

May 2022

## Kerala Needs a Women's Movement for Breast Cancer: An Exploratory Study on Breast Cancer Awareness in Kerala

Sheeja Rajagopal  
IIT Madras

Follow this and additional works at: <https://vc.bridgew.edu/jiws>



Part of the [Women's Studies Commons](#)

### Recommended Citation

Rajagopal, Sheeja (2022) "Kerala Needs a Women's Movement for Breast Cancer: An Exploratory Study on Breast Cancer Awareness in Kerala," *Journal of International Women's Studies*: Vol. 24: Iss. 1, Article 6. Available at: <https://vc.bridgew.edu/jiws/vol24/iss1/6>

This item is available as part of Virtual Commons, the open-access institutional repository of Bridgewater State University, Bridgewater, Massachusetts.

This journal and its contents may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, re-distribution, re-selling, loan or sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Authors share joint copyright with the JIWS. ©2022 Journal of International Women's Studies.

## **Kerala Needs a Women's Movement for Breast Cancer: An Exploratory Study on Breast Cancer Awareness in Kerala**

By Sheeja Rajagopal<sup>1</sup>

### **Abstract**

The incidence of breast cancer is on the rise globally, and the Indian state of Kerala is no exception. Kerala has a vibrant and exciting history of social and political struggles centered on the female breast, as is evidenced by the system of breast tax applicable to lower caste women and the breast cloth revolt. Despite this long history of public attention, the diseased female breast remains an area of silence. In Western countries, the Breast Cancer Movement has played a significant role in bringing awareness on breast cancer. Unlike in the Western world and certain other parts of India, Kerala has not seen a Breast Cancer Movement, and there are no public spaces available for discussion of breast cancer. Research has shown that breast cancer diagnosis and treatment are often delayed in the case of Asian women. This study analyses the personal narratives of women with breast cancer to identify the reasons for this delay which usually affects the survival of women. Several social, economic, and cultural factors that contribute to the delay in diagnosing and treating breast cancer come up in these narratives. The attempt here is to understand breast cancer in the social and cultural context of Kerala. In the light of the evidence shown by my research, I argue that the absence of breast cancer movements or activism is a major cause of the current situation in Kerala. It is essential for a movement organised by women to bring about a radical change in the Kerala scenario concerning women with breast cancer.

*Keywords:* Breast cancer movement, Breast cancer awareness in Kerala, Personal narratives, Female body and illness

### **Introduction**

Western medicine, from the end of the 18<sup>th</sup> century, had generally perceived illness as a physiological process understood and described best by medical professionals, often relegating the patient's perspective to the background (Armstrong, 1985). By the 1980s, medical sociologists started arguing that the way western medicine understands diseases should include their social, cultural, economic, geographic, and gendered facets (Lupton, 2012). Also, the study of illness experience from the patient's perspective has gained prominence across disciplines. Scholars argue that patient accounts of their illness experience provide new and valuable insights and perspectives on diseases (Armstrong, 1985; Frank, 1995; Hawkins, 1999).

Breast cancer today has become a major health concern globally, with reported/diagnosed and actual incidence of breast cancer being on the rise. According to the World Health Organization (WHO), breast cancer is the most common cancer in women both in the developed and in the less developed world. Studies reveal that almost 50% of breast

---

<sup>1</sup> Sheeja Rajagopal received her PhD in English Studies from IIT Madras for her work on breast cancer narratives from Kerala. Her current research interests include areas like the female body and illnesses, eco-feminist literature, and women's writing. She has published articles and presented conference papers on breast cancer narratives, eco-feminist writings, oral history, and women writers from Kerala. She teaches English at a Deemed University in Chennai, India.

cancer cases and 58% of deaths occur in less developed countries<sup>2</sup>. According to a study conducted in 2012 by the WHO (GLOBOCAN), 70218 women in India died from breast cancer, a figure that is much higher than that of the US (43909) and China (47984)<sup>3</sup>. Yet, very little is written or spoken about this disease and what it does to the bodies and lives of women, especially those belonging to countries like India. There is a lacuna in terms of information and research conducted to collect data like early detection, and the impact of screening and treatment facilities for women with breast cancer in low and middle-income countries (Coughlin& Ekwueme, 2009). Various social, cultural and economic factors have an impact on women receiving access to timely breast cancer screening and treatment. In this study, I explore the prevailing conditions regarding awareness, early diagnosis and access to medical intervention for women with breast cancer in Kerala. Using interviews with women as primary texts, I try to identify the reasons that prevent women from getting an early diagnosis which is crucial for the success of breast cancer treatment.

I also try to highlight the significance of the Breast Cancer Movement in spreading breast cancer awareness in the Western world. I argue how such movements were unable to spread beyond the Anglo-American world and make an impact in the lives of women from the developing world.

### **Delayed Diagnosis and Medical Intervention**

In the case of breast cancer, early diagnosis is often the key to successful treatment and recovery. Research has shown that in developing nations, breast cancer mortality rates are much higher than those of developed nations because of the delay in diagnosis (Porter, 2008). Nair et al. in their 1993 study on women with breast cancer in Kerala state, "The 5-year survival rates were 90% for patients with Stage I, 65% for those with Stage II, 33% for those with Stage III, and 6% for those with Stage IV disease" (p. 1794). Their study asserts that women diagnosed in the early stages of breast cancer have a better chance of successful treatment and survival, thus emphasising the importance of an early diagnosis. Rajaraman et al. state that, "The 5-year relative survival for breast cancer varies from 76.3% for localised cancers to 14.9% for advanced-stage disease" (2015). They also point out that early detection of breast cancer not only results in a better outcome but also lessens the cost of treatment. However, existing research points to the fact that women from lesser developed countries often receive delayed medical intervention in case of breast cancer. In a study on breast cancer in Asian women, G. Agarwal, Pradeep, V. Aggarwal, Yip, & Cheung (2007) state that, "It is not uncommon for women to be aware of a breast lump for many years before seeking medical attention. Many such patients seem to have an attitude of denial of this fact, postponing seeking medical attention until an overt secondary change of the disease such as skin edema or ulceration or symptomatic metastatic disease" (p. 1037). In their 2011 study on the impact of clinical breast examination in Trivandrum, Kerala, Sankaranarayanan et al. state that limited access to early detection and treatment results in the death of a significant number of breast cancer patients from low and middle-income countries. In this paper, I try to outline some of the reasons why breast cancer diagnosis and treatment are delayed for women from Kerala.

---

<sup>2</sup> WHO report quoted by Menelaos Ioannidis and Innovative Technology and Science Limited in their report on developing an application for breast cancer screening in India. For further details -

<https://gtr.ukri.org/projects?ref=103706#/tabOverview>

<sup>3</sup> "GLOBOCAN 2012: Estimated cancer incidence, mortality and prevalence worldwide in 2012" is a survey conducted by International Agency for Research on Cancer (IARC), WHO. According to the GLOBOCAN website of WHO, "The aim of the project is to provide contemporary estimates of the incidence of, mortality and prevalence from major types of cancer, at national level, for 184 countries of the world."

## Breast Cancer Movement

The Breast Cancer Movement originated in the United States due to women's need to break the silence that surrounds the topic of breast cancer, question existing norms on how a woman with breast cancer should look and behave and challenge the way the medical establishment approached breast cancer. Breast cancer support groups, which played a significant role in helping women cope with breast cancer, were the focal points in the origin of the breast cancer movement (Kaufert, 1998; Kolker, 2004; Brenner, 2000). Beginning in the 1970s, breast cancer advocates started bringing public attention to issues like – access to breast cancer detection and patient autonomy in deciding treatment for breast cancer. The Reach to Recovery programme, conceptualised in the late 1950s by women who had undergone radical mastectomies and later adopted by the American Cancer Society, provided support to women with breast cancer (Batt, 2003; Kaufert, 1998). Such programmes were adopted in countries like Canada, Australia, Britain, and Japan. In the 1990s, the focus of breast cancer advocates shifted to a new ground – appeal for more government funding for cancer research. Added to this are the fundraising programmes like Pink campaigns which use cause-related marketing to raise funds for breast cancer research.

Several factors contributed towards the opening up of spaces where breast cancer can be discussed publicly. Celebrities and public figures like Shirley Temple, Betty Ford, and Happy Rockefeller shared their breast cancer experience with the public (Kolker, 2004; Lerner, 2003). Early breast cancer autobiographies like Audre Lorde's *The Cancer Journals* (1980) and Deena Metzger's *Tree: Essays and Pieces* (1981) spoke about the need to break the silence surrounding breast cancer. Women's groups that began as support groups for breast cancer patients and survivors gradually evolved into a powerful social and political movement aimed at improving women's lives. As Patricia A. Kaufert (1998) points out, "The history of the breast cancer movement offers a rare example of the emergence of a formal, structured, highly self-conscious resistance movement, put together by women, and in defense of their lives" (p. 289).

The Breast Cancer Movement is not without its own share of criticism on various grounds. There is a feminist critique that the image of the breast cancer survivor portrayed in most campaigns is always that of a successful, healthy, and feminine woman, often excluding the experiences of many women (King, 2006). Very often, programmes offering support like Reach for Recovery are designed to address the problems of white middle-class women. For example, Audre Lorde in her *The Cancer Journals* remembers wondering if there were "black lesbian feminists" in the Reach for Recovery programme and points out how the pink prosthetic offered to her, with assurances of "you'll never know the difference", did not even match her skin tone. Several support groups and programmes were criticised for focusing on the physical appearance of women with breast cancer and for their sexist and heteronormative approaches often sponsored by cosmetic companies (Lorde, 1998; Pitts, 2004). In addition to this is cause marketing, where companies adopt breast cancer as a cause, pledging contributions to breast cancer research and thus adding value to their brands. They market products with Pink Ribbons or bring out special pink packages to show their commitment to the cause of breast cancer and encourage customers to buy the product and contribute to the cause. Campaigns like Think Before You Pink try to educate customers on how, very often, very little money from the purchase goes to the cause (King, 2006).

To summarise, as a result of the relentless effort put in by breast cancer activists and volunteers, the issue of breast cancer caught the attention of the public in Western societies. The Breast Cancer Movement resulted in increased breast cancer awareness and the increased availability of early detection facilities. What is even more significant is that the breast cancer movement created platforms where breast cancer can be discussed openly.

## Background of the Study

The social and cultural context of Kerala<sup>4</sup> makes it an interesting site for a study on breast cancer. To begin with, Kerala has a vibrant and interesting history of social and political struggles centred on the female breast<sup>5</sup>. The evolution of the female breast in popular, cultural, and material imagination makes an interesting backdrop for this study. This includes but is not limited to concepts of dress and covering the breast, breast and sexuality, attitudes towards the female breast and a sense of shame associated with the breast. Another reason is that unlike in the Western world and in certain other parts of India, Kerala has not seen a Breast Cancer Movement and there are no public spaces available for discussion of breast cancer. Even breast cancer support groups are not present in most places and women do not have a space where they can discuss breast cancer.

Kerala, a southern state in India, is uniquely placed, given its high sex ratio, female literacy, and education when compared to other states of India. Though the much celebrated 'liberated women'<sup>6</sup> of Kerala make advancements in all fields, their voices are largely absent on discussions surrounding the breast – health, surgeries, medical access, space for discussion, etc. This silence that marks the discourses on the 'politics of the breast' is particularly significant when one reads it against Kerala women's historical resistance movements such as '*maru marakkal samaram*' (breast cloth revolt)<sup>7</sup> and their revolt against the sexist and exploitative policies like '*mulakkaram*' (breast tax)<sup>8</sup>. These events also point to the fact that female breasts have remained at the centre of much debate and political activity in Kerala, therefore making the state an interesting locale for a study on breast cancer awareness.

Susan Sontag (1989) is one of the earliest writers to point out the dangers of the negative metaphors and connotations that pervade discussions on cancer. This has resulted in a sense of shame among cancer patients making it difficult for them to disclose their diagnosis or even seek medical attention. Thatcher Carter (2003) in her article on autobiographies by women with breast cancer, notes, "Patients, in part because of the cultural

---

<sup>4</sup> Kerala, one of India's Southern states, is noted for its high literacy rates, good sex ratio, and social development. For more information on the famed 'Kerala Model' of social development, refer Kurien, J. (1995). The Kerala model: Its central tendency and the outlier. *Social Scientist*, 70-90.

<sup>5</sup> Kerala has witnessed social and political struggles centred on the female breast. The struggle to get the rights to cover the breasts, the breast tax imposed on lower caste women and the struggles against this are some examples. Even among upper-class women, covering the upper body was a relatively recent phenomenon, influenced by Christianity and Victorian Morality. This gradual change in perceptions regarding the social and political repercussions of these are discussed in detail by J. Devika (2010) in *Kulastree'yuum 'Chanthappennum' Undaayathengane? Adhunikamalayali Streekalute Charitrathinu Oru Aamugham* [The Birth of the 'Well-born' Woman and the 'Market Woman': An Introduction to the History of Malayalee Women].

<sup>6</sup> In the popular imagination, Kerala woman is educated, employed and financially independent. The 'Kerala Model' of social development has brought in changes to the lives of women, and this had led to the stereotype of liberated Keralite women. While it is true that women in Kerala usually get much better educational and employment opportunities than women from many other parts of India, discrimination does exist in subtle forms in various spheres.

<sup>7</sup> The breast cloth revolt refers to the revolt that happened in the first half of the nineteenth century in South Travancore, demanding rights for lower caste women (particularly Channar caste) to wear an upper cloth and cover their breasts. Earlier, lower caste women were not allowed to cover the upper part of their body. As a result of the revolt, women from all castes were allowed to wear a blouse and/or an upper cloth to cover their breasts (Devika 136).

<sup>8</sup> '*Mulakkaram*' was imposed on women of lower castes by the rulers of Travancore. An Ezhava woman called Nangeli has protested against this tax by chopping off her breasts and presenting them to the King's representatives who came to collect the tax. There are arguments that there could be elements of mythology in the Nangeli story. To bring official recognition to Nangeli's sacrifice, artist T. Murali has painted a series of pictures of the incident, now published in his book, *Amana - The Hidden Pictures of History* (2016).

meanings of the body parts in which cancer is found, have pervasively hidden cancer of all types” (p. 653). The shame associated with breasts and the unwillingness to show their breasts to a male doctor prevents women from seeking medical help. Marilyn Yalom in her book *A History of the Breast* (1998) explains that it was difficult for women to show their painful breasts to a doctor and that it caused them great embarrassment. Agarwal et al. in their study list “sociocultural barriers of hesitation on the part of women to have her breasts examined and seek treatment” as a reason for the delay in getting breast cancer diagnosed among women. This sense of shame associated with the female breasts is a very real problem in Kerala, and this could get in the way of women getting a timely diagnosis.

## Methodology

For this study, I followed a narrative approach and made use of the qualitative interview to understand the experiences of women with breast cancer. “Oral interviews are particularly valuable for uncovering women’s perspectives,” writes Anderson and Jack (1991, p. 11). An interview is a useful tool for qualitative research as it can be used to capture the experiences of ‘ordinary’ women who are often left out of many research projects (Fraser, 2004). The interviews were conducted on two or more sessions, and the questions were mostly open-ended, allowing the participants to narrate their experiences without interruption. I also framed questions that allowed the participants to speak about the events that led to their diagnosis in detail. To make the participants feel comfortable while talking about a traumatic experience, I conducted the interviews mostly in the homes or workplaces of the participants and let the participants choose the place for the interview in all cases. In most cases, I was alone with the participants during the entire interview, to give them the time and space to communicate freely about this deeply personal experience. There were only two exceptions – one participant had a friend with her at the time of the interview, and another one had her daughter, who was a doctor, with her. The interviews were audio-taped after obtaining permission from the participants. In the case of this study, all the interviews were conducted in Malayalam, which was my first language as well as that of the participants. I transcribed and translated the interviews into English for detailed analysis.

As breast cancer is seen as a very sensitive and private issue in the Kerala context, the participants for this study were identified using a kind of snowball sampling. In the snowball sampling method, a researcher generates “a study sample through referrals made among people who share or know of others who possess some characteristics that are of research interest” (Biernacki & Waldorf, 1981). I used contacts from volunteers of support groups, pain and palliative care providers and referrals from participants and friends and relatives of breast cancer patients and survivors to identify participants for this study. One major challenge was, very often, women refused to talk about their breast cancer experience or even acknowledge their breast cancer. Coming from the social and cultural milieu of Kerala, many women found it difficult to talk about a disease and body part that was considered shameful.

The 25 participants for this study came from different parts of Kerala. Most participants were either undergoing treatment for breast cancer or in a remission after successful treatment. Financially, eight participants were upper-middle-class women, five came from the lower middle class and twelve were working-class women. The youngest participant was 37 years old at the time of the interview, while the oldest was 83 years old. Eight participants were homemakers, while the others were working women. Six participants used to work outside the home before their breast cancer diagnosis but became homemakers after their diagnosis and treatment. Table 1 lists the basic profile and details (excluding personal information and identity) of the participants. All the women who participated in the study have undergone either mastectomy or lumpectomy as a part of their treatment.

**Table 1. A Basic Profile of the Participants**

<b>Participant</b>	<b>Age</b>	<b>Education</b>	<b>Work</b>
P1	37	Upper Primary School	Daily wage labourer
P2	83	High School	Homemaker
P3	48	Post-Graduation	Government Job
P4	38	Upper Primary School	Daily wage labourer
P5	50	Lower Primary School	Daily wage labourer
P6	51	Lower Primary School	Homemaker
P7	56	Upper Primary School	Seasonal daily wage jobs
P8	54	Upper Primary School	Homemaker
P9	48	High School	Homemaker
P10	49	High School	Seasonal daily wage jobs
P11	54	No formal education	Daily wage labourer
P12	48	High School	Daily wage labourer
P13	37	Graduation	Homemaker
P14	50	Upper Primary School	Daily wage labourer
P15	38	College Dropout	Part-time Job
P16	48	High School	Homemaker
P17	40	College Dropout	Homemaker
P18	35	Graduation	Own business
P19	52	Lower Primary School	Daily wage labourer
P20	49	Upper Primary School	Seasonal daily wage jobs
P21	50	Upper Primary School	Seasonal daily wage jobs
P22	35	Post-Graduation	Government Job
P23	42	High School	Homemaker
P24	30	Graduation	Government Job (on contract)
P25	43	College Dropout	Part-time Job

### Research Findings

This research confirms that observations made in existing research on diagnosis and treatment for diagnosis and treatment for women with breast cancer from South Asia, hold true for women from Kerala. Almost half of the participants of this study accepted that their breast cancer diagnosis and subsequent treatment was delayed for various reasons. Table 2 gives a brief description of the participants who had a delayed breast cancer diagnosis and their reasons for the same. There are social, cultural, economic, gender and public policy-related reasons behind their delayed diagnosis and treatment. This study is an attempt to understand some of the reasons behind delayed breast cancer diagnosis and treatment among women in Kerala.

**Table 2. List of Participants who had a Delayed Diagnosis and their Reasons for the Same**

<b>Participant</b>	<b>Reason for Delayed Diagnosis</b>
P2	Lack of awareness regarding breast cancer
P3	Family responsibilities
P5	Lack of awareness regarding breast cancer
P6	Lack of awareness, financial problems
P7	Family responsibilities, lack of awareness reading breast cancer

P8	No proper diagnostic facilities in the area
P9	Sense of shame regarding the breasts, no female doctor available
P12	Lack of awareness, financial problems
P14	Wrong initial diagnosis, financial problems
P16	Sense of shame regarding the breasts, no female doctor available
P18	Family responsibilities, lack of awareness reading breast cancer
P19	Lack of awareness, financial problems
P21	Family responsibilities, lack of awareness reading breast cancer

Due to concerns that range from household responsibilities and financial burden to lack of awareness and proper medical access, women very often neglect their health. Many of the participants in the study agree that they did not get an early diagnosis or early medical intervention which is crucial for the success of breast cancer treatment. In this section, I examine, in detail, the various reasons the participants shared for not taking signs given by their body seriously. It is to be noted that this study is situated in a place where women have very limited access to awareness programmes and have not seen any kind of breast cancer movement.

### **Lack of Awareness**

Six participants admitted that their lack of awareness regarding cancer has made them ignore signs like painless lumps and occasional pains in breasts or armpits. One woman who disregarded the lump in her breast for several months said, "In my mind, cancer was a disease that happened to other people, not women like me. No one had ever told me about examining my breasts or going to a doctor in case of a doubt". Most participants shared this sentiment that they thought of breast cancer as a disease that happens to other people – people with posh lifestyles, people who ate a lot of non-vegetarian food, and people who were obese. Women who have experienced breast cancer do not get a space to reach out to others or speak or write about their illness experience. Without an opportunity to listen to and understand the experiences of women diagnosed with breast cancer, such misconceptions regarding breast cancer are very common in Kerala, promoting women to disregard early symptoms of breast cancer.

Some women did speak about the existence of small support groups and spaces that they considered safe, where they could speak about their breast cancer experience. These spaces were provided by self-help groups, women's colleges, survivor groups and so on. Even though these are small groups with limited reach and have a small number of women, they do provide these women a space to come together and share their breast cancer stories.

### **Working Women from Low Income Households**

Some women who participated in the study were daily wage workers and many of them admitted that they did not go to a doctor immediately after they felt a lump in the breast or a twinge of pain. Most of these women did not want to lose a day's wages over what they thought was an inoffensive lump or casual pain. One participant said that she ignored the lump in her breast because, "At that time, I was working and would tell myself that it was not worth losing a day's wages in order to meet the doctor. Also, I would want someone to accompany me to the doctor, but then if they came along with me, they too would end up missing work that day." This was one major reason which working-class women had for not going to a doctor immediately, for not attending classes and camps for cancer awareness and screening, and for not making changes that happen to their body seriously. In the struggle to provide for the family and make a livelihood, they are forced to ignore their own health.

### Family Responsibilities

Helen Keleher (2009) writes, “Education is a core social determinant of health, one that is infused with gendered norms about the value of education for girls and women, their social status, and traditional attitudes to female roles in households and communities” (p. 166). She argues that education paves the way for economic independence as well as awareness regarding women’s health, bodies and rights. Educated women show better awareness regarding health and have better access to medical facilities and health providers. Several studies point to the fact that educated and working women often show greater awareness regarding health and wellness, the availability and importance of health care services and seek modern health care when required (Navaneetham and Dharmalingam, 2002; Keheler, 2009; Elo, 1992). In the light of these observations, one would assume that delay in getting diagnosed and starting treatment happens only to uneducated women from poor backgrounds and highly educated women promptly seek medical help. An analysis of personal experience narratives of women with breast cancer from Kerala, who participated in this study, suggests that there are exceptions. There are well-educated women who forget to take care of themselves while balancing the multiple roles of professional, homemaker and mother. Between the taking care of children and other family members, managing a home, and handling a demanding career, many of them do not get time to notice changes in their bodies. Four well-educated women who participated in this study reported that they often neglected their own bodies in their struggle to balance work and duties at home. One striking example is that of a well-educated and financially independent participant with a proven family history of breast cancer. In spite of repeated reminders from aunts and cousins who were diagnosed with breast cancer, she chose not to do a screening test for many years as she was busy with a fulltime job and two school-going children. She states that this was not even a conscious choice, it never occurred to her to take that time off from her responsibilities for herself. She recollects taking an oil massage and shower on an unexpected holiday and discovering the lump. She says, “If it were not for that unexpected free time and that bath, I wouldn’t have discovered it then... This is something that happens to us women, we don’t have time for ourselves. Now I feel thankful to God that I decided to take that bath that day and discovered the lump before it had spread much”. Later on, she published a small book in Malayalam about breast cancer treatment and diagnosis, the need for breast awareness and the importance of conducting self-examinations.

### Sense of Shame

In Kerala culture, women are taught to remain modest and maintain silence regarding their bodies. J. Devika (2005) points out how, during the 1950s, newly-formed caste-based organizations which played a major role in modernizing and organizing people from different caste groups<sup>9</sup> made a conscious effort to project the image of the ‘well-covered’, domestic, feminine and modest woman as the ideal. This image of the ideal woman, who is domestic, maternal, and modest, is pushed by religious and educational institutions, thereby enforcing strict silence on topics like body and sexuality. Many of the participants in this study even found it embarrassing to use the Malayalam word *Mula* in their narratives to speak about their breasts. Instead, they would use the terms *nenchu* or *maru* which refer to the chest area in general. Several women who participated in this study said that there were no female doctors in hospitals near their place. They have hesitated before going to a hospital with their problem because of their reluctance to let a male doctor examine their breasts.

---

<sup>9</sup> Caste-based organizations like the Shree Narayana Dharma Paripalana Yogam of the Ezhavas, the Nair Service Society of the Nairs, the Yogakshema Sabha of the Namboodiris, the Pulaya Mahasabha of the Pulayas played a role in organizing people, creating in them a sense of community and in modernising the caste groups.

One participant recollects that she once went to the hospital to get her breasts (which were very painful at that time) examined by a female doctor she knew but did not speak about her breasts because there was a male doctor in the room. She remembers that day, "When I went inside the consulting room there was a male doctor and a lady doctor, and I suddenly became ashamed. Out of shame, I didn't show my breasts to the doctor. I normally go to see the lady doctor alone and therefore didn't have them examine me that day." Another participant who is a nurse by profession said that in her hospital there are women who come and insist that the female nurses should examine their breasts and report their observations to the male doctor. These women are conditioned to believe that there is something shameful in letting a man see their breasts, even for medical purposes. Deep cultural conditioning has made these women value notions of false modesty and honour more than their own health and well-being.

In a culture where women are taught to value their virtue more than even their lives, it is common for women to endure the pain than deal with the embarrassment of consulting a male doctor. They learn to associate a certain sense to shame with the female body parts and find it difficult even to talk about these parts. In addition to this, in these patriarchal societies, women are conditioned to believe that their bodies belong to their husbands. Thus, it becomes a grave mistake to let another man see or touch their breasts which carry sexual significations. All these notions of false modesty together prevent women from getting medical help as soon as they spot some symptoms of breast cancer.

### **Proper Medical facilities**

Kerala has a strong public health system and access to medical facilities and primary health care is much better compared to many other states of India. However, there is a disparity between rural and urban areas when it comes to screening and treatment facilities for diseases like cancer. Women from rural parts of Kerala often do not have access to good diagnostic facilities and as a result, they lose valuable time before a proper diagnosis is made. Three women who participated in the study said that they went to a doctor and conducted some tests as soon as they felt the lump, but their cancer was not detected at that time. These women lack access to proper medical facilities in their areas and were therefore unable to get a proper diagnosis. One participant said that the doctor who examined her breasts and checked the lab test reports concluded that the lump in her breast was just fat tissue. The treatment gets delayed for several women, especially in rural areas, because they do not have access to proper medical facilities to get a correct diagnosis. Very often, reassured by a false diagnosis, they return to their normal lives, only to suffer greatly later.

### **Discussion**

In their multi-national collaborative study on breast cancer in Asian women, Agarwal et al., (2007) note that women do not always get proper medical help even when they show symptoms of breast cancer for various reasons. In this study, I attempted to identify some of the social, economic and cultural factors that prevent women with breast cancer from getting timely diagnosis and treatment. The reasons for delayed diagnosis and treatment of breast cancer include lack of awareness, lack of medical facilities, gender inequalities in access to medical facilities, family roles and expectations from women, and a sense of shame surrounding the female body. In the light of the findings from this study, I argue that a mass movement headed by women with breast cancer is necessary for the Kerala scenario.

General cancer awareness campaigns and screening programmes have come to the public sphere only in recent times (over the last ten years or so) in Kerala. Awareness regarding early symptoms of breast cancer, breast self-examination, screening and diagnostic tests, and treatment facilities are limited, especially in rural areas. Studies reveal that women

in India are often not aware of or harbour misconceptions regarding the risk factors, warning signs, or techniques for early detection of breast cancer (Somdatta and Baridalyne, 2008). Lack of awareness regarding symptoms of breast cancer, knowledge of and access to proper diagnostic facilities is a major cause of delay in getting a proper diagnosis. The responses of the participants point to the fact that lack of public platforms to discuss breast cancer does limit opportunities for proper breast cancer awareness among women in Kerala. The breast cancer movement has been pivotal in creating awareness regarding breast cancer and empowering women to have control over their treatment process in the West (Kaufert, 1998; Kolker, 2004). To begin with, breast cancer awareness programmes that bring breast cancer into the public eye are in a nascent stage in Kerala. What we have are isolated medical camps and awareness classes organised by different voluntary organisations, hospitals or the government. The responses of the participants in this study make it clear that these are no women's collectives or breast cancer-specific voluntary groups working on creating breast cancer awareness in Kerala. Support groups for breast cancer patients that provide support for women with breast cancer are non-existent. This is to be read alongside the fact that breast cancer support groups played a major role in the rise of the breast cancer movement in many countries.

In the socio-cultural milieu of Kerala, a sense of shame and modesty is associated with the female body in general and the breasts in particular (Devika, 2005). This sense of shame very often prevents women from seeking medical help when they suspect they have symptoms of breast cancer. This sense of shame, coupled with the absence of public platforms that discuss breast cancer makes women with breast cancer guarded. This points to the need for more support groups that provide women a space to discuss their bodies in the context of breast cancer and thus overcome their inhibitions regarding the female breast.

In rural areas and low-income households, awareness regarding illnesses and access to proper medical facilities are limited to all people. Even within this group, women are often discriminated against in terms of access to and continuation of proper medical care. Iyer, Sen, and Ostlin (2010) point out that in low-income countries women tend to receive less medical care than men, as they generally have “poorer access to and control over resources within households” and very often they are left with “little time or opportunity for health-seeking” (p. 82). The study proves that women from low-income households are doubly disadvantaged when it comes to access to medical intervention even when they suspect lumps in their breasts. The absence of a proper breast cancer movement and related voluntary groups prevent the messages regarding self-tests and diagnostic facilities from reaching women, especially those from lower-income households. In the United States, the Breast Cancer Movement played a significant role in forcing the federal government to increase funding for breast cancer care and research and more importantly, the movement was able to frame breast cancer as a public health problem (Kaufert, 1998; Kolker, 2004). In the case of Kerala, this absence of a breast cancer movement is felt in interventions in policymaking to make special provisions for women from lower-income groups to get timely diagnosis and treatment.

One positive thing which many of the participants shared is that once they went through the breast cancer experience, they spoke about it in their close groups (where they felt comfortable and that they would not be judged) warning their friends about the possibility of this dangerous disease. Women from the working class often used their self-help group, Kudumbasree<sup>10</sup> meetings to talk to their friends about breast cancer. Various studies have ratified the role of Kudumbasree in improving the socio-economic situation of women,

---

<sup>10</sup> Kudumbasree is a women empowerment programme implemented by the State Poverty Eradication Mission (SPEM) of the Government of Kerala. The term ‘kudumbasree’ in speech may refer to the Kudumbasree programme, the Kudumbasree network or an individual kudumbasree unit. Refer <http://thekudumbasreestory.info/index.php/what%E2%80%99s-kudumbasree> for more information.

through promoting collective action, entrepreneurship, micro-finance loans and other poverty alleviation programmes (Devika and Thampi, 2007; Rajagopal, 2020). With a powerful history of women empowerment through self-help groups and collective action, Kudumbasree units provide an ideal space for women to come together to share breast cancer experiences and spread awareness. Other participants also mention similar 'safe spaces' like meetings in women's colleges, cancer survivor meetings, etc., where they can share their breast cancer stories and also educate other women. So in their own different ways, women from Kerala are slowly breaking the silence surrounding breast cancer and making an effort to create new spaces to discuss and spread awareness on breast cancer. It is quite possible that these individual efforts could someday lead to a movement that can transform the lives of women with breast cancer.

The breast cancer movement in the West was able to bring women together and struggle for a cause and transform into a mass movement that could bring about a positive change in the lives of women (Kaufert, 1998). Even simple steps that led to the growth of this mass movement – support groups, sessions of breast cancer awareness, individual protests, creating a space to talk about breast cancer – all these could bring about a difference to the lives of women with breast cancer in Kerala. At the very least, these could change the status of 'breast cancer' from being a taboo word to a speakable name of a disease which needs proper medical attention. And if it indeed grows to a mass movement seeking changes at the policy level, it is definitely going to be a landmark movement in the history of Kerala.

### **Conclusion**

In western countries, the breast cancer movement has helped women by creating awareness, influencing policy decisions, making screening and diagnostic facilities more accessible and providing support to patients and survivors. Considering the hurdles that women in Kerala face regarding breast cancer diagnosis and treatment, there is a pressing need for a movement fighting for the cause of women with breast cancer. To begin with, access to support groups focussed on creating awareness regarding breast cancer screening and treatment and providing support for breast cancer patients would make a difference in the lives of women in Kerala. These support groups should be able to address issues like sense of shame surrounding the female breast, and silence surrounding breast cancer and provide a space for women to speak about their bodies. It is also important to create awareness programmes that educate women on different aspects like self-examination, screening tests, early diagnosis, cancer treatment and so on. At a policy level, there should be an effort to establish breast cancer screening centres, improve access to cancer treatment in rural areas, and provide support to women with breast cancer.

## References

- Agarwal, G., Pradeep, P. V., Aggarwal, V., Yip, C. H., & Cheung, P. S. (2007). Spectrum of breast cancer in Asian women. *World Journal of Surgery*, 31(5), 1031-1040.
- Anderson, K., & Jack, D. C. (1991). Learning to listen: Interview techniques and analyses. In S. B. Gluck and D. Patai (Eds.), *Women's words: The feminist practice of oral history* (pp. 11-26). New York: Routledge.
- Armstrong, D. (1984). The Patient's View. *Social Science & Medicine* 18(9), 737-744.
- Batt, S. (2003). *Patient no more: The politics of breast cancer*. Melbourne: Spinifex Press.
- Biernacki, P., & Waldorf, D. (1981). Snowball sampling: Problems and techniques of chain referral sampling. *Sociological Methods & Research*, 10(2), 141-163.
- Brenner, B. A. (2000). Sister support: women create a breast cancer movement. In A. S. Kasper & Susan J. (Eds.), *Breast cancer: Society shapes an epidemic* (pp. 325-353). New York: Palgrave Macmillan.
- Carter, T. (2003). Body count: Autobiographies by women living with breast cancer. *The Journal of Popular Culture*, 36(4), 653-668.
- Coughlin, S. S., & Ekwueme, D. U. (2009). Breast cancer as a global health concern. *Cancer Epidemiology*, 33(5), 315-318.
- Devika, J. (2005). The aesthetic woman: Re-forming female bodies and minds in early twentieth-century Keralam. *Modern Asian Studies*, 39(2), 461-487.
- Devika, J., & Thampi, B. V. (2007). Between 'Empowerment' and 'Liberation' The Kudumbashree Initiative in Kerala. *Indian Journal of Gender Studies*, 14(1), 33-60.
- Elo, I. T. (1992). Utilization of maternal health-care services in Peru: the role of women's education. *Health Transition Review*, 49-69.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.
- Fraser, H. (2004). Doing narrative research: Analysing personal stories line by line. *Qualitative Social Work*, 3(2), 179-201.
- Hawkins, A. H. (1999). *Reconstructing Illness: Studies in pathography*. Purdue University Press.
- Iyer, A., Sen, G., & Östlin, P. (2010). Inequalities and intersections in health: a review of the evidence. In G. Sen & P. Östlin (Eds.), *Gender equity in health: The shifting frontiers of evidence and action* (pp. 70-95). New York: Routledge.
- Kaufert, P. A. (1998). Women, resistance, and the breast cancer movement. In M. Lock and P. A. Kaufert (Eds.) *Pragmatic women and body politics* (pp. 287-309). New York: Cambridge University Press.
- Keleher, H. (2009). Gender norms and empowerment: 'What works to increase equity for women and girls. In G. Sen & P. Östlin (Eds.), *Gender equity in health: The shifting frontiers of evidence and action* (pp. 183-205). New York: Routledge.
- Kolker, E. S. (2004). Framing as a cultural resource in health social movements: funding activism and the breast cancer movement in the US 1990–1993. *Sociology of Health & Illness*, 26(6), 820-844.
- Lam, W. W., & Fielding, R. (2003). The evolving experience of illness for Chinese women with breast cancer: a qualitative study. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 12(2), 127-140.
- Lorde, A. (1980). *The Cancer Journals*. Argyle, NY: Spinsters Ink.
- Lupton, D. (2012). *Medicine as Culture: Illness, disease and the body*. Sage.
- Metzger, D. (1978). *Tree: Essays & pieces*. Berkeley, Calif: North Atlantic Books.
- Nair, M. K. et al., (1993). Overall survival from breast cancer in Kerala, India, in relation to menstrual, reproductive, and clinical factors. *Cancer*, 71(5), 1791-1796.

- Navaneetham, K., & Dharmalingam, A. (2002). Utilization of maternal health care services in Southern India. *Social science & medicine*, 55(10), 1849-1869.
- Pitts, V. (2004). Illness and Internet Empowerment: Writing and reading breast Cancer in cyberspace. *Health*, 8(1), 33-59.
- Porter, P. (2008). "Westernizing" women's risks? Breast cancer in lower-income countries. *New England Journal of Medicine*, 358(3), 213-216.
- Rajagopal, N. (2020). Social impact of women SHGs: A study of NHGs of 'Kudumbashree' in Kerala. *Management and Labour Studies*, 45(3), 317-336.
- Rajaraman, P, et al. (2015). Recommendations for screening and early detection of common cancers in India. *The Lancet Oncology*. 16(7), e352-e361.
- Sankaranarayanan, Rengaswamy, et al. (2011). Clinical breast examination: Preliminary results from a cluster randomized controlled trial in India. *Journal of the National Cancer Institute*. 103(19), 1476-1480.
- Somdatta, P., & Baridalyne, N. (2008). Awareness of breast cancer in women of an urban resettlement colony. *Indian Journal of Cancer*, 45(4), 149.
- Sontag, S. (1989). *Illness as metaphor and AIDS and Its Metaphors*. New York: Picador.
- Yalom, M. (1998). *A history of the breast*. New York: Ballantine Books.