methods because the researcher is gathering experiential material. Although the lived experience is unique to every individual, the researcher ought to be able to convey a meaning that is fundamental to the experience no matter which specific individual has had that experience. (34)

A cross sectional study has been conducted in Arabic, Bahraini breast cancer survivors reported favorable overall global quality of life. Factors associated with a major reduction in all domains of quality of life included the presence of metastases, having had a mastectomy as opposed to a lumpectomy and a shooter time elapsed since diagnosis. The most bothersome symptoms were fatigability, upset due to hair loss and arm symptoms were fatigability, and also upset due to this. The study identifies the categories of women at risk of poorer quality of life after breast cancer. (35)

The assessment of a study showed that the main feelings generated by the breast cancer diagnosis I women, observing that the diagnosis involves not only the physical and physiological condition but also the psychological and social area of the patient's life. The main feelings and sensations found in the studies found were associated with changes in self-image, low esteem, and bio psych-social effects caused by fear, anxiety, depression, worry and anguish and the restructuring of body image when there is

mastectomy whether partial or total.(36)

A study of 81 women with breast cancer in Nigeria showed that married African women have significant emotional, physical and social problems following primary treatment of breast cancer. Of the 81 patients included in the study, 38.3% had divorced or separated 3 years after therapy compared with the national average of 2.6%. (37).

Methodology and materials:

Design and Participants:

This cross sectional descriptive study will be conducted on 96 women (out of 100) in HCG MSR cancer center Bangalore state of Karnataka during March 2016 to October 2016. Inclusive criteria will be the age of over 30 years.

Data collection;

Simple random sampling method will be used for data collection. The questionnaires were distributed among rural women over 30. Each participant had taken 15 minutes to complete the questionnaire. Illiterate participants were interviewed, and their questionnaires were completed by the researcher. The questionnaire included 24 items and was composed of 3 parts. The first part evaluated the democratic characteristics in 4 items including age(30-40, 40-50, 50-60, 60-above), education (illiterate, elementary school ,high school, Pre university college, under graduation , and post graduated) occupation(government , private, self-employed and house wife)and marital status.(married, divorced, unmarried, widowed and single). The second part measured the

awareness level and included 21 items in four areas of general awareness about cancer(3items), awareness about breast cancer risk factors(8 items),awareness about mammography (7 items),and awareness about breast cancer symptoms(6 items). Third part calculated the misconception and the stigma about breast cancer (15 items). Correct answers were scored one, and wrong answer were scored zero.

The general awareness scores ranged from 0-21. Scores of 0-7 indicated poor awareness, scores of 8-14 indicated average awareness about breast cancer and score of 15-21 indicated good awareness about breast cancer .Different dimensions of awareness were scored as follows. The total score of general awareness ranged from 0-3. Score of 0-1 indicates poor awareness, scores of 1-2 indicated average awareness. The score of breast cancer risk factors ranged from 0-8, where scores of 0-3 indicated poor awareness, and score of 6-8 indicated good awareness. In mammography dimension, the total score ranged from 0-7, where scores of 0-3 indicates poor awareness, scores of 3-5 indicated average awareness. Regarding awareness about symptoms of breast cancer, the total score ranged from 0-6, where scores of 0-2 indicated poor awareness, scores of 2-4 indicated average awareness, and scores of 4-6 indicated good awareness. The third part included 15 items of distress and stigma included (cultural beliefs, myths and perceptions, psycho social distress).

Data analyses:

Descriptive statistics (mean, frequency, frequency percentage) were used to determine the frequency of demographic characteristics and the level of women's awareness and stigma about breast cancer chi-square test was used to examine the relationship between awareness and demographic characteristics. SPSS V22 was used for data analysis. $P \leq 0.05$ was considered significant.

Results:

Demographic characteristics of participants

Two hundred and sixty six questionnaires (out of 300) were completed and returned by the participants. Response rate was 86.6% out of 266 participants; age information was available for 261. The age range was of participants was 30-60 years above .Mean age of participants was 27±2.1. More than 83.8% of participants were house wives. Regarding education 26.8% of participants were illiterate, 19.9% had elementary school education, 18.4% had middle school education, 19.2% had a pre university college education, 5.7% had under and post-graduation and 10% had a post graduate degree. Demographic characteristics are listed in table 1.

Participant's awareness about breast cancer:

Twenty-four items evaluated the awareness of participants about general awareness, risk factors, breast cancer signs, and mammography. Most participants (154, 57.9%) had average awareness about breast cancer. In the general dimension most participants believed that only females are affected by breast cancer (Table 3). Most participants (166, 62.4%) had average awareness about breast cancer risk factors (Table 2).

Most participants believed that use of oral contraceptive (138, 52.3%), old age (153, 57.5%), and menarche at age less than 12(207, 795) are the most important risk factors of breast cancer (Table 3). Most participants (137, 51.5%) had good awareness about mammography (Table2). Most of the participants believed mammography is painless (189, 74.4%) and safe (185, 73.1%), while 181 participants (72.4%) believed that mammography at age less than the age 50 (Table 3). Most participants (194, 72.9%) had poor awareness about breast cancer symptoms (Table 2). Most participants did not know that the changes in breast shape (232, 88.2 %,), dimpling of breast skin (192, 72.3%) and nipple discharge (183, 69.6%) are the main symptoms of breast cancer (Table 3).

Participant's myths, misconception and social stigma about breast cancer:

Most of the participants 180 (67%) strongly agreed that people are feeling uncomfortable about being near them. 32% are disagreed moderately. 203(76%) participants agree moderately that antiperspirants deodorant and tooth paste cannot cause breast cancer. Only the 63(24%) respondents are disagree moderately. 200 (75%) are agree strongly for the habits like alcohol and tobacco consumption will raise the cancer. Only 55(25%) respondents dis agree moderately. 230(87%) Participants are strongly disagreed that implants will not raise the cancer. And only 33(13%) participants strongly agreed implants raise the cancer. All the respondents266 (100%) are strongly agreed the people who are hearing the cancer disease will be afraid. Most of the participants 240(90%) agree strongly cancer is a death sentence for the survivors. Almost 250(97%) participants not sure that all the lumps are the cancer lumps. 41(15%) participants are agree moderately only those with family history will get breast cancer rest of them disagree moderately. 260(99%) participants are strongly agreed the breast cancer is a hindrance to life. 200(76%) participants are agreed slightly diagnosed of breast cancer is a curse of god for their bad things and 64(24%) participants are disagree moderately not. 130(49%) participants are moderately agreed that they are neglecting from the family, reaming 136(51%) participants are disagree moderately. 229(90%) of the participants are strongly agreed that they feel ashamed by their diagnosis. Rest of 26(10%) disagree slightly. 260(98%) of participants agreed strongly they feel they should punished and only 4(2%) are disagree moderately. 197(74%) participants are moderately agreed that improper breast feeding may cause the breast cancer and only 69(26%) participants disagree strongly. Most of the participants 188(71%) are slightly agreed that they feel guilt and suicidal. 207(77%) participants are strongly agreed that once they have had cancer they can never be normal again and 65(33%) disagreed moderately.

Table 1. Socio-demographic Characteristics study of Participants.

Age distribution (n-249)	**Number**	**Percentage**
30-40	108	41.4
40-50	94	36
50-60	38	14.6
60-above	9	3.4
Education(n-261)		
Illiterate	70	26.8
Elementary	52	19.9
Middle school	48	18.4
High school	50	19.2
Under graduate	15	5.7
Post-graduation	26	10

Table-1

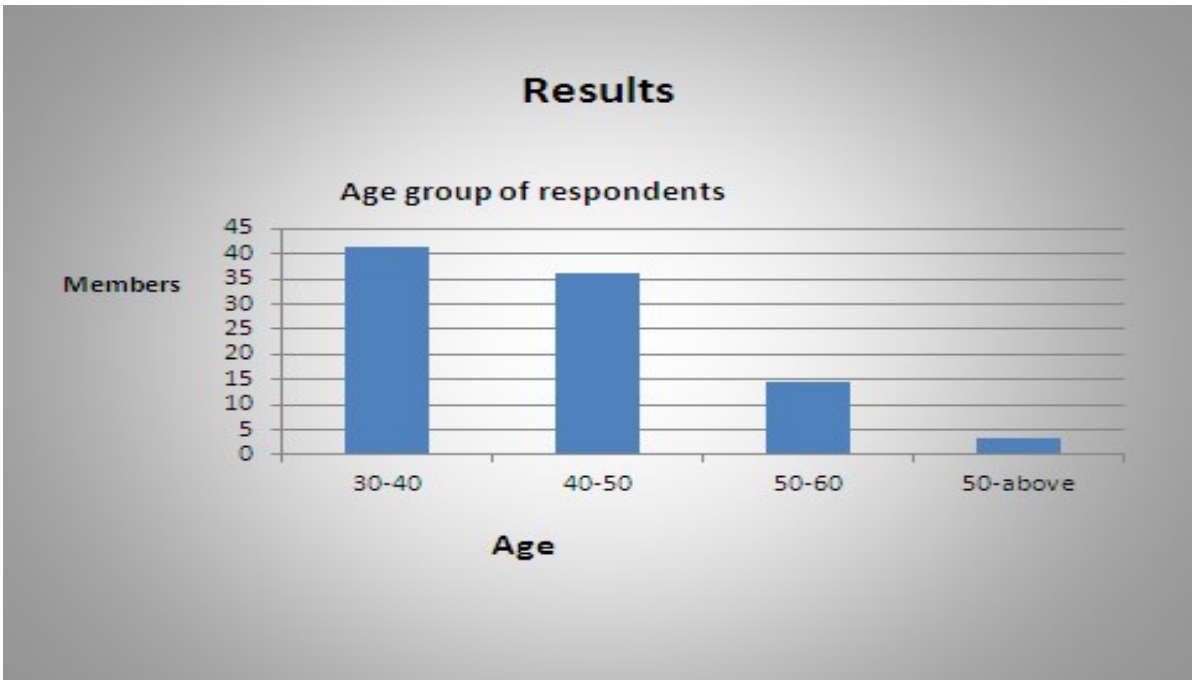


Table-1(1)

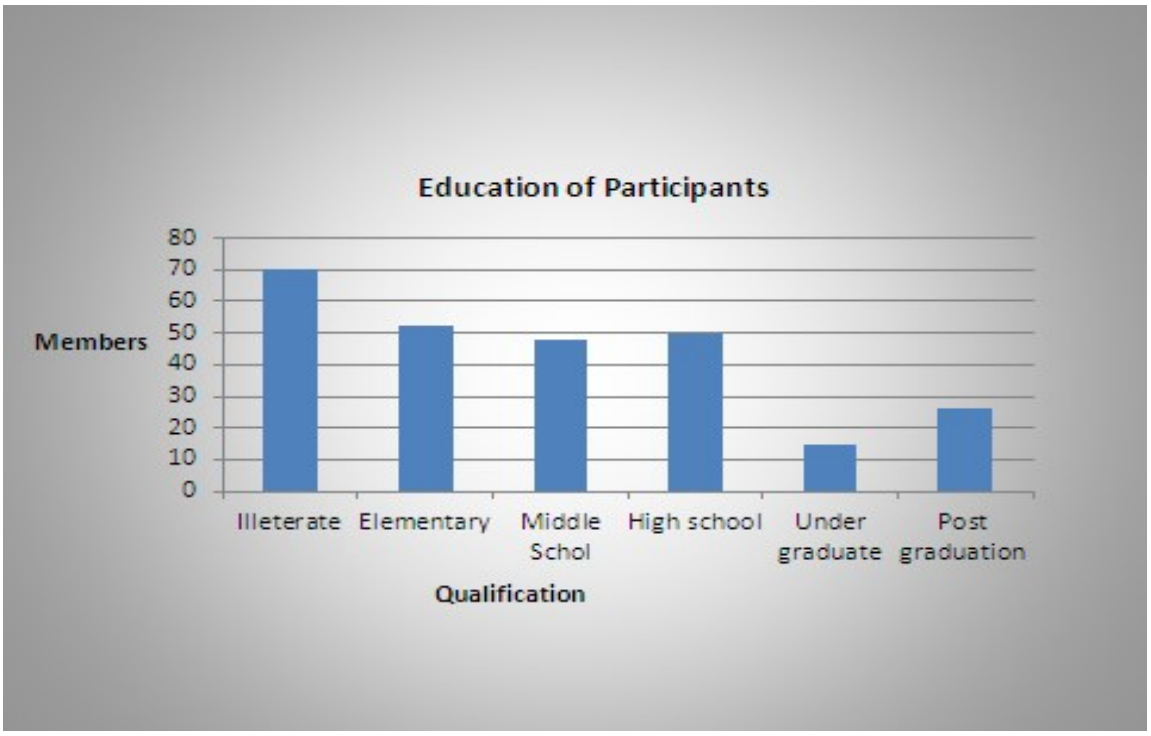

Education of Participants
Members
80
70
60
50
40
30
20
10
0
Illeterate
Elementary
Middle Schol
High school
Under graduate
Post graduation
Qualification

Table -2 Awareness about breast cancer:

Variable	level	Frequency (no)	Percent (%)	Mean ± SD
General awareness about breast cancer.	Poor	130	48.9	1.5±0.9
	Average	99	37.2	
	Good	37	3.9	
Awareness about breast cancer risk factors.	Poor	80	30.1	4.4±1.5
	Average	166	62.4	
	Good	20	7.5	
Awareness about mammography.	Poor	104	39.1	4.8±2.7
	Average	25	9.4	
	Good	137	51.5	
Awareness about breast cancer symptoms.	Poor	194	72.9	1.5±1.4
	Average	58	21.8	
	Good	14	5.3	
Overall awareness.	Poor	15	5.6	12.2±3.8
	Average	154	57.9	
	Good	97	36.6	

Table-2

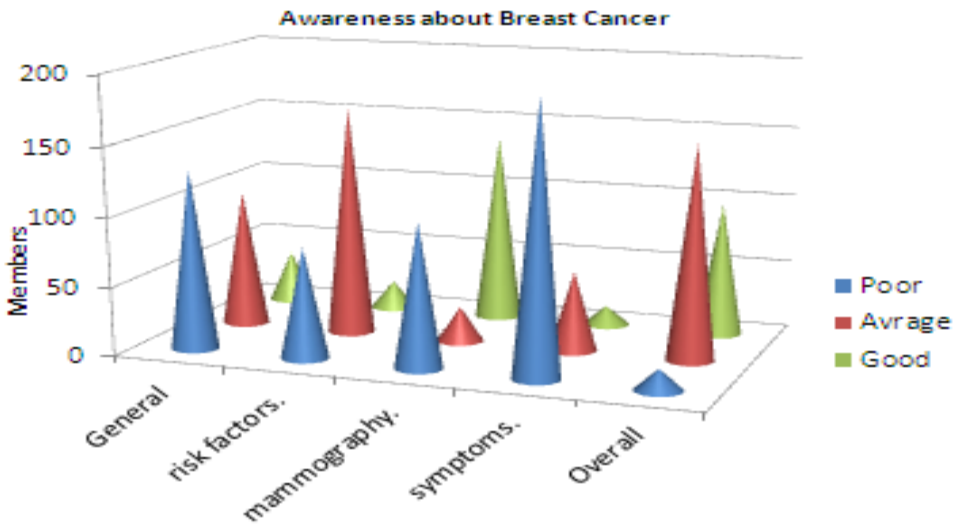


Table.2 (1) Frequency and percentage of Respondents answers about different Domains of Awareness about Breast Cancer.

General Awareness about cancer	Yes	No

Only females are affected by breast cancer (n-265)	74(27.8)	191(71.8)
Breast cancer can be transmitted from one person to another .(n=266)	191(71.8)	75(28.2)
Breast cancer is the leading cause of death in India	148(55.6)	118(44.4)
Awareness about breast cancer risk factors	Yes N (%)	No N (%)
Family history of breast cancer (n=264)	94(35.6)	170(64.4)
Use of oral contraceptive (n-264)	138(52.3)	126(47.7)
Old age (n=262)	153(57.5)	109(41)
Obesity (n=262)	108(40.6)	155(58.3)
Smoking(263)	49(18.6)	214(81.4)
Low fat diet(n=262)	235(89.7)	27(10.3)
Breast feeding (n=263)	179(68.1)	84(31.9)
Menarche at age less than 12 years (n=262)	207(79)	55(21)
Awareness about mammography	Correct N (%)	Incorrect N (%)
What is mammography? (n=252)	170(67.5)	82(32.5)
How often should it be used? (n=253)	159(62.8)	94(37.2)

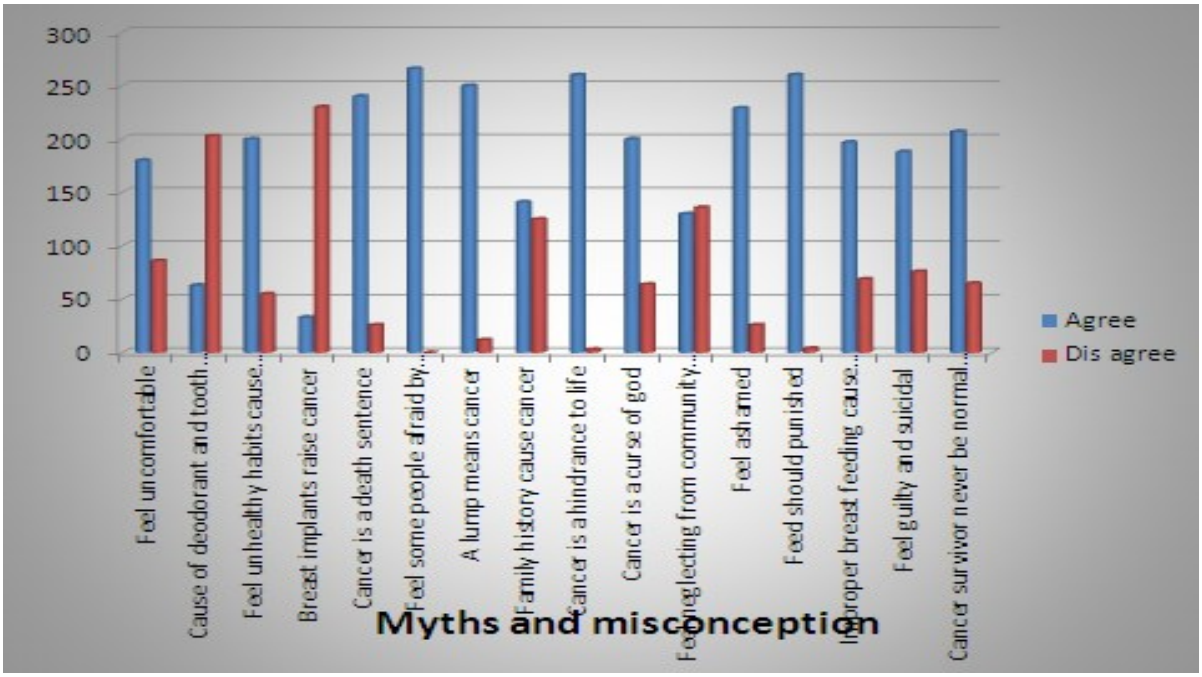
What is its benefit? (n=253)	150(59.3)	103(40.7)
Is mammography painful? (n=254)	189(74.4)	65(25.6)
Is mammography safe(n=253)	185(73.1)	68(26.9)
Can it detect early stage breast cancer before it is palpable? (n=252)	61(63.9)	91(36.1)
Is mammography more beneficial in wome≥50 years than those <50 years? (n=250)	181(72.4)	69(27.6)
Awareness about breast cancer symptoms	Yes N (%)	No N (%)
Painless breast lump(n=263)	68(25.9)	195(74.1)
Lump under armpit(n=263)	113(43)	150(57)
Nipple discharge(n=263)	80(30.4)	183(69.6)
Change in breast shape (n=263)	31(11.8)	232(88.2)
Pain In breast region(n=262)	48(18.3)	214(81.7)
Dimpling of breast skin (n=262)	70(26.7)	192(72.3)

Table-3, Breast Cancer stigma of the participants:

Misconception and stigma about breast cancer	Yes	No

	N (%)	N (%)
Some people feel uncomfortable about being near to you?(n=266)		
Do you think Antiperspirants, deodorants and tooth paste may cause cancer? (n=266)	180(67)	86(32)
Do you feel unhealthy habits like alcohols and tobacco consumptions will raise the cancer? (n=255)	63(24)	203(76)
Breast implants raise your breast cancer? (n=263)	200(25)	55(25)
Do you feel some people are afraid by hearing your diagnose?(n=266)	33(13)	230(87)
Is cancer is a death sentence? (n=264)		
A lump means you have cancer? (n=262)	266(100)	0
Only those with family history of breast cancer will get breast cancer? (n=266)	240(90)	26(10)
Do you think that breast cancer is a hindrance to life? (n=263)	250(97)	12(3)
Do you think breast cancer diagnosed is a curse of god for your bad things? (n=264)	141(53)	125(47)
Do you feeling you are neglecting from the family and community? (n=266)	260(99)	03(1)
Do you feel ashamed by your diagnose?(n=255)	200(76)	64(24)
Do you feel you should punished ?(n=264)		
Do you think improper breast feeding may causes the breast cancer? (n=266)	130(49)	136(51)
Do you feel guilty and suicidal?(n=264)	229(09)	26(10)
Do you think that once you have had cancer you can never be normal again ?(n=266)	260(98)	04(2)
	197(74)	69(26)
	188(71)	76(29)
	207(77)	65(33)

Table-3


300
250
200
150
100
50
0
Feel uncomfortable
Cause of deodorant and tooth...
Feel unhealthy habits cause...
Breast implants raise cancer
Cancer is a death sentence
Feel some people afraid by...
A lump means cancer
Family history cause cancer
Cancer is a hindrance to life
Cancer is a curse of god
Feeling neglecting from community...
Feel ashamed
Feed should punished
Improper breast feeding cause...
Feel guilty and suicidal
Cancer survivor never be normal...
Agree
Dis agree
Myths and misconception

Discussion:

Awareness and social stigma of rural women about breast cancer was investigated in this study. Result showed that most participants had moderate awareness and major effect of stigma and misconceptions. We show in this study participants had (I) Incomplete knowledge of breast cancer risk factors and early detection methods, and (II)current belief in common myths and folklore regarding the causes of breast cancer. Result showed that most women (55%) had poor awareness about breast cancer .this difference can be attributed to the difference in population. Most of the women had high misconception and stigma about breast cancer. More than (75%) women's are having the adjustment problem to stress of breast cancer its treatment. A review of the literature reveals low breast cancer literacy with regards to risk to risk factors, among Indian women, irrespective of their socio-economic and educational backgrounds with little correlation between awareness level and strength of evidence of risk factors. We found no relatively low and wide variation in awareness risk factors for breast cancer among women in India over 10 years publications, even as breast cancer became the most common cancer in the country. Women more commonly believed that unhealthy habits related to alcohol and tobacco consumption were more important risk factors than reproductive history, which is a much stronger determinant of breast cancer.

Limitations:

This study has some limitations that should be noted. This was a descriptive study, in which the self-report questionnaire were completed, quickly with yes or no, and frequency responses. The questionnaire included only most important risk factors, symptoms, mammogram and the misconception and stigma associated with breast cancer. This is an observational study about the breast cancer in a supportive.

Conclusion:

Almost a century of dealing with cancer has passed. A hundred years ago, a woman with breast cancer was dead women. Today, this is no longer the case. Thousands of women all over the world now have the chance to live normal life after receive a successful treatment. Yet, breast cancer remain one of the leading cause of death among women, and even if the death rates have been declining in the past few years, women at different ages should continuously test for breast cancer because detecting the disease at a very early stage can be very helpful and the treatment might not even be noticed.

Indian women need to aware of both modified and non-modifiable risk factors for breast cancer to adopt appropriate practices for prevention. There is an urgent call for more effective nation and state wide cancer literacy programs as well as engagement with community –level organization and the health system. With wide variations in the state-level burden, a coordinated, intensive health promotion intervention programs on risk factors, prevention, screening and management for breast cancer is prudent. Training on the latest evidence regarding breast cancer risk factors should be offered to health care

provider and community workers to raise their cancer literacy so they can then transmit this knowledge to other sections of the society. Continuing medical education programs with enhanced emphasis on breast cancer I the curricula of nursing at institutional level and other health care training institution should be a priority for women's health in the country.

Breast cancer awareness is an attempt to increase knowledge and reduce stigma. It aims to encourage women to be more aware of their breasts, thereby promoting earlier presentation and diagnosis. Breast cancer advocacy refers to the strategies employed predominantly by breast cancer survivors and well-wishers towards treatment and support. Survivorship refers to holistic living, and cancer navigation to the development of a support and referral system to ensure that all cancer patients receive optimal care.

In order to challenging cancer related stigma and finding opportunities for decreased breast cancer awareness, it is also urgent to address the cancer problem at a national and international levels. Communication is critical to decreasing cancer related myths and stigma, raising breast cancer awareness and disseminating cancer education. The global cancer community should capitalize upon positive shifts in attitudes and disseminate effective media campaigns and behavioral interventions to decrease the incidence of and morbidity and mortality associated with breast cancer. When facing breast cancer, people around the world want information and emotional support for themselves and their families. We need to strengthen patient advocacy in international settings to build a global grassroots movement having accurate perceptions of breast cancer; to prevent stigma from inhibiting people in their breast cancer control efforts; to help people affected by breast cancer receive the support , services, and information they need: all of which will help in decreasing the global breast cancer burden.

Breast cancer is here to say, and calling it "that which is not to be named' will not make it disappear.it must be named and faced.

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