Evaluation of Suffering and Distress in Breast Cancer Patients of Indian Heritage Undergoing Treatment.

Short title: Psychological symptoms in breast cancer patients of Indian heritage

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Abstract

Background Breast cancer is now the most common cancer among women in India. The rising incidence is thought to be due to increased life expectancy, urbanisation, and adoption of western lifestyles. However, little is known about the psychological impact of the disease and its treatment among women of Indian heritage living anywhere in the world, and how their culture influences their experience of cancer-related psychological concerns.

Aim. To improve the knowledge about the psychological concerns among Indian heritage women with breast cancer on treatment and what helps to relieve or worsen these distresses. I also aimed to explore the cultural context within which Indian women with breast cancer living in India experience the psychological concerns, and its impact. **Methods.** To understand what is already known about the psychological concerns of Indian women with breast cancer living anywhere in the world, I conducted a mixed-methods systematic literature review using Centre for Reviews and Dissemination methods, and modified critical interpretive synthesis, through the lens of cultural distress theory. To explore the experience of distress/suffering as well as factors affecting them, in Indian women with breast cancer living in India with special focus on patients undergoing treatment, I conducted in-depth interviews with 20 women from Kerala undergoing treatment for breast cancer. To investigate the cultural context in which Indian women with breast cancer experience their disease and treatment I conducted five focus groups with (health care workers (2 groups)) lay public (3 groups). Both interview and focus groups were conducted in the regional language (Malayalam) and English as indicated, verbatim transcribed, translated into English, and back translated and data subjected to thematic analysis. Cultural distress and cultural task analysis theories were used to underpin the primary qualitative studies.

Findings The available data from India and Canada indicate that the psychological concerns are like 'Western' women but are experienced within a common culture of Indian women. Family structure, religion and community appear to both protect against and cause distress in relation to an expected core role (wife, mother, family carer), and male dominance - particularly in decision making. Both qualitative studies described psychological impact relating to body image, particularly hair loss, change of family role and their need for support. Like the review findings, family and faith were recognised as the major framework providing key support but also significant stress. Both clinicians and lay groups were also concerned about the financial implications of the disease and its treatment, and issues around lack of early cancer detection. Lay people and nurses also commented that poor communication and lack of empathy from doctors aggravated distress.

Conclusion Indian women with breast cancer living in India and Canada experience psychological morbidities which profoundly affect, and are affected by, their role in their family and the wider community. Culturally congruent care, including accessible communication and information, may help prevent and alleviate distress whether in India or in a migrant community. Clinical and lay communities were aware of the widespread psychological impact affecting women with breast cancer which are amplified by the patriarchal context within which they live. Family and faith provide a strong support structure but are also a cause of distress, as core roles and expectations are challenged by this disease of womanhood. These insights are useful for clinicians aiming to provide culturally congruent breast cancer care for Indian women anywhere in the world.

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Author Declaration

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PUBLICATIONS, PRESENTATIONS AND PRIZES ARISING FROM THIS WORK

Prizes

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Publications

- Daniel, S., Venkateswaran, C., Singh, C. et al. "So, when a woman becomes ill, the total structure of the family is affected, they can't do anything…" Voices from the community on women with breast cancer in India: a qualitative focus group study. Support Care Cancer (2021). https://doi.org/10.1007/s00520-021-06475-4 (From Chapter 6)

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- Daniel S, Clark J, Gnanapragasam S, Venkateswaran C, Johnson MJ. Psychological concerns of Indian women with breast cancer in different national contexts: a systematic review and mixed-methods synthesis. BMJ Supportive & Palliative Care. 2020 May 11. (From Chapter 4)

Oral presentations

- "So, when a woman becomes ill, the total structure of the family is affected, they can't do anything, so the kid's studies will be affected, husband's work is affected" – Voices from the community on women with breast cancer in LMIC; a qualitative focus group. July 2021 HYMS Postgraduate Research Conference, Hull (From Chapter 6)

- ‘I don’t talk about my distress to others; I feel that I have to suffer my problems...’ Voices of Indian women with breast cancer: a qualitative interview study”. Journal club at Karkinos Health Care PLC - an end-to-end technology driven oncology focused managed healthcare platform. The attendees are predominantly from non-medical technology background and working from different parts of the country. (From Chapter 5)
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Poster presentations

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- Systematic literature review on the psychological concerns of Indian women undergoing breast cancer treatment. Association for Palliative Medicine Palliative Care Congress 2019. March 2019 Published Abstract in: BMJ Supportive & Palliative Care 2019; 9: A38. Daniel S et al. (From Chapter 4)

1 INTRODUCTION TO BREAST CANCER IN INDIA.

1.1 Background

Breast cancer is the commonest form of cancer among women of all racial and ethnic groups both in the developed and the developing world. The rising incidence of breast cancer in the developing world is thought to be due to increase in life expectancy, increased urbanization and adoption of western lifestyles. The total number of cases of breast cancer diagnosed in women all over the world in 2018 was over two million (1), which is about 24% of new cancer cases and 15% of cancer deaths. Incident cases are expected to increase by more than 46% by 2040 (2). The incidence varies between ethnic groups in the United States with highest among non-Hispanic women followed by white women, black women and Asian/Pacific Islander women (3). Similarly in the UK, South Asian and Black women have a lower risk of breast cancer than white women (4); but worse outcomes despite equal access to health care (5).

1.2 Etiology

The etiology of all invasive breast cancers is unknown, but certain factors are thought to play a role. These include

1.2.1 Genetic factors

There are a number of genetic mutations linked to breast cancer in about 5% to 10% of cancers. The commonest are the BRCA1 and BRCA2 mutations (6), which increase the cumulative lifetime risk of developing breast cancer to 72% and 69% respectively (7). These are one of the reasons for early onset cancers and familial aggregation.

1.2.2 Hormonal factors

An early menarche is linked to a higher risk of occurrence of breast cancer due to a longer period of exposure to oestrogens (8), while prolonged breast feeding decreases the risk of occurrence of breast cancer (9). Prospective studies have demonstrated the correlation between increased levels of endogenous sex hormones and a significant elevation in the risk of breast cancer especially in post-menopausal women (10). Similarly the use of hormone supplements post menopause is linked to an increased risk of breast cancer which increases with the duration of treatment (9), however similar correlation with oral contraceptive usage has not been established (11).

1.2.3 Dietary habits and life style

Breast cancer is now considered a life style disease and there are a number of modifiable risk factors linked to breast cancer including diet rich in fat leading to obesity as well as processed products, flavour enhancing products and other chemicals in food which can cause malignant transformation of mammary gland cells (12). It has been shown that regular physical activity at 3-5 times/week reduces the risk of breast cancer recurrence by 20-40% and is often recommended to obese women with breast cancer after the primary surgical procedure (13).

1.3 Treatment

Standard treatment for early-stage breast cancer is primary surgery with or without breast reconstruction or primary systemic therapy followed by surgery. Further adjuvant therapy, which includes radiotherapy, chemotherapy, biological therapy or endocrine therapy, is offered depending on assessment of prognostic and predictive factors and potential benefits and side effects of the treatment (14). The development of physical symptoms like pain, paraesthesia and oedema after treatment was found to be related to the type of surgery as well as the use of other treatment modalities including radiotherapy and chemotherapy (15).

1.4 Psychological symptoms in breast cancer patients

A preliminary and informal scoping search of the literature (using MeSH headings for breast cancer and psychological symptoms; single database only [Medline]; no date limits) found several studies evaluating the psychological symptoms of breast cancer patients both in relation to the disease or its treatment. Psychological symptoms are common in women diagnosed with breast cancer due to the considerable distress associated with cancer diagnosis, fear of relapse or death, body image issues and treatment related side effects (16). A five year observational cohort study among 170 women with early breast cancer showed that nearly 50% of the women with early breast cancer had depression, anxiety, or both, in the year after diagnosis, 25% in the second, third, and fourth years, and 15% in the fifth year (17). The factors contributing to persistence of symptoms include previous psychological treatment, lack of an intimate confiding relationship, younger age, and severely stressful non-cancer life experiences (17).

A four-month observation of 151 women, with early-stage breast cancer who had initial surgical treatment followed by chemotherapy and or radiotherapy, found that women who underwent mastectomy reported more cancer related distress and avoidance of reminders of cancer, than those who underwent lumpectomy. Moreover, the chemotherapy plus radiotherapy group reported more intrusive negative thoughts than the radiotherapy only group (18). However, in a different study assessing psychological outcomes of different treatment modalities, the prevalence of anxiety and depression was found to be similar in the post-operative period irrespective of mastectomy or lumpectomy (19). Nearly half of women who had mastectomy and 37% of who underwent lumpectomy were anxious two weeks postoperatively. When assessed after a year, this number declined but was still high at 28% and 27% respectively. Moreover, between 15% and 29% of women irrespective of treatment were found to be depressed at each assessment.

Post treatment breast cancer patients were screened for depression and anxiety in two separate studies conducted in the United Kingdom and Australia (20, 21). They found that 10-12% of patients had borderline clinically relevant levels of depression and 45-46 % of patients had significant anxiety. Psychological symptoms and social isolation are not only distressing for patients but are also associated with reduced compliance with medical treatment (22). A meta-analysis on patient adherence and medical treatment outcomes showed that the risk for non-compliance with medical treatment increases threefold in patients with depression (23).

Few studies related to women of Indian heritage, and there was no systematic review to identify the extent of the evidence and knowledge gaps in this population.

1.5 Impact of cultural background

Women from diverse cultural backgrounds have differences in cancer care experiences. A study among Chinese-American and Non-Hispanic White breast cancer survivors showed that Chinese immigrants are at risk for greater distress compared to US born Chinese and

Non-Hispanic survivors (24). In conventional Eastern views of care, physicians represent an authority of medical knowledge and are highly respected and cancer is considered as an incurable and stigmatized disease. This makes the women less liable to communicate their wishes to physicians or challenge them and have some self-imposed barriers to accessing care which include not seeking preventive care such as screening (25). It was noted that Chinese survivors reported different side effects (e.g., skin problems) from treatments and more immigrants turned to traditional Chinese medicine to find cures when their physical distress was less well relieved than their US born counterparts.

Breast cancer survivors, living in Iran, experienced a poor quality of life across a broad spectrum of health domains, including social, emotional and spiritual in a cross-sectional study conducted among sixty-eight patients undergoing radiotherapy (26). Multiple regression analysis indicated that social functioning, pain, and arm symptoms were more important in predicting the general quality of life. The radiotherapy treatment was associated with arm pain and oedema which has strong association with quality of life. This highlights the need for psychosocial support during their period of treatment.

A qualitative study on experiences of women with breast cancer living in Syria, regarding chemotherapy reported both psychological discomforts, including hopelessness, fear, altered body image, depression, and negative emotion as well as physical symptoms of fatigue, nausea, vomiting, loss of hair, and pain as the most disabling symptoms. Interestingly, contrary to their cultural practices to repress breast cancer discussion, the women in the study found this difficult and verbalized their need for society support and acceptance (27).

A systematic review of breast cancer experience and survivorship among Asian Americans has highlighted the commonly reported treatment side effects as fatigue, irritability, loss of physical strength, recurring pain and poor quality of life (28). Asian American women described their sadness and unwillingness to recall the cancer experience, and anxiety during physical examination, due to cultural taboos which prevent them from talking about cancer or touching one’s body (28). This can often result in the avoidance of self-exams and screenings. They also reported feelings of self-consciousness and inadequacy, and perceived cancer as a stigma, not able to openly discuss with their families, their fear of relapse of disease and death all contributing to their distress. Further, Asian cultural and gender socialization expects Asian American women to be altruistic and fostering of their husband and family, serving as caregivers with obligations, not as dependants (29).

Another systematic review of the literature of breast cancer and coping among American women of colour demonstrates vital differences in how women of diverse cultures respond to related stressors and variations in their coping strategies (30). In studies with multiple ethnic groups, positive forms of coping such as self-distraction, venting and positive reappraisal were more common among women of colour than white women. Qualitative studies also indicate that among racially/ ethnically diverse subgroups, religious beliefs and norms affect appraisal and coping responses.

Focus group discussion and key informant interviews among women from various ethnic backgrounds, living in the United States, have shown the influence of culture in accessing psychosocial care and using coping mechanisms (28). Research conducted among African Americans, Latina, Asian and Caucasian women indicated that women's responses to breast cancer often include fear, worry and denial irrespective of their ethnic background. However, particularly among older women of colour and more recent immigrants, cultural beliefs may deter their accessing psychosocial care, since they may be reluctant to discuss emotional problems and personal feelings with mental health professionals. Family has been highlighted as primary resource for support for breast cancer survivors, particularly for Asians and Latinas.

Cultural beliefs therefore appear to play a role in women's responses to the diagnosis and treatment of cancer, as well as accessing medical help, and are distinct from the Western culture of autonomy and individualism. The difference in experiences and responses between the immigrants and natives probably indicates migration of culture with the population.

1.6 Breast cancer in India

Despite these reports of psychological distress and impact of cultural background, there appears to be little or no research to explore psychological distress among breast cancer patients undergoing treatment in the Indian subcontinent. Over last ten years or so, breast cancer has been rising steadily in India and is currently the most common cancer in women in India, ahead of cervical cancer (31, 32). Both, the incidence, as well as deaths, due to breast cancer is greater than cervical cancer accounting for 25% to 31% of all cancers in women in Indian cities (33). Breast cancer accounts for about one-quarter of all cancers in Indian women; about half of all cancer related deaths. In 2020, 3465951 (24.1%) women were newly detected with, and 1121413 (15.4%) women died of, breast cancer in India (34). In most Asian societies, the majority of breast cancers are diagnosed at a relatively late stage. International Agency for Research on Cancer (IARC) registry data shows that that 45% of newly diagnosed cases of breast cancer and 55% of breast cancer related mortality currently occur in low- and middle-income countries. The survival from breast cancer in North America is more than 80% while it is 40% in low-income countries. This is mainly because of a lack of early detection programmes and inadequate resources for treatment (35).

Most of the cancers are diagnosed at a late stage, 50% of which are locally advanced cancers probably due to lack of awareness, a non-existent large scale breast cancer screening program and socio-cultural barriers like the Purdah system, and an unwillingness to expose self or subject themselves to screening breast examinations and imaging (36). There is a low level of awareness of breast cancer risk factors among Indian women, irrespective of their socio-economic and educational background (37). Primary treatment is delivered through public sector hospitals, private and employer-funded insurance, personal out-of-pocket fees, community-based and non- profit organisations, and by external funds from loans and grants (38, 39).

It is important to understand the cultural background of the population to give us insight into the decision-making process, their behaviour in relation to cancer screening and diagnosis as well as to understand the psychological response to diagnosis and treatment.

1.7 Indian history, culture, diaspora and immigration

1.7.1 Historical background

India, the seventh largest country in the world, located in South Asia, is the world's biggest democracy and the second most populous country. It has one of the oldest civilizations of the world with a continuous history. India is a birthplace of four religions, Hinduism, Buddhism, Jainism, and Sikhism, which is reflected in the vital and decisive role religion plays in life of its people (40). It is believed that the earliest inhabitants came as small groups to the subcontinent nearly 50,000 years ago from Africa by way of the coast (41). Later from 7000 BC, along the banks of river Indus, humans settled down and developed agriculture based economy, which was later known as Indus Valley civilization (42). This had a mixture of ethnic groups comprising of hunter-gatherer, migrant farmer and pastoralist communities. The interesting discoveries of human figurines from the time indicates that women held high positions in society, the people worshiped natural forces with feminine divine power (43), however there was some division of labour with women mostly engaged in grinding grain and preparing food (41).

1.7.2 Indian culture and the role of women

The cultural development of the country began in the second millennium BC when the oldest known texts ‘Vedas’ were written and this was followed by development of Sanskrit language and a classical civilization on the banks of sacred river Ganga under the ancient empires of Mauryas and Guptas (44). This period also showed the development of Hinduism which continued to flourish despite a long series of foreign invasion and is also marked by the declining status of women and the development of the caste system (45). The Laws of Manu, an important book written during this period, described a series of legal injunctions and moral prescriptions effectively tying the women to patriarchal family requiring them to observe submissiveness to father, husband and son (45). The book reduced the property rights of women, recommended significant difference in ages between husband and wife, encouraged early marriage for women and banned widow remarriage. The Law describes women to be care takers of the home, responsible for running of the family smoothly, looking after aged in-laws and nurturing the children (43). However, the impact of the book was limited in areas where Sanskrit tradition was weak, such as the state of Kerala where matrilineal descent among Nayar Hindus continued till nineteenth century. This system referred to as ‘Marumakkathayam system of inheritance’ is the law by which succession to property is traced through females and not through males (46). The two Hindu epics written during this time, Ramayana and Mahabharata also describe instances where birth of son was an event of celebration, while daughters were considered as source of misery and worry, even for royalty (47). Another prevailing custom described in the laws was the practice of ‘kanyadan’ or the gift of virgin daughter in marriage which occurs between two males, father and the groom, which gives man the greatest spiritual merit and an unidirectional flow of gifts from the bride's to groom's family which later developed and came to be known as the dowry system (48). The dowry system continues to be a social evil in the country and in spite of laws prohibiting the practice, National Crime Records Bureau of India, recorded a total of 8,618 female deaths related to dowry disputes in 2011 (49).

The Buddhist age witnessed a serious change in the status of Indian women with adoption of daughters made valid, and acceptance of women as nuns to Buddhist monasteries which changed the general belief that the birth of son was indispensable to attain salvation and also helped in propagating the religion and also was a great incentive for female education among aristocracy (43, 47). A new form of Buddhism called 'Tantric Buddhism' taught that enlightenment can be achieved through everyday activities and characterised women to be ancillary in male yogic practices to attain enlightenment (45).

The spread of Islam into South Asia at around 1000 AD resulted in the development of Purdah system or veiling of Muslim women. In addition, Hindu men began to veil their wives as a protection from possible dishonour by Muslim men and as a form of social prestige. This occurred around the same time as Sanskrit writings which reinforced the already existing patriarchal culture. Women were also physically secluded to emphasise the importance of female chastity to maintain family honour and pride in withdrawing women from economically fruitful public activities. Physical seclusion usually occurs in a part of house commonly referred to as 'harim' or 'zenana', this was considered to be a woman's abode where various activities including sexual relationships, reproduction in the family, socialization of children and daughters-in-law and general household management takes place. But these 'harims' were also considered as areas of power where the highest authority was with the oldest female who is usually the wife of the eldest male. In spite of the general patriarchy the young women experienced, on a daily basis the Indian women face the cultural norms placed by the mothers, mother-in-law and daughter-in-law (45).

The eighteenth century saw the development of sections that would characterise the modern social environment during the time of Mughals; women were considered to be safeguards of fortune and mothers of kings. The honour of Sultan was based on the impeccable virtue of mother, wife, daughters and sisters. A few powerful women managed to play important role in politics both inside and outside the Mughal Empire either as rulers in their own right or on behalf of their husbands or preserving power for their sons. However, women who ruled or acted on the behalf of husbands received criticism as they were threatening the established order while women who held power for their son received praise. One such woman was Mumtaz Mahal, wife of Mughal emperor Shah Jahan, on whose memory the iconic Taj Mahal was built, when she died after birth of her fourteenth child. She was much loved by her husband, was also knowledgeable about major policies and was in charge of the imperial seal (45). Female seclusion ('Purdah') system and 'sati' became expressions of female purity, piety, devotion and heroism, women's place was considered to be at home with low participation in education and wage labour (50). 'Sati' originated as a social custom among Aryans and later among tribes migrating from central Asia to South Asia, it is a practice whereby the virtuous woman dedicated to her husband, burns to death on his funeral pyre, even though in the 'puranas', which are a class of religious literature that dates from fourth to fourteenth century AD, Sati is also mentioned as a Goddess who is the first wife of Lord Siva and commits self-immolation because of an insult to her God-Husband.

Another warrior queen who was mythologized years later was Rani Lakshmi of Jhansi, who fought against the British for the rights of her adopted son after her husband died and joined the revolt of Indian troops of 1857 or 'sepoy mutiny', later succumbed to injuries received in the battle. She was described as "the only man among the rebels" by General Hugh Rose after her death and was a potent symbol of courageous resistance and female identity (45).

The contact of Indian culture with that of the British also brought improvement in the status of women (43). Several Indian women appeared as major political leaders during conflicts against British, and British officials constructed a hierarchy according to the status of women based on claims that position of women reflected the level of development of civilisation, although Indian women were given inferior position as compared to European women. In the latter part of nineteenth century, several woman reformers emerged, fighting against social problems like child marriage, sati, promoted widow remarriages, and fought for female education. Christian missionaries, Indian religious leaders and British officials promoted female education so that they would be better companions for their educated husbands and suitable mothers for their sons. Later, women started working and earning mostly in the field of education and medicine by the elite group, while non elite group women entered the manufacturing area, textile industry, agricultural sector like tea and coffee plantations. In the late nineteenth century Indian women formed organisations and associations by their own initiative and thereby gained organisational and debate skills and later played important role in social reforms (45). Another factor in the revival of women's position was the influence of Mahatma Gandhi who encouraged women to participate in the Freedom Movement (43) and women participated in more revolutionary movements including communist movement and were actively involved in the relief work among the people affected by the Bengal famine (45). However, in spite of this improvement in the role of women, the prevailing expectation of subservience to father, then husband, then son with regard to important decisions continues in the family system in India.

1.7.3 Family system in India

Families are important institutions that play a key role in the lives of most Indians. India, traditionally, has a joint or extended family system which is mentioned in some of the sacred Hindu books and has been so for centuries. It consists of number of married couples and their children who live together in the same house (51). This conventional joint family system has not only persisted, but also been further reinforced in the face of urban-industrial civilisation (52). In joint family systems, members of the family have their duties defined based on gender and personal experience (53). The joint family system was a part of the religious belief system in Hinduism with family Gods and family life cycle rituals largely responsible for maintaining joint families in India. This custom is also responsible for the economic uplift of some of the major business families in the country (52). However, the joint family has intrinsic weaknesses with arrangement of roles and a regular pattern of beliefs and traditions which is rooted in Hinduism's belief in the inequality between sexes and occupations, Indian family is by and large patriarchal in structure (52, 54). The patriarch of the Indian family is a protective totalitarian figure, respected by all family members (55). There is also a predominance of marriage between close relatives, which is more common in South India where the institution of joint family is stronger than in the rest of the country (53), these however has been more matriarchal and matricentred (56). On marriage, a girl leaves her ancestral family and becomes a part of the joint family of her husband. Women often take the role of a fostering parent who is esteemed and cherished similar to the Indian epics which portray women as bound by tradition, diligent , self-sacrificing, self-denying, and yet powerful (57).

In almost all patriarchal societies in ancient times, the birth of a son is preferred to a daughter. This is no different in India and seen as early as during the Vedic and Indo-Iranian age. Boys are also known to be given privileged treatment than girls since childhood with more precedence in the area of nourishment, schooling, and career which is more so in northern states of country. The poor sex ratio of the females to males in almost all northern states, which constitute 60% of India's population, indicates the low status of women and poor nutritional status. Kerala is an exception; the state boasts the highest female literacy rates, highest female to male sex ratio and lowest population growth in the whole of India (52). However, tradition and custom still govern the actions of a large majority of women in India (54). The dowry system which developed during the medieval times in royal families was established further during the middle of 19th century among common people and it continue to exist in various parts of the country today (47). This places additional burden on families having female children leading to instances of female infanticide and foeticide in different parts of the country which has been first reported during British rule and unfortunately continuing to date (58). Girls are trained from childhood to be submissive, virtuous and separated from boys (52). Once they are married, which is usually arranged by the parents, they are expected to adhere to the cultural belief that Indian women should conceive within one year of marriage; a belief usually reinforced by family members (59, 60). The women are stigmatised if they remain childless, either voluntarily or involuntarily (61) to the extent that this was allowed as grounds for divorce in lower caste marriages (52). In fact, there are passages in religious books which describe the ill fortune of childless women such that even beggars refuse to accept alms from her (51), indicating the deeply embedded stigma in Indian culture.

1.7.4 Religion

India has the uniqueness of being the land from which four important religions namely Hinduism, Buddhism, Sikhism and Jainism originated. At the same time, the country is home to several indigenous faiths and tribal religions which have survived the influence of major religions for centuries. According to 2011 census about 99.7% of population declared their religion (62), this overwhelming influence of religion is embedded within the country's culture and society. As described above, religious practices have been evidenced from prehistoric times and religion is closely intertwined with cultures, caste system, family life and the status of women in family and community. All the four major religions teach '*dharma*' or the principle that can maintain universe, *'karma'* or action and *'bhakti'* or way of devotion which seemed to carried on by seculars and pluralistic group too (63). People tend to consider 'karma', God and spirits, as important causes of life's events like disease and suffering. Religion and spirituality plays an important role in how most Indians cope with diagnosis of illness, some consider it as fate or 'kismet' or the result of their 'karma' while it is seen that people have better mental health and greater adaptability to stress if they are religious (64).

1.7.5 History of Emigration

According to United Nations International Migration report of 2015, out of the 244 million international migrants worldwide, 104 million (43%), were born in Asia with 18 million coming from India (65). India therefore has the largest diaspora in the world with majority of international migrants living in 10 countries, including United States of America, United Kingdom and Canada (66).

India has a long history of migration which dates from the early nineteenth century, when large number of families migrated to East and South Africa, West Indies, Fiji Islands, western regions of Canada and the United States for the purpose of labour. Until the end of the 1960s the UK was the main beneficiary of Indian migrants, skilled and unskilled, principally due to colonial ties between the two countries and the advantage of having English language as the medium of education in India, particularly at the higher, professional and technical levels (67). Later on, a new flow occurred to the U.S.A., and Canada, including both low skilled and skilled workers, as well as students pursuing higher education, which contributed to a significant growth of families of Asian Indian heritage especially in North America (54, 67). Immigration of South Asians into Canada commenced at the start of twentieth century with the entry into British Columbia by Sikhs from the State of Punjab

(68). Immigration continues and is responsible for the diffusion of culture and religion to different parts of the world , India still maintains to have the largest pool of skilled labour in the world and will be largest source of emigrants in the predictable future (67, 69).

1.8 Acculturation

Acculturation refers to the psychosocial adjustment and adaptation to a new culture for people from another culture (70). It has been shown from the studies among migrant Indians in the UK and America, that they tend to keep certain aspects of their traditional life style from back home while embracing few modern regimes; perseverance of deep religious faith and family loyalty being the most important ones. Women are inspired to work while husband takes their share of household responsibility, nevertheless, the engrained patriarchy persists with male member deemed to be the authority figure and decision maker and couples maintain a lasting obligation to marriage (54). Similar studies among South Asian women in Canada as compared to Anglo Saxon immigrants showed that, though the former women were embedded in their conventional values of their cultural legacy; they also demonstrated contemporary, future adapted ambition. They are extremely devoted to family and home; keep up values and traditions and at the same time are highly ambitious and aspire for great accomplishment (68).

Growing up in a country with a long history, rich and varied cultural heritage, and in families with strong spiritual and religious milieu and a patriarchal mindset, can affect the aspirations and dreams of an Indian woman. Most of them have their destinies already laid down for them and immigration to another country likely occurs through marriage alliance which is usually fixed by families, although now there are increasing number of unmarried young women migrating for higher education and employment. These women try and adapt themselves to the country of resettlement but still retain the aspects of the culture they are born with. It is seen that immigrants are healthier on arrival to the United States than residents, but the longer same immigrants live there more this health advantage declines which is attributed to the structural stress that results from lack of assimilation within the society and the subsequent lack of acculturation (71). Mental health issues in migrants are recognized, including the challenges faced because of language and cultural differences; the effect of culture and society in shaping of symptoms and illness behaviour on diagnosis, coping and treatment; effect of employment, social status and integration, differences in family structure and process affecting adaptation, acculturation and intergenerational conflict (72, 73).

Culture which, an individual attains as a result of interaction between personalities and settings, has shared elements and can be transmitted across time and generations (74). Studies have shown that culture influences an individual's communication, decision making related to life, health care and self-care practices and that conventions, beliefs, rituals, and behaviours can become more apparent when people face significant illness and end-of-life decisions (75, 76). So the care offered to individuals should be culturally congruent and ideally should be offered by health care professionals who recognise their own culture and boundaries (76). The physiological and behavioural outcomes in patients who do not receive care that incorporates their cultural beliefs can be studied under the framework of 'cultural distress' (77) which can contribute to heightened sickness behaviours (78).

1.9 Summary

Breast cancer is a common cancer and psychological distress is common in the groups of women with breast cancer who have been studied. We know that cultural background has an impact on the patient's experience and psychological response to their disease and treatment. The ancient and rich culture of India has developed over the years with influences from various religions, rulers, caste system reflecting a strong patriarchal family structure. The culture can potentially travel with the person and may thereby affect the responses and behaviours of migrant women anywhere in the world. It is therefore important to understand this in order to appreciate why women behave as they do.

We know something about Asian women who are immigrants in western cultures, but there is a gap in knowledge about how this affects women treated in the Indian subcontinent. It is important to know because a) if they are distressed and need support, then there are interventions and services, including palliative care services, which may help them and b) distress can affect compliance with treatment – the distress aggravated by still-prevalent incorrect beliefs about cancer. Hence, there is a need to gather more information on this important aspect of management of breast cancer in the Indian subcontinent to reduce this distress, improve their holistic care in India and abroad and ensure better compliance with treatment. This thesis will focus on the concerns of women undergoing treatment as a first step, recognising that women "beyond" treatment may have different or additional concerns in relation to more imminent end-of-life (those with advanced disease) or fear of recurrence (those in remission).

2 AIMS AND OBJECTIVES

2.1 Introduction

Chapter 1 gave a summary of the psychological symptoms faced by breast cancer patients all over the world as well as the lack of data from patients of Indian origin in a scoping search. It also showed how the culture can influence the cancer care experiences of migrants of different countries. I have also described how the ancient and rich culture of India has changed over the years but still retain the strong patriarchy and family values which could influence the decision-making capability of Indian women around the world. This chapter will describe the overarching research aim and questions that are addressed in this thesis.

2.2 Overarching research aim

The overarching research aim is to improve the knowledge and our understanding of the psychological concerns among women of Indian heritage with breast cancer receiving treatment and what helps to relieve or worsen these concerns. In addition, I also aimed to explore the cultural context within which Indian women receiving treatment for breast cancer living in India experience the psychological concerns, and its impact. The purpose of this inquiry is to help in developing support services and comprehensive care tailored to their needs.

The focus is on women undergoing treatment as a first step in filling this large gap in knowledge within the scope of a PhD. I recognise that women beyond treatment, both with or without active disease, are likely to have significant psychological concerns too, many of which will be common to those on treatment, but some of which will be a result of their different disease and treatment status and aim of care.

The area of interest, psychological concerns, is broad and beyond diagnosed mental health conditions recognising that impact on mental wellbeing is likely to be wider than only problems meeting diagnostic criteria for e.g., depression.

2.3 Research questions

The questions arising from the research aims are

1. What are the psychological concerns of women of Indian heritage with breast cancer receiving treatment, in relation to the diagnosis and its treatment?

2. What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?

2.4 Objectives

1) To understand what is already known about the psychological concerns of women of Indian heritage with breast cancer living anywhere in the world.
2) To explore the experience of distress/suffering in Indian women with breast cancer living in India with special focus on patients undergoing treatment.
3) To investigate the cultural context in which Indian women with breast cancer experience their disease and treatment through understanding the general awareness of healthy volunteers of the impact of breast cancer on Indian women in the community.
4) To understand the factors which aggravate or ameliorate (including solutions to address or prevent) the psychological concerns including those arising from their Indian cultural context.

In order to achieve this aim, I used a multiple methods approach, which includes mixed-methods systematic literature review (quantitative and qualitative data with synthesis) followed by qualitative studies (individual interviews with patients; focus groups of clinicians and lay people) with final synthesis of all findings. The philosophical and theoretical approaches, with their rationale for use, are given in **Chapter 3.** The rationale for the methods used is detailed in the relevant chapters.

The three studies used to answer the thesis’ questions are:

1. Systematic literature review of the psychological concerns in relation to breast cancer treatment of Indian women living anywhere in the world. Data synthesis occurred in two steps; i) narrative synthesis will be applied to the quantitative data, and thematic synthesis applied to the qualitative data, ii) a modified critical

interpretative synthesis will be used to bring together the findings from each component.

2. Qualitative interview study of Indian women living in India undergoing breast cancer treatment in one hospital setting in South India.
3. Focus group discussions with health care professionals, community volunteers and members of the public in one setting in South India.

Although ideally, the studies would have been performed sequentially, with the interview and focus group study designs and analyses being informed by the findings of the systematic review, I was unable to do this due to constraints around data collection opportunities in India (during my year out of training program in Yorkshire, UK). This meant that interview data collection was concurrent with the systematic review, and the focus group study design needed to be complete prior to the interview data analysis.

Once all studies were completed, the findings from each were synthesised to integrate the findings in relation to the overarching thesis's research questions. (Table 1)

Table 1 Summary of questions, aims and objectives by thesis component

Overarching aims	1. To improve the knowledge about, and our understanding of, the psychological concerns among women of Indian heritage with breast cancer receiving treatment and what helps to relieve or worsen these concerns. The psychological concerns will be explored with regard to their prevalence, breadth and impact. 2. To explore the cultural context within which Indian women receiving treatment for breast cancer living in India experience the psychological concerns, and its impact	
Thesis Component	Research Questions	Objectives
Thesis	1. What are the psychological concerns of women of Indian heritage receiving treatment for breast cancer in relation to breast cancer and its treatment? 2. What are the influences which aggravate or	1) To understand what is already known about the psychological concerns of Indian women with breast cancer living anywhere in the world. 2) To explore the experience of distress/suffering in Indian women with breast cancer living in India with special focus on patients undergoing treatment. 3) To investigate the cultural context in which Indian women with breast cancer experience their disease and treatment through understanding the general awareness of healthy volunteers of the

	ameliorate these psychological concerns including those arising from their Indian cultural context?	impact of breast cancer on Indian women in the community. 4) To understand the factors which aggravate or ameliorate (including solutions to address or prevent) the psychological concerns including those arising from their Indian cultural context?
Mixed-methods Systematic Review	1 What are the psychological concerns of women of Indian heritage receiving treatment for breast cancer in relation to breast cancer and its treatment? 2 What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?	1 To determine the psychological concerns of women of Indian heritage living anywhere in the world in relation to breast cancer treatment in terms of their prevalence, breadth and intensity. 2 To find out the factors which influence the psychological concerns both positively and negatively.

Qualitative interviews	What are the psychological concerns of Indian women with breast cancer living in India, in relation to breast cancer and its treatment? What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?	1 To understand the psychological concerns of Indian women with breast cancer living in India and during treatment. 2 To find out the factors which influence the psychological concerns both positively and negatively.
Qualitative focus groups	1 What is the cultural context in which Indian women living in India experience the disease and treatment?	1) To investigate the cultural context in which Indian women with breast cancer experience their disease and treatment through understanding the general awareness of healthy volunteers of the impact of breast cancer on Indian women in the community.

2.5 Summary

The overarching aim of the thesis is to explore the psychological concerns of Indian women with breast cancer and the factors which affect these concerns. A multiple methods study design is used which includes a systematic literature review of qualitative and quantitative data (**Chapter 4**), a qualitative interview study among women with breast cancer (**Chapter 5)** and a qualitative focus group study among health care professionals and members of the public **(Chapter 6)** with a final synthesis of findings **(Chapter 7).**

3 METHODOLOGY

3.1 Introduction

Chapter 1 gave a summary of the psychological symptoms faced by breast cancer patients all over the world as well as the lack of data from patients of Indian heritage found in a scoping search. It also showed how the culture can influence the cancer care experiences of migrants of different countries. I have also described how the ancient and rich culture of India has changed over the years but still retain the strong patriarchy and family values which could influence the decision-making capability of Indian women around the world.

In **Chapter 2,** I described the overarching research aim and questions that are addressed in this thesis.

This chapter explains rationale for the methodology used to answer each of the research questions of the thesis which are as below.

The research questions are:

1. What are the psychological concerns of women of Indian heritage receiving treatment for breast cancer in relation to breast cancer and its treatment?
2. What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?

Three study designs have been used to answer both questions:

1. Systematic literature review of the psychological concerns of Indian women in relation to breast cancer treatment living anywhere in the world.
2. Qualitative interview study of Indian women living in India undergoing breast cancer treatment.
3. Focus group discussions among health care professionals, community volunteers and representative members of the public.

From the literature review, it was clear there were very few qualitative data from Indian women living in India and from Indian health professionals and none from the Indian lay public. Therefore, studies two and three were important to address this significant gap.

3.2 Design approaches used in this thesis

There are two types of research strategies generally used in health and social research: quantitative and qualitative. Quantitative research is generally construed as a research strategy that highlights quantification in gathering and evaluation of data. It mostly places importance on testing of theories and involves a logical approach to the connection between theory and research. It incorporates the practices and norms of the natural scientific model and of positivism in particular; and represents a view of existence as an external, objective and discoverable reality (79).

Qualitative research is concerned with the meanings people attach to their experiences of the social world and how they make sense of the world. It tends to study people in their natural settings and in their own territory (80). It recognises 'the intimate relationship between the researcher and what is studied' (81).

3.3 Theoretical perspective

Qualitative research has an important role in both forming new theory and modifying existing theory. Although my aim was not to form new theory (using established theory), my research could develop theory depending on findings, or at least show its relevance in my study population. The theoretical perspective which formed the basis of the research is symbolic interactionism (82). Symbolic interactionism describes how human beings act towards things and another on the basis of the meanings they have for them; the meaning arises from the social interaction they have with fellow human beings. Furthermore these meanings are affected by the interpretive process which is used by the person in dealing with the entities he or she encounters (83). The view originated in the mid-twentieth century from a number of influences, including Scottish moralist and American pragmatist philosophers. The greatest of this perspective was from the American philosopher George Herbert Mead (1934) and his theories about the relationship between self and society (82). Denzin describes it as a 'tough-minded respect for the reality of the world of experience' (84). According to symbolic interactionism, the primary mode of communication of individuals with others is through language and symbols and it is induced both by phenomenology and more immediately by the pragmatism (85). They pay attention to interpretation of subjective viewpoints and how they make sense of their world from their own unique perspective as opposed to how social institutions define and impact individuals (82). This concept was further extended by Snow, in 2001, to four major categories: the principle of interactive resolve, the principle of symbolization, the principle of emergence, and the principle of human agency (86). The dominant positivist approach usually tends to examine society from top down and how the macro-level institutions and social structures affect the individuals while symbolic interactionists believe that individuals act based on the meanings objects have for them. This is the first basic assumption regarding the theory, underlying which is the presumption that the world exists separate and apart from the individual, but that the world is interpreted through the use of symbols (language) in the process of interaction. The second assumption is that meaning for an individual emerges out of the ways in which other individuals act to define things and thirdly meanings are allocated and adjusted through an informative process that is ever changing, subject to redefinition, rearrangement and manipulations (87). There are a number of studies in breast cancer where symbolic interactionism has been previously used as a theoretical perspective. Symbolic interactionism used to build a theoretical model on the experience and meaning of the breast reconstruction process in women with breast cancer has helped us to understand how women overcome difficulties, value their life, develop self-care and face life with courage and faith (88). It has been used to interpret the different meanings women assign to radiotherapy, which is an important modality of treatment for breast cancer, and to ascertain if women modify their behaviour if the meaning changes for them. Women often work through their predetermined ideas, pursue additional information and experience radiotherapy for themselves before they change their behaviour and approaches to radiotherapy. These findings can guide health care workers to foresee and listen to women’s fears, and provide information to address these fears at each consultation (89).

3.4 Epistemological position

All theoretical perspectives are influenced by epistemology. 'Epistemology' is concerned with ways of knowing and learning about the social world and focuses on questions such as: how can we know about reality and what is the basis of our knowledge?(90). The preferred epistemological view taken by me to answer the research questions is interpretivism in which the researcher and the social world impact on each other’s facts and values. As the findings are liable to be influenced by the researcher’s thoughts and values, it is unlikely that impartial, value free research can be conducted, although I can declare and be transparent about my conclusions. Interpretivism is a term that has traditionally been defined as an alternative to the positivist convention. Positivists believe that social phenomena can be studied only by methods used in the natural sciences and that knowledge develops inductively through the gathering of confirmed, observable (and therefore countable) facts (90). In this thesis, I needed an approach that helped me to understand the subjective, rather than objective, meaning of social action (79). Interpretivists argue that social reality can be described in a variety of ways all of which are valid. Reality is made up of these interpretive process and the aim is to describe and recreate these evolutions and change them into scientific explanations of social phenomenon (91). In my study, I am talking to participants and asking them to describe their experiences which are later analysed and given meaning by me, although I have not directly observed them, hence I have used interpretivism is my preferred epistemological position.

The way I have applied these approaches to my thesis studies are detailed in Chapters 4, 5 and 6.

3.5 Other theories used in the thesis

A theoretical framework of cultural distress was used to inform the analytical themes and final discussion (77) of systematic literature review and qualitative interview study . There are various ways to define culture but any definition should incorporate three main components: (1) culture is the product of the interaction between humans and environments, (2) culture consists of shared elements, and (3) culture is transmitted across time and generations (74). Cultural distress can be defined as an undesirable response embeddeded in a cultural conflict in which the patient lacks control over the environment and the practices taking place in the patient–provider encounter and can affect the patient in physiological and social ways. This framework identifies that cultural distress is experienced when patients receive care which does not consider their beliefs and whether they experienced ‘otherness’.

The combined synthesis of the findings pertaining to the research question from both quantitative and qualitative studies was conducted using a modified critical interpretive synthesis approach (92). This is an inductive approach to create an overarching theory by integrating different theoretical categories, that is, to interpret the findings from diverse methods rather than merely aggregating them (93). In the focus group discussion, though my data collection did not use a framework, the data analysis was influenced by a theoretical framework of 'cultural task analysis' (94) which talks about how the various tasks responsibilities that are generated, gathered and passed on to generations can influence the decision making process of the individual. The encounter with the culture of an individual starts very early in life as part of socialisation and the resulting psychological tendencies become routine and part of life. The cultural mandates can vary according to what the person is exposed to, it can either be independent as in Western culture or dependent on others as commonly seen in the East. This difference in the mandate can influence various aspects of psychological processes (95, 96).

3.6 Summary

In this chapter, I have described and justified the methodologies used in my thesis. The overarching theoretical framework used is 'symbolic interactionism' with interpretivism as the preferred epistemological position. In addition, a theoretical framework of cultural distress was used in the analysis of systematic literature review and semi structured interview study while 'cultural task analysis' was used to analyse the focus group data. The research questions are:

What are the psychological concerns of women of Indian heritage receiving treatment for breast cancer in relation to breast cancer and its treatment?', and 'What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?' The data collection was through systematic literature review, interview study and focus group discussion.

The next chapter (**Chapter 4**) will present the systematic literature review.

4 PSYCHOLOGICAL CONCERNS OF INDIAN WOMEN WITH BREAST CANCER IN DIFFERENT NATIONAL CONTEXTS: A SYSTEMATIC REVIEW AND MIXED-METHODS SYNTHESIS

4.1 Introduction

Chapter 1 gave a summary of the psychological symptoms faced by breast cancer patients all over the world as well as the lack of data from patients of Indian heritage in a scoping search. It also showed how the culture can influence the cancer care experiences of migrants of different countries. I also described how the ancient and rich culture of India has changed over the years but still retain the strong patriarchy and family values which could influence the decision-making capability of Indian women around the world. In **Chapter 2** I described the overarching research aim and questions that are addressed in this thesis. **Chapter 3** described the methodology chosen to answer the research questions posed in this thesis. This chapter presents the methods used, the findings and a discussion of the findings from the systematic review and mixed method synthesis to answer the research questions:

What are the psychological concerns of women of Indian heritage receiving treatment for breast cancer in relation to breast cancer and its treatment? The psychological concerns will be explored with regard to their prevalence, breadth and impact.

What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?

4.2 Rationale for using systematic Literature review methodology

My systematic literature review aimed to answer the question, what are the psychological concerns of women of Indian heritage receiving treatment for breast cancer in relation to breast cancer and its treatment? To gather pertinent information from a large amount of available data, I needed an approach to efficiently combine information. There are a number of studies done on psychological symptoms of breast cancer patients either during treatment or who are on follow up as well as patients from various ethnicities. The focus of the review was to understand what is identified in literature about the psychological symptoms of Indian women with breast cancer living anywhere in the world who are currently undergoing treatment or who has had treatment in the past. The review was conducted in accordance with the Centre for Reviews and Dissemination (97). A systematic review is a synthesis of available research literature on a given topic, designed so that the data incorporated are obtained and analysed in a structured, transparent and reproducible manner (98-100). It includes a clearly stated set of objectives with pre-defined eligibility criteria for studies with a lucid and reproducible methodology. The search strategy attempts to identify all studies that would meet the eligibility criteria; there is a rigorous assessment of the validity of the findings of the included studies, and a systematic presentation and synthesis, of the characteristics and findings of the included studies (100). The advantages of using a systematic literature review for the purpose of the study are consistency and generalisability of findings, limitation of bias and processing of large quantity of data into manageable segments (97, 98). Systematic reviews conducted in accordance with a written protocol before the beginning of review will reduce the likelihood of reporting bias, while searching all the available data base including clinical trial registries, regulatory agency websites, and conference abstracts will reduce the incidence of publication bias (101). Also, adopting a broad search strategy, predefined search terms and uniformity in inclusion and exclusion criteria, would enable me to include studies beyond my own subject areas and networks thereby reducing my bias (102). The search resulted in both observational study designs and qualitative studies. Observational studies are types of analytic studies which attempts to quantify the relationship between two factors, that is, the effect of an intervention or exposure on an outcome. Analytical studies can be experimental and observational (103, 104). Well-designed observational studies which are considered as level 2 or 3 in hierarchy of evidence are now considered comparable to randomised controlled trials as far as results are considered (105, 106). Observational studies are divided into three main types; cohort, case control and cross-sectional studies. Cross sectional studies are prospective, case control studies are retrospective and cohort studies can be either prospective or retrospective (104). Cohort studies examine multiple outcomes for a given exposure as well as rare exposure, assess causality and rates, but could be susceptible to selection bias and require long durations for follow up which makes them more expensive. Case control studies are good for examining rare outcomes, as well as multiple exposures, are quick and inexpensive to conduct but could potentially have recall bias (104).

4.3 Review objectives

4.3.1 Primary objective

To determine the psychological concerns of Indian women in relation to breast cancer treatment in terms of their prevalence, breadth and intensity.

4.3.2 Secondary objective

To find out the factors which influence the psychological concerns both positively and negatively.

4.4 Systematic literature review method

4.4.1 Eligibility criteria for selecting studies

Both qualitative and quantitative studies which explored psychological distress in Indian women with breast cancer were eligible. In the quantitative studies, studies including screening tools or severity measures of anxiety (all types e.g., generalised anxiety disorder, panic etc.) and/or depression mental health disorders, or which included quality of life tools which had a mental health component. The inclusion and exclusion criteria are described in Table 2.

Table 2 Eligibility criteria for selecting studies

	Inclusion criteria	**Exclusion criteria**
Type of study/ design	Qualitative studies were included. Quantitative observational studies reporting measures of psychological concerns were included.	Single case history reports (unless using accepted qualitative methodology), reviews and opinion pieces were excluded. Experimental or quasi-experimental studies and conference abstracts are excluded.
Types of participants	Studies including adult breast cancer patients of Indian heritage living within and outside the Indian subcontinent were considered. Studies of patients who were currently undergoing	Studies of male breast cancer patients or children were excluded.

	Inclusion criteria	**Exclusion criteria**
	treatment and those who had undergone treatment in the past were included.	
Type of Exposure	Studies including all modalities of treatment for breast cancer i.e. surgery, chemotherapy and radiotherapy were included. There was no limit in the time since treatment.	Studies of effects of treatment for other primary tumours. If breast cancer patients were included in a study along with other primary tumour types, the study was excluded unless the data pertaining to the breast cancer patients could be extracted.
Outcome measures	Studies which described or measured the psychological concerns of the study participants.	Studies reporting physical adverse outcomes only were excluded. For example, a study reporting chemotherapy induced nausea and vomiting or hair loss would be excluded unless the study measured psychological distress in relation to this. That is, the study was excluded if it only reported severity and prevalence of this side-effect of treatment.

4.4.2 Search Methods

4.4.2.1 Search strategy

The following databases were searched, current at 7 May 2019:

MEDLINE: 1946 to 7 May 2019; Ovid EMBASE: 1974 to 7 May 2019; EBSCO; CINAHL: 1981 to 7 May 2019; Proquest; PsycINFO: 1806 to 7 May 2019.

The search terms were developed in conjunction with Ms Jenny Makeham, librarian at Leeds Teaching Hospitals NHS Trust. The search terms were developed to specifically look for studies among Indian patients conducted both in the country and outside the Indian subcontinent. I used both free text and thesaurus matching and UK and US spelling for all searching and included all possible years and was tailored to each database.

The EBSCO host discovery science database was also searched (EBSCO Discovery service (EDS) 2001 to December 2017) after consulting with Ms Indira Nair, librarian at Amrita Institute of Medical Sciences and research centre. These contributed additional papers from Indian journals not accessible from the other databases.

Table 3: shows the search strategy and the search string for searching in Ovid MEDLINE. This search was adapted to use in the other databases.

Search area	**Terms with Boolean operator**	**Dates for database**	**Medline Hits**
Population A	("breast cancer").ti,ab OR ("breast malignancy").ti,ab OR ("breast lump *").ti,ab OR ("breast neoplasm*").ti,ab OR ("breast tum*").ti,ab OR (carcinoma ADJ3 breast*).ti,ab OR exp "BREAST CANCER"	1946 to 15 February 2017	318131
Population B	(Asian*).ti,ab OR (indian*).ti,ab OR INDIAN/		121772
Intervention C	(radiotherap*).ti,ab OR (radiat*).ti,ab OR ("radiation oncology").ti,ab OR (chemoth*).ti,ab OR (treatment*).ti,ab OR (surgery).ti,ab OR (mastectomy).ti,ab OR (lumpectomy).ti,ab OR exp RADIOTHERAPY / OR "RADIA TION ONCOLOGY" / OR exp"DRUG THERAPY" / OR exp MASTECTOMY/		5085660
Outcome D	("hair loss").ti,ab OR (anxiety).ti,ab OR (depression).ti,ab OR(lymphed*).ti,ab OR (lymphoed*).ti,ab OR ("body image ").ti,ab OR (psycholo*).ti,ab OR (suffering).ti,ab OR (distress).ti,ab OR ("body image ").ti,ab OR		2370716

Search area	**Terms with Boolean operator**	**Dates for database**	**Medline Hits**
	(psycholo*).ti,ab OR ("physical symptom*").ti,ab OR (pain).ti,ab OR (edema*).ti,ab OR (oedema*).ti,ab OR ("hair loss").ti,ab OR (anxiety).ti,ab OR (depression).ti,ab OR (lymphed*).ti,ab OR (lymphoed*).ti,ab OR ("hair loss").ti,ab OR (anxiety).ti,ab OR (lymphed*).ti,ab OR (lymphoed*).ti,ab OR (alopecia).ti,ab OR (depression).ti,ab OR (lymphed*).ti,ab OR (lymphoed*).ti,ab OR "DISTRESS SYNDROME"/ OR "BODY IMAGE" / OR exp PAIN/ OR exp EDEMA/ OR exp ALOPECIA/ OR ANXIETY / OR exp DEPRESSION/ OR exp L YMPHEDEMA/		
Limits	Remove duplicates Adult English		
Strategy	E= A and B and C and D		136
	Searches E will have titles and abstracts assessed for retrieval of papers		

The initial search was limited to English language articles. A further search done, specifically looking for papers in the regional languages available in various databases like Hindi, Bengali, Malayalam, Punjabi, Sanskrit, Marathi and Urdu, did not result in any additional results. Reference sections of relevant review articles and included studies were also scanned to identify additional eligible studies.

4.4.2.2 Study selection

The search strategy was repeated in other databases and results combined after removal of duplicates. Two reviewers were involved in all stages of study selection and independently reviewed the title and abstract and, where necessary from full papers retrieved. This was myself and another researcher from the Wolfson Palliative Care research centre at Hull York Medical School (Joseph Clark (JC)). Any discrepancy was finalised after discussion with a third researcher (Miriam Johnson (MJ)). A full text copy was obtained for all included studies, or if there was insufficient information for exclusion at this stage. Two studies did not have full text online; paper copies were retrieved after contacting DELNET via the librarian. Results of all the searches were collated using Endnote basic reference management software and duplicate reports deleted. The plan was to contact original authors if any further information was required to make decision, or in the event of missing key information such as missing data or if the full text was missing. The PRISMA (preferred reporting items for systematic reviews and meta-analyses) flow chart (Figure 1) shows the selection process for included studies (107). Excluded studies were recorded in a table in Appendix 1 with reason(s) for exclusion.

4.4.3 Data extraction plans

The data extraction tool was developed based on Table 7.3 of chapter 7 of Cochrane Handbook Checklist of items to consider in data collection or data extraction (108). Data from the included studies were added to a data extraction form and a separate table was developed for quantitative and qualitative studies and piloted in two studies. Data were independently extracted with the help of another researcher (Sam Gnanapragasam(SG)) from the research centre.

4.4.4 Quality appraisal

Observational studies were appraised using the **St**rengthening the **R**eporting of **Ob**servational studies in **E**pidemiology (STROBE) checklist (109) (Table 6). Although this is designed as a reporting rather than an appraisal tool, it was felt that this approach helped identify both inadequate reporting of methods and areas of bias in the design where it was reported.

Qualitative studies were appraised using the **C**ritical **A**ppraisals **S**kills **P**rogramme (CASP) (See Table 7) checklist for qualitative studies (110). Findings were tabulated to demonstrate the key strengths and weaknesses in study design.

4.4.5 Data analysis

The various approaches to the synthesis of qualitative and quantitative evidence include narrative synthesis, qualitative approaches , quantitative approaches, Bayesian approaches, (111) while qualitative data alone can be synthesised using meta-ethnography, critical interpretive synthesis, thematic synthesis, realist review and meta-aggregation (112). Narrative synthesis, which uses words and texts to summarise and explain the findings of the review was used to analyse the quantitative data. It generates new insights and knowledge using systematic and transparent methods (111). It follows a four step process which includes developing a theory, and preliminary synthesis, exploring relationship within and between studies and assess the strength of the synthesis (97).

The qualitative studies were analysed using thematic analysis (113) which is a three step process which includes the line-by-line coding of the findings of primary studies; the organisation of these codes into related areas to build illustrative themes and the elaboration of analytical themes. The quotes from individual participants as well as researcher were coded separately and then themes were developed. Both inductive (allowing themes to arise from specific observations) and deductive (working within existing knowledge about the psychosocial impact of breast cancer, looking specifically within our data for similarities and differences) processes were involved (114).

Quantitative data were described, tabulating design, participants and main findings and then the findings were brought together in a narrative synthesis summarising and exploring relationships between and within studies along with quality appraisal of the robustness of the findings (97). Qualitative data were subjected to thematic synthesis to form generalizable findings whilst taking the context of each study into account (115). Direct quotes from patients and researcher comments on the findings were extracted for coding. After familiarising myself with the data I conducted line by line coding of the primary articles. A coding framework was formed following discussion with the supervisor, which was then used to code all qualitative papers. Descriptive and analytical themes were formed from the codes after discussion. Both inductive (allowing themes to arise from the specific observations) and deductive (working within existing knowledge about the psychosocial impact of breast cancer, looking specifically within our data for similarities and differences) processes were involved (114).

4.4.6 Theoretical framework

A theoretical framework (Cultural Distress) was used to inform the analytic themes and final discussion (77). This framework identifies that cultural distress is experienced when patients receive care which does not take into account their beliefs and is experienced as “otherness”. A critical interpretative synthesis approach was then used to identify and synthesise the findings pertaining to the research question from both quantitative and qualitative studies (92).

4.5 Findings

The literature search yielded 571 records; of which 20 studies met the inclusion criteria for this review (see Figure 1 PRISMA flow chart). Two papers were excluded in the final stage due to poor quality (116, 117).

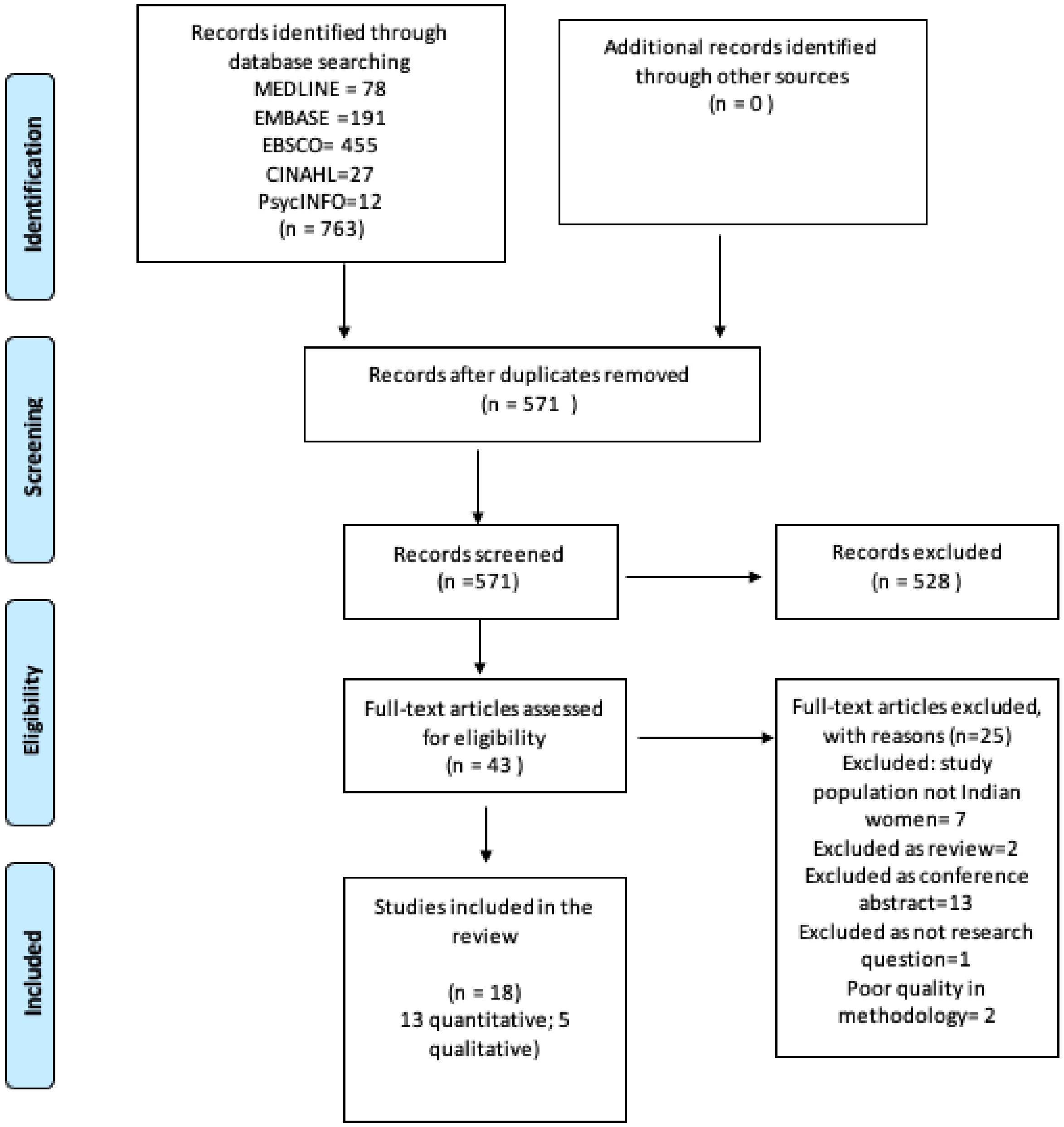

Figure 1: PRISMA flowchart of studies included in systematic review

4.5.1 Included papers

Out of the 18 papers, 13 (118-130) were observational quantitative and five were qualitative studies (131-135). Among the observational studies nine were cross sectional (119-126, 128), three were cohort (118, 127, 129) and one was matched case control (130).

The characteristics of included studies are summarised in table 4 and 5.

Table 4 Included studies: Quantitative studies

Reference/Authors **Country**	**Design**	**Aims**	**Measures**
PARMAR et al (2005) (118) India	Prospective Cohort	To assess the validity of EORTC QLQ C30 and BR 23 in Indian breast cancer patients	(EORTC QLQ-C30); BR 23
Kaur et al (2014) (119) India	Descriptive cross-sectional study	Investigate the QOL in patients of breast cancer beyond the 1st year of their treatment and to identify their specific information and rehabilitation needs. Patients were divided into 3 groups according to duration of follow up.	(FACT-B) version 4
Shah etal (2010) (120) India	Cross-sectional study	To assess the QoL of patients of carcinoma breast and to ascertain pitfalls and make suitable correction for future studies on Indian patients	QoL four-part questionnaire: Part 1 and 2 = Physical in capacitance Part 3 and 4 = Emotional and psychological

Reference/Authors **Country**	**Design**	**Aims**	**Measures**
			impairment
Pandey etal (2005) (121) India	Cross sectional	To identify the determinants of QOL of Indian women with breast cancer treated with curative intent.	(FACT-B)
Mahapatro etal (2005) (122) India	Cross-sectional study	To explore the various concerns, coping mechanisms and body image disturbances and extent of resolution of concerns as well as to study the level of anxiety and depression in mastectomized and lumpectomized patients.	Concern and Coping Checklist by Devlen Hospital Anxiety and Depression Scale
Carlson etal (2013) (123) Canada	Cross sectional Survey	Further explore and confirm findings from the qualitative phase by gaining deeper insight into a larger and more diverse group of south Asian women. Better understand the content and format preferences of those women for a survivorship care plan.	Survey developed and validated with white breast cancer survivors at the BCCA Vancouver Island Cancer Centre questionnaire consisted

Reference/Authors **Country**	**Design**	**Aims**	**Measures**
			of 27 questions
Purkayastha etal (2017) (124) India	Cross-sectional Study	To study the prevalence of depression among breast cancer patients undergoing treatment and to correlate its association with their QOL	Patient Health Questionnaire (PHQ-9) WHOQOL-BREF for quality of life
Dubashi etal (2010) (125) India	Cross-sectional Study	To describe the QOL among breast cancer women with age less than or equal to 35 years at the time of diagnosis. To determine the contribution of sociodemographic, medical, and psychosocial factors on the QOL. To study the impact of breast conservation treatment and mastectomy on the QOL	EORTC module QLQ – C30 and the BR 23 Questionnaire.
Tripathi etal (2017) (126) India	Cross-sectional study	To assess the perceived stigma and its associations with sociodemographic, affective symptoms, and treatment-related issues in women following surgery for breast cancer.	Hospital Anxiety and Depression Scale (HADS) Body Image After Breast Cancer Questionnaire
Brahmbhatt etal	Cohort study	To evaluate psychosocial status of patients who underwent surgery	GHQ-28 and HADS

Reference/Authors **Country**	**Design**	**Aims**	**Measures**
(2012) (127) India		for cancer.	
Chintamani etal (2011) (128) India	Cross-sectional study	Aim of assessing the levels of anxiety and depression in breast cancer patients in the Indian scenario and to correlate these levels with response to neoadjuvant chemotherapy	Hospital Anxiety and Depression Scale (HADS)
Damodar etal (2014) (129) India	Cohort	To evaluate the QOL and affecting factors on it among south Indian cancer patients	EORTC QLQ-C30 EORTC QLQ-BR23
Singh etal (2015) (130) India	Case control	Approximate the depression, anxiety, and stress (DAS) levels in homogenous surviving cancer patients receiving chemotherapy as compared to normal control. To correlate the primary objective with different demographical parameter such as age, gender, duration of cancer diagnosis, chemotherapy cycles, cancer types, etc.	Depression Anxiety and Stress scale (DASS-21)

EORTC QLQ C30: European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire-Core 30; **BR23:** Breast cancer specific module; **QOL :**quality of life; **BCT** :Breast conservation treatment; **MRM**: Modified Radical Mastectomy ; **FACT-B** :Functional Assessment of Cancer Therapy- Breast; **BCCA** : Breast Cancer Care Agency ;**PHQ-9**: Patient Health Questionnaire; **WHOQOL-BREF** :World Health Organization Quality of Life Instruments; **HADS:** Hospital Anxiety and Depression Scale; **GHQ-28** :General Health Questionnaire; **PWB**: Physical well-being; **SWB:** Social well-being; **FWB**: Functional well-being; **EWB** :Emotional well-being; **RT:** Radiotherapy; **BCS**; Breast Conservation Surgery;

Table 5: Included studies: Qualitative

Reference/ **Authors** **Country**	**Aims**	**Data collection**	**Results Summary**
Gurm etal (2006) (131) Canada	To understand the experience of Canadian Punjabi speaking South Asian women in order to inform health care practices.	**Methodology** Inductive and deductive process of analysis **Data collection** Focus group methodology	Two themes expressed by all women: Spiritual beliefs as dominant context for understanding cancer Distress at diagnosis. Other themes: patient inclusion, family systems, emotional expression
Barthakur etal (2017) (132)	To understand breast cancer survivorship trajectory from an Indian	**Methodology** Descriptive	**Body image:** Impact on identity, surgery-related issues, hair

Reference/ **Authors** **Country**	**Aims**	**Data collection**	**Results Summary**
India	perspective and to understand the impact of the diagnosis of breast cancer and its treatment on body image and sexuality issues	phenomenological approach. **Data collection** semi-structured interview	loss, adjustments to clothing, and encountering difficult situations. **Sexuality** changes due to the treatment, partner's challenges and adjustments made, and attitudes held toward sexuality
Howard etal (2007) (133) Canada	To explore women's stories of breast cancer in order to uncover how they made sense of their experiences	**Methodology** Narrative analysis **Data collection** In-depth Interviews	Four storylines that emerged were: Getting through a family crisis, dealing with just another health problem, living with never-ending fear and suffering, and learning a ''lesson from God.'' A minor theme: Breast Cancer as a Family Experience
Carlson etal (2013)	To explore the experiences and concerns of female south Asian breast	**Methodology**	**Universal Themes**

Reference/ **Authors** **Country**	**Aims**	**Data collection**	**Results Summary**
(134) Canada	cancer survivors after treatment, to determine their understanding of follow- up care and to better understand their preferences for the content of a care plan. To understand the influence of age, social situation and culture affect the experiences of SA BCSS after treatment, especially as they transition from oncology to community care.	Thematic and content analysis. **Data collection** Focus group and one to one interview	***Physical Impacts****:* Fatigue, Cognitive change, Loss of libido Nerve damage and pain Reproductive or pregnancy issues **Psychosocial impact:** Body image, sexuality Depression Fear of recurrence and uncertainty Intimacy and relationships **Unique to South Asian women** Quiet acceptance Peer support
Nyblade et al (2017) (135)	To explore the cause and manifestation of Stigma in breast	**Methodology** Thematic analysis	The three major themes were **Drivers** (causes) of stigma including cancer as

Reference/ **Authors** **Country**	**Aims**	**Data collection**	**Results Summary**
India	cancer patients.	**Data collection** In-depth interviews	contagious, punishment death sentence; the **manifestations** of stigma described, Isolation, Verbal Abuse, Harassment, loss of employment, reduced marriage prospects and the **consequences** that follow stigma.

SA BCSS: South Asian Breast Cancer Survivor

4.5.2 Quality appraisal

Almost all the quantitative studies showed deficiencies in various aspects. The study design was not mentioned in the title or abstract in five papers (118, 120, 121, 125, 128). Singh *et al* described their study as a cross-sectional study but from the description of methods it appeared to be a matched case control (130). There were missing details of study settings (121, 126, 128), and potential sources of bias (119, 121-129), which was acknowledged as a limitation in only one study (124). Only two (123, 124) papers gave a rationale for sample size, seven (118-121, 123, 126, 128) explained how missing data were handled, but detailed description of participant selection was provided by only three studies (123-125).

Two quantitative studies (116, 117) were considered to be of such high risk of bias due to design problems, that they were excluded from analysis. These two studies scored poorly in quality appraisal, and poor design issues included use of non-validated tools, deficiencies in sample selection. Conclusions were not supported by the study findings and quantitative analysis of qualitative data was reported.

Among the qualitative studies, four of the five studies were of high quality. One study (132) was found to be of low quality in various aspects including poor methods, lack of clear research aims, thereby making it impossible to see whether these have been achieved. Though there were some interesting data from the qualitative interviews, the implications of the findings were not satisfactorily discussed. The detailed reporting is given in table 6 and table 7.

Table 6: STROBE analysis

Paper		Carlson etal [24]	Mahapatro etal (122)	Purkayastha etal (124)	Dubashi etal (125)	Pandey etal (121)	Brahmbhatt etal (127)	Chintamani etal (128)	Tripathi etal (126)	Shah etal (120)	Damodar etal (129)	Parmar etal (118)	Kaur etal (119))	Singh etal (130)
Introduction														
Background/ rationale	Scientific background	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Objectives	Specific objectives,	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Methods														
Study Design	Study design early in the paper	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Setting	Setting	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Participants	Eligibility criteria	Yes	Yes	Yes	Yes	UC	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Variables	Define all outcomes, exposures	Yes	UC	Yes	UC	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Paper		Carlson etal [24]	Mahapatro etal (122)	Purkayastha etal (124)	Dubashi etal (125)	Pandey etal (121)	Brahmbhatt etal (127)	Chintamani etal (128)	Tripathi etal (126)	Shah etal (120)	Damodar etal (129)	Parmar etal (118)	Kaur etal (119))	Singh etal (130)
Data sources/ measurement	Give sources of data	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bias	Efforts to address potential sources of bias	UC	UC	No	UC	UC	UC	No	No	Yes	No	Yes	No	No,
Study Size	how the study size was arrived at	No	UC	Yes	UC	No	No	No	No	No	No	No	No	No
Quantitative Variables	Quantitative variables were handled in the analyses	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	UC	Yes	UC
Statistical methods	All statistical methods	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Paper		Carlson etal [24]	Mahapatro etal (122)	Purkayastha etal (124)	Dubashi etal (125)	Pandey etal (121)	Brahmbhatt etal (127)	Chintamani etal (128)	Tripathi etal (126)	Shah etal (120)	Damodar etal (129)	Parmar etal (118)	Kaur etal (119))	Singh etal (130)
	Any methods used to examine subgroups and interactions	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Missing data	UC	UC	Yes	No	No	No	No	No	No	No	UC	No	No
	Sensitivity analyses	No	No	No	No	No	No	No	No	No	No	No	No	No
Results														
Participants	Numbers of individuals at each stage of study	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Reasons for non-	Yes	UC	Yes	UC	No	No	No	No	No	Yes	Yes	No	No

Paper		Carlson etal [24]	Mahapatro etal (122)	Purkayastha etal (124)	Dubashi etal (125)	Pandey etal (121)	Brahmbhatt etal (127)	Chintamani etal (128)	Tripathi etal (126)	Shah etal (120)	Damodar etal (129)	Parmar etal (118)	Kaur etal (119))	Singh etal (130)
	participation at each stage													
	Flow diagram	No	No	No	No	No	No	No	No	No	No	No	No	No
Descriptive Data	Characteristics of study participants	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Number of participants with missing data	No	No	No	No	No	No	No	No	No	No	No	No	No
Outcome Data	Numbers of outcome events	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Main Results	Unadjusted estimates and confounder-adjusted	No	Yes	N/A	Yes	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Paper		Carlson etal[24]	Mahapatro etal (122)	Purkayastha etal (124)	Dubashi etal (125)	Pandey etal (121)	Brahmbhatt etal (127)	Chintamani etal (128)	Tripathi etal (126)	Shah etal (120)	Damodar etal (129)	Parmar etal (118)	Kaur etal (119))	Singh etal (130)
	estimates													
	Report category boundaries	N/A	Yes	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Other analyses	Other analyses done	No	N/A	N/A	N/A	No	N/A	No	No	N/A	No	No	No	No
Discussion														
Key Results	Summarise key results	Yes	UC	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Limitations	Discuss limitations	Yes	No	Yes	No	No	No	No	Yes	No	No	No	No	Yes
Interpretation	Cautious overall interpretation	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Paper		Carlson etal [24]	Mahapatro etal (122)	Purkayastha etal (124)	Dubashi etal (125)	Pandey etal (121)	Brahmbhatt etal (127)	Chintamani etal (128)	Tripathi etal (126)	Shah etal (120)	Damodar etal (129)	Parmar etal (118)	Kaur etal (119))	Singh etal (130)
Generalisability	Generalisability (external validity)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Other Information														
Funding	Source of funding stated	yes	No	No	No	No	No	No	Yes	No	No	No	No	No

N/A Not Applicable UC Unclear

Table 7: CASP checklist for qualitative papers

Screening questions	**Gurm etal (131)**	**Howard etal (133)**	**Barthakur etal (132)**	**Carlson etal (134)**	**Nyblade etal (135)**
Was there a clear statement of the aims of the research?	Yes	Yes	Can't tell	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes
Is it worth continuing?	Yes	Yes	Yes	Yes	Yes
Was there research design appropriate to address the aims of the research?	Yes	Yes	Can't tell	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	No	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been	No	Yes	Can't tell	No	Yes

Screening questions	**Gurm etal (131)**	**Howard etal (133)**	**Barthakur etal (132)**	**Carlson etal (134)**	**Nyblade etal (135)**
adequately considered?					
Have ethical issues been taken into consideration??	Can't tell	Can't tell	No	Yes	Yes
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes
How valuable is this research?	Findings described in relation to relevant literature	First systematic exploration of immigrant Punjabi women’s experiences of breast cancer, further research needed	Discussed contribution to existing knowledge, new areas of research	Discussed contribution to existing knowledge, new areas of research	Discussed contribution to existing knowledge, new areas of research

4.5.3 Observational studies

4.5.3.1 Cohort studies

There were three prospective cohort studies which included psychological outcomes: body image, global quality of life**,** anxiety, depression (118, 127),physical function, role function, future perspective (129). One was a validation study of the European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire-Core 30 (EORTC QLQ -C30) and the breast cancer specific module (BR23) in Indian women (118). Among the other two studies, one evaluated the quality of life using the tools EORTC QLQ-C30 and BR23 (129), while the other used two tools General Health Questionnaire(GHQ-28) and Hospital Anxiety and Depression Scale (HADS)(127). The follow up of patients was for six months (127, 129)and three years (118).

4.5.3.2 Cross-sectional studies

Among the cross-sectional studies, three studies evaluated severity of anxiety and depression (122, 124, 128) and four studies analysed domains of quality of life like physical, social/family well-being, functional and emotional well-being (119, 121, 124, 125). The other measures evaluated included various somatic symptoms, and social dysfunctions like stigma, vulnerability, transparency, arm concern, body concern (126), dependency, invalidity, restriction and problems with chores, feelings, sadness and inner tension (120), concerns, coping mechanism, breast cancer treatment, overall patient satisfaction with follow-up care, information needs at discharge and completion of treatment (123). The various tools used were HADS (122, 126, 128) Functional Assessment of Cancer Therapy-Breast (119, 121), Concern and Coping Checklist (122), Patient Health Questionnaire (124), World Health Organization Quality of Life Instruments (124), EORTC QLQ-C30 and Breast Cancer specific module (125), and Body Image After Breast Cancer questionnaire (126).

4.5.3.3 Matched case control

Singh *et al* conducted a prospective noninterventional, observational study to evaluate the depression, anxiety, and stress (DAS) levels in surviving cancer patients receiving chemotherapy as compared to normal control and explore associations with clinico-demographic characteristics such as age, gender, duration of cancer diagnosis, chemotherapy cycles, cancer types using Depression Anxiety and Stress scale (130).

4.5.4 Qualitative studies

Three of five qualitative studies (131-135) used interviews (132, 133, 135) one used focus group discussion (131), and one used interviews and focus groups (134). Three studies recruited participants from a migrant community living in Canada (131, 133, 134) and two were from Indian women living in India (132, 135).

4.5.5 Setting and sample size

The participants for fifteen studies were recruited from a hospital (118-131, 135), while three of them were recruited from Non-Governmental Organisation and community (132-134). Of the studies from India, both north and south India were represented with three conducted in Maharashtra (118, 120, 122) two each from Kerala (121, 124) and Delhi (119, 128) and one each from other states (125-127, 129, 130, 132, 135). The studies were conducted mainly in the English language (n = 12)(118, 119, 122, 123, 125, 128, 129, 131-135) followed by various Indian regional languages including Hindi (118, 131, 132, 134), Malayalam (121, 124, 125) Urdu (131, 134),Punjabi (123, 131, 133, 134),Telugu (125, 129), Tamil (125, 135), Marathi (118), Kannada (135) and Gujarati (118). All papers were translated and published in English.

The study sample size ranged from 12-504 (average 116.4), out of the 13 observational studies only two studies gave a description of how the sample size was agreed on (123, 124). Purposive sampling was used in two of the qualitative studies and the sample size was determined by thematic saturation (132, 134).Four studies were from Canada(123, 131, 133, 134) and the rest from India.

4.5.6 Population

The studies included information about 2039 patients of whom 2036 (99.8%) were women and three (0.15%) were men. The patients were aged between 18 -92 years. A minority (120, 6.06%) women were living in Canada and 1919 (94.11%) were living in India. Twelve papers (118-125, 128, 132-134) reported the employment status of the patients; a total 380/1703(22.3%) patients were employed. From the 11 studies reporting marital status (118-126, 131, 133), 1378/1727(80%) women were married. Only four studies (122, 124, 128, 133) described the patient's family system. In three studies, most participants belonged to a nuclear family system (parents, children) (122, 124, 128), in the fourth, participants were mainly from joint family system (grandparents, parents, children) (133). The educational background was described in 14 papers, ten from India (118-122, 124-126, 128, 132) and four from Canada (123, 131, 133, 134). A quarter (497/1850 patients, 26.8%) had educational qualifications above graduate level while 279/1850 (15.08%) were illiterate. Religious affiliation of participants was reported in five studies only giving a total of 466 Hindus, 101 Christians, 92 Muslims and 32 Sikhs (121, 130-133). Stage of the disease was only reported in two (119, 121) papers with most women presenting with stage 2 or 3 breast cancer. Twelve (118, 119, 121-123, 125, 126, 128, 131-134) studies reported the treatment modalities; nine studies included a range of treatment modalities, but three with non-surgical only (123, 128, 131). The total number of women who had chemotherapy was 569 /1330 (42.7%) while 499/1330 (37.5%) had modified radical mastectomy (MRM) and 237/1330 (17.8%) had breast conserving treatment.

4.5.7 Outcomes

The main outcomes of the individual studies are summarised in Table 8 and 9

Eight studies included a quality of life measure using tools like FACT B (119, 121) a validated questionnaire (120, 130)WHOQOL-BREF (124) EORTC QLQ c-30 (118, 125)QLQ BR23 (125, 129).Six studies measured anxiety and/or depression; four used HADS (122, 126-128) one used the PHQ9(124) and one used DASS21 (130). One study measured concerns and coping using the Concern and Coping Checklist by Devlen (122) and one measured body image specifically using the body image after breast cancer questionnaire (126).

Table 8: Outcome: Quantitative studies

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
PARMAR et al (2005)(118) India	Prospective Cohort	To assess the validity of EORTC QLQ C30 and BR 23 in Indian breast cancer patients	**N** = 193 **Women** = 100% **Language**: English, Gujarati Marathi and Hindi **Age**: 44.2 years (range 24–72 years) **Level of education** Primary:101 Secondary:31 Graduation:42 Postgraduation:19 **Religion: N/A** **Socio economic status: N/A** **Occupation**: Housewife:135 Service:51 Professional/Others:7	(EORTCQLQ -C30); BR 23	Primary: Validity and reliability of questionnaire Secondary: body image, global QoL	BCT maintained a better body image through visit 1 ($p<0.001$) and visit 2 ($p=0.055$) compared with women who underwent mastectomy. Chemotherapy significantly affected the global QoL with poor scores during treatment

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
			Marital status Unmarried:8 Married :174 Divorcee/Widow:11 **Number of children** **Primary cancer**: breast **Treatment**: MRM :39.9 % BCT: 60.1 % adjuvant chemotherapy 90%, hormone therapy 51% radiotherapy 75% **Stage of disease**			

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			Duration: October 1998 to September 2001			
Kaur et al (2014)(119) India	Descriptive cross-sectional study	Investigate the QOL in patients of breast cancer beyond the 1st year of their treatment and to identify their specific information and	**N** = 154 **Women** = 100% **Language**: English **Age:** Group 1(1-2 years): 47.4±8.8 Group 2(2-5 years): 43.3±10.3 Group 3(>5 years): 59.1±9.37 **Level of education** illiterate :102 Can read and write :52	(FACT-B) version 4	Physical well-being (PWB), Social well-being (SWB), Functional well-being (FWB) and Emotional well-being (EWB). The fifth subscale contains 9 items	FACT-B score: Group III (89.83 ± 12.80) > Group II (85.75 ± 20.15) > Group I (79.06 ± 14.60): better QOL for patients >5 years follow-up Group II best social, emotional and FWB but their breast specific QoL was worse than other groups. Group III patients best PWB score

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
		rehabilitation needs. Patients were divided into 3 groups according to duration of follow up.	**Religion** Hindu :126 Muslim :18 Sikh :4 Christian :5 **Socio economic** Low :114 Middle :38 High :1 **Occupation:** Unemployed :141 Employed :13 **Marital status**		and is specific for breast cancer (BCS).	Breast specific subscale was poorest in Group II patients (Group II vs. Group III, p = 0.039) Patient's age, marital status, education, employment, social class, clinical stage and recurrent disease had a significant impact on patient's QOL Almost 100% patients wanted more information about their disease, their chance of cure and life expectancy, possibility

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
			Single :0 Married :141 Widowed :13 **Number of children: N/A** **Primary cancer**: breast Stage I-20%, Stage II-49%, Stage III-30.5% **Treatment**: MRM :142 Chemotherapy:147 RT:34 Hormone:150			of disease affecting other family members, the duration of treatment, the expense, 56% were bothered by shoulder/arm-pain and shoulder, lack of energy, limb swelling. Restriction in sexual relationship was reported by 37% patients, 36% wanted counselling and risk assessment of their family members to allay their fears.

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			BCT:10 **Duration**: March 2009 to March 2010			
Shah etal (2010) (120) India	Cross-sectional study	To assess the QoL of patients of carcinoma breast and to ascertain pitfalls and make suitable correction for future studies on	**N** = 250 Enrolment at diagnosis (N=46) completion of Treatment (N=83) undergoing treatment(N=121) **Women** = 100% Language: N/A **Age** 48.2 years (26–92 years) 40–55:51% 55–70 :26%	QoL four-part questionnaire: Part 1 and 2 = Physical in capacitance Part 3 and 4 = Emotional and psychological	Part 3 & 4 used parameters like dependency, invalid, restriction on chores, problems with chores, feelings, sadness and inner tension.	QoL results seen as per group of patients: a. Good QoL: 43% b. Excellent QoL: 12.8% c. Moderately compromised QoL: 30.6% d. Severely compromised QoL: 8% e. Poor QoL: 5.6% The illiterate group (105

Reference/ **Authors** **Country**	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
		Indian patients	25–40 :29 over 70 years :27 **Level of education** illiterate :42% graduates :26 **Occupation**: housewives :82% Rest employed: teaching **Religion** **Socio economic** **Marital status** Married:250	impairment		patients) reported better QoL in all walks of life

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			Number of children:2-3 0: 1 Variables: age, education, co morbidity, stage of disease, treatment and radiotherapy. **Primary cancer**: breast Treatment: N/A Duration: N/A			
Pandey etal (2005) (121) India	Cross sectional	To identify the determinants of QOL of Indian women with	**N** = 504 **Women** = 100% **Language**: Malayalam **Age:** 47.6 years (20–80) **Level of education**	(FACT-B)	Physical, social/family well-being, functional and emotional well-being, the fifth	Physical well-being 19.8± 4.7; social family well-being 19.9 ± 5.3; Emotional well-being 14 ± 14.9 and functional well-being 13 ±

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
		breast cancer treated with curative intent.	Illiterate:23 ≤5 :96 6–10:255 11–12 :55 Graduate/tech: 40 Post graduate :29 **Religion** Hindu:323 Muslim :71 Christian :94 Others/Don't know:13 **Socio economic**		subscale contain 9 items and is specific for breast cancer	5.7. The mean scores for breast subscale were 23.0 Univariate analysis. Younger women (<45 years), women having unmarried children, nodal and/or metastatic disease, and those currently undergoing active treatment showed significantly poorer QOL scores in the univariate analysis. Multivariate analysis Religion, stage, pain, spouse

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
			Low: 167 Middle:164 High:171 **Occupation**: HW/Unemployed :380 Employed:81 Self/Business/Daily:31 Don't know:10 **Marital status**: Single :23 Married:377 Widow/Divorce:100 **Number of children** Variables: age, education, co morbidity, stage of disease,			education, nodal status, and distance travelled to reach the treatment centre as indicative of patient QOL.

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			treatment and radiotherapy. **Primary cancer**: breast T1 (6.6%) T2 disease (34.7%) T3 (16%) and T4 (15%) Tx (27.7%) **Treatment:** No treatment (43.4%), Excision (16.7%) MRM (21.9%) BCT (0.4%) Don't know (17.6%) **Duration:** N/A			
Mahapatro etal (2005) (122) India	cross-sectional study	To explore the various concerns, coping	**N** = 75 **Women** = 100% **Language**: English	Concern and Coping Checklist by	Concerns and coping mechanism	Sexual role and performance concern showed a statistically significant difference (p<0.05) between the lumpectomized

Reference/ **Authors** **Country**	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
		mechanisms and body image disturbances and extent of resolution of concerns as well as to study the level of anxiety and depression in mastectomized and lumpectomiz	**Age**: Mastectomy 42±7.14 and lumpectomy 42.74±6.23 years, **Level of education** higher than secondary level of education: 100% **Religion: N/A** **Socio economic**: middle majority **Occupation**: housewives: majority Rest: clerical to legal jobs. **Family**: Nuclear **Marital status:** Married majority **Number of children: N/A** **Primary cancer**: breast **Treatment**: Lumpectomy(n=25)	Devlen Hospital Anxiety and Depression Scale	Severity of anxiety and depression.	and mastectomized groups. The mean (SD) values were 1.12±0.44 and 1.38±0.56, respectively. Resolution in concerns was also seen only in sexual role and performance concern where resolution in the mastectomized group was to a lesser extent than the lumpectomized group (p<0.01; statistically significant). The mean (SD) was 3.82+1.68 and 4.76+0.83, respectively.

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
		ed patients.	Mastectomy (*n*=50) **Duration**: 1 year			No statistically significant difference between the two groups for hospital anxiety and depression scores.
Carlson etal (2013)(123) Canada	Cross sectional Survey	Further explore and confirm findings from the qualitative phase by gaining deeper insight into a larger and	**N** = 64 **Women** = 100% **Language**: English, Punjabi **Age** :<44 Years :6 45–54 Years:19 55–64 Years :21 >65 Years :18 **Level of education** <High school:13	Survey developed and validated with white breast cancer survivors at the BCCA Vancouver Island	Impact of breast cancer treatment, overall patient satisfaction with follow-up care, information needs at discharge and completion of treatment, and	95.4% had visited their family doctor within several months (0.5–24 months) after discharge. Main physical effects of concern were fatigue and anxiety concerning health was the main psychosocial impact. Younger age was more concerned about physical appearance, depression, and

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
		more diverse group of south Asian women. Better understand the content and format preferences of those women for a survivorship care plan.	High school:24 Certificate/diploma:10 Bachelor degree :9 >Bachelor degree 8 Not specified 3 **Religion:** N/A **Socio economic: N/A** **Marital status** Married :42 Never married :4 Widowed:12 Divorced/separated :3 Not specified :3	Cancer Centre questionnaire consisted of 27 questions	demographic information	the impact of cancer on family members while older groups were concerned about family obligations and work issues. 14.1% described strain on their marriage and on their relationships with family and friends as significant issues. With regards to survivorship care plan most common “very useful” elements were a summary of diagnosis and treatment, and nutrition and supplement information.

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
			Work status Employed :16 Self-employed:6 Homemaker:8 Unemployed:4 Retired:20 Unable to work:8 Not specified :2 **Number of children**: N/A **Family**: N/A **Primary cancer**: breast **Treatment**: Chemotherapy 31 (48.4%) Hormone therapy 48 (75%)			

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			Radiotherapy 45 (70.3%) **Duration**: 3 and 60 months post treatment Survey once, reminder in one month.			
Purkayastha etal (2017) (124) India	Cross-sectional Study	To study the prevalence of depression among breast cancer patients undergoing treatment and to correlate its	**N** = 270 **Women** = 267 **Men**= 3 **Language**: Malayalam **Age** 18-30: 5 31-40:24 41-50: 83	Patient Health Questionnaire (PHQ-9) WHOQOL-BREF for quality of life	Screen for depression Four domains of QOL physical, psychological, social relationship, and environmental.	Of the 270 patients, 21.5% had depression with 22% had moderately severe to severe depression. Patients with depression experienced overall a poor QOL. 22 patients reported their overall QOL was “poor” and 34

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
		association with their QOL	51-60: 91 61-70: 52 71-80:15 **Level of education** Below graduation:120 Graduation and above:150 **Occupation**: Employed:105 Unemployed:165 **Religion** **Socio economic** **Marital status** Married:233 Single:5			Patients reported to be dissatisfied with their health. There was an association between depression and domains of QOL. Patients with depression had lower scores in all domains when compared to those without depression

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			Widowed:25 Divorced or separated:7 **Family**: Nuclear :158 Joint :9 Other:103 **Number of children** **Primary cancer**: breast **Treatment**: Not reported **Duration**: August 2014 to August 2016			
Dubashi etal	Cross-sectional	To describe the QOL	**N** = 51	EORTC module	EORTC: Five multi-item	The effect of breast cancer on the occupation and marital

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
(2010) (125) India	Study	among breast cancer women with age less than or equal to 35 years at the time of diagnosis. To determine the contribution of sociodemographic, medical, and psychosocial	**Women** = 100% **Language**: English, Tamil, Telugu, and Malayalam **Primary cancer**: breast **Age** 21 – 25 :7 26 – 30:27 31 – 35 :17 **Level of education** Primary :27 Secondary :17 Graduate :6	QLQ – C30 and the BR 23 Questionnaire.	functional subscales: Physical health, role function, emotional function, cognitive function and social function; three multi-item symptom scales measuring fatigue, pain, and emesis; a global health subscale and six	status was minimal. The global health status and the functional scores were high, while the overall sexual function was lower. The global health status (p = 0.04) was higher in the mastectomy group. The arm symptoms (p = 0.027) and pain were higher in the Breast conservation surgery (BCS) group. The sexual symptoms

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
		factors on the QOL. To study the impact of breast conservation treatment and mastectomy on the QOL	Postgraduate:1 **Religion** **Socio economic** **Occupation**: Housewife :39 Labourers :11 Professionals :1 **Marital status** Married :46 Single :5 **Number of children** **Treatment**: MRM :64.7%		items to assess the financial impact and general symptoms. BR-23 module incorporates three functional scales (body image, future perspectives, and sexuality) and four symptom scales (arm symptoms,	appeared to be higher in the ovary ablated group when compared to the ovary preserved group. The sexual functional scores (p = 0.02) and sexual enjoyment scores (p = 0.003) were better in the mastectomy group

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
			BCT: 35.3% adjuvant chemotherapy: 100% hormone therapy 82.4% **Duration**: 1994 to 2005		breast symptoms, hair loss, and side effects), fear of recurrence and partner response, sexual dysfunction, and menopausal symptoms	
Tripathi etal (2017) (126) India	cross-sectional study	To assess the perceived stigma and its associations	**N** = 134 **Women** = 100% **Language**: local vernacular language **Primary cancer**: breast	Hospital Anxiety and Depression Scale (HADS)	Six subscales: stigma, vulnerability, transparency, arm concern,	Univariate High levels of stigma were associated with lesser educational attainment, (p = 0.01)

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
		with sociodemographic, affective symptoms, and treatment-related issues in women following surgery for breast cancer.	**Age**: 52 years (44–60 years.) **Level of education** school education or less:78 college education: 56 **Religion** **Socio economic** **Marital status** Married 99 Single: 35 Number of children **Treatment**: MRM: 72	Body Image After Breast Cancer Questionnaire	body concern, and limitation subscales	breast conservation surgery (BCS) vs mastectomy (p = ≤0.001) having an anxiety disorder (p = 0.03) and depression (p < 0.01) Multivariate Stigma as the dependent variable, being less educated (p = 0.02) and opting for BCS (p = ≤0.001) were associated with higher stigma.

Reference/ **Authors** **Country**	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			BCT: 62 adjuvant chemotherapy :32.8% **Duration**: N/A			
Brahmbhatt etal (2012) (127) India	Cohort study	To evaluate psychosocial status of patients who underwent surgery for cancer.	**N** = 29 **Women** = 100% **Language**: English, Gujarati Age Level of education Religion Socio economic Marital status Number of children	GHQ-28 and HADS	GHQ-28: anxiety/insomnia, depression, somatic symptoms, and social dysfunctions HAD: anxiety and depression	Significant increasing total GHQ-28 score in breast cancer patients who underwent modified radical mastectomy or breast conservative surgery therapy ($p = \leq 0.001$) GHQ-28 sub scores also indicative of greater social dysfunction ($p = \leq 0.001$), anxiety/insomnia ($p = \leq 0.001$), somatic symptoms ($p < 0.01$), and severe depression (p <

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
			Primary cancer: breast **Treatment**: Not known **Duration:** January 2011 and May 2011			0.001) Anxiety and depression levels increased significantly (p < 0.01) after surgical treatment in breast cancer patients from the HAD scale
Chintamani etal (2011) (128) India)	Cross-sectional study	Aim of assessing the levels of anxiety and depression in breast cancer patients in the Indian scenario and	**N** = 84 **Women** = 100% **Language:** English **Age** **Level of education** Illiterate (46, 54.7%) **Religion**	Hospital Anxiety and Depression Scale (HADS)	Anxiety Depression	The mean depression scores in the breast cancer patients included in this study was 4.9 (range 1–6). The mean depression score in responders after neoadjuvant chemotherapy was found to be 5.6 (range 1–16), whereas the mean score in non-

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
		to correlate these levels with response to neoadjuvant chemotherapy	**Socio economic** **Occupation**: housewives (68, 79.7%) **Marital status** **Family**: joint and nuclear families were equal (50% in each category). **Number of children** **Primary cancer**: breast **Treatment**: Neo adjuvant chemotherapy 100% Responders to neoadjuvant 49 (58.3%) Non-responders: 35 (41.7%) **Duration**: Not given			responders was 10.2 (range 4 – 20). 24 (70.5%) non-responders had depression vs 11 (22.0%) responders 24 (57.1%) patients from nuclear families showed significant levels of depression, vs 11 (36.2%) patients of joint families (p <0.05).

Reference/ **Authors** **Country**	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
Damodar etal (2014) (129) India	Cohort	To evaluate the QOL and affecting factors on it among south Indian cancer patients	**N** = 41 **Women** = 100% **Language**: English, Telugu **Age** Young adult (19-35):15 Adult (36-50):9 Old adult (51-64):9 Young older (65-74) :8 Old (75-84) :0 **Level of education** **Religion** **Socio economic** **Marital status**	EORTC QLQ-C30 EORTC QLQ-BR23	Functional scale: physical function, role function, body image future perspective Symptom scale: Insomnia, breast and arm symptoms	Functional scale: physical function, role function significant Extended functional scale using EORTC QLQ-BR23 questionnaire: future perspective was found to be significant (p <0.05) Symptom scale: fatigue, pain, arm symptoms and upset by hair loss were found to be significant (p <0.05). Global health status when paired with physical function, role function, insomnia, body

Reference/ **Authors** **Country**	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
			Number of children **Primary cancer**: breast Treatment: Duration: January and June 2011			image, future perspective in functional scale and breast symptoms, arm symptoms in symptoms scale were found to be significant
Singh etal (2015) (130) India	Case control	Approximate the depression, anxiety, and stress (DAS) levels in homogenous surviving cancer patients	**N** = 60 **Women** = 100% **Language**: local understandable language Age: Level of education Religion Socio economic	Depression Anxiety and Stress scale (DASS-21)	Anxiety Depression Stress	Significant difference was noted in mean stress score in different cancer type with more stress in breast cancer patients Mean score for depression 9.5 (5.8) Anxiety 5.1 (4.85) Stress 9.87 (5.30)

Reference/ Authors Country	**Design**	**Aims**	**Study population**	**Measures**	**Outcome Measures (Psychological health)**	**Results Summary**
		receiving chemotherapy as compared to normal control. To correlate the primary objective with different demographical parameter such as age, gender,	Marital status Number of children **Primary cancer**: breast Treatment: **Duration**: January 2014 to September 2014			

Reference/ Authors Country	Design	Aims	Study population	Measures	Outcome Measures (Psychological health)	Results Summary
		duration of cancer diagnosis, chemotherapy cycles, cancer types, etc.				

EORTC QLQ C30: European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire-Core 30; **BR23:** Breast cancer specific module; **QOL :**quality of life; **BCT** :Breast conservation treatment; **MRM**: Modified Radical Mastectomy ; **FACT-B** :Functional Assessment of Cancer Therapy- Breast; **BCCA** : Breast Cancer Care Agency ;**PHQ-9**: Patient Health Questionnaire; **WHOQOL-BREF** :World Health Organization Quality of Life Instruments; **HADS:** Hospital Anxiety and Depression Scale; **GHQ-28** :General Health Questionnaire; **PWB**: Physical well-being; **SWB:** Social well-being; **FWB**: Functional well-being; **EWB** :Emotional well-being; **RT:** Radiotherapy; **BCS**; Breast Conservation Surgery;

Table 9: Outcome: Qualitative

Reference/ **Authors** **Country**	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
Gurm etal (2006) (131) Canada	To understand the experience of Canadian Punjabi speaking South Asian women in order to inform health care practices.	**N** = 20 **Women** = 100% **Language**: Punjabi, Hindi Urdu, English **Age**: 53.0(32–80) **Religion** **Socio economic** **Occupation**: Full or part time :5 Homemaker:3 Unemployed/disability :10 Retired:2	**Methodology** Inductive and deductive process of analysis **Data collection** Focus group methodology **Analysis** The data were manually divided into individual ideas expressed then sorted into clusters and short descriptive and interpretive categories. Constant comparison was used to assign the phrases into one of 46 descriptive categories, and then again into 32 categories which were then arranged into higher-order interpretive themes. Analytic procedure utilized both an inductive and deductive process	Two themes expressed by all women: Spiritual beliefs as dominant context for understanding cancer Distress at diagnosis. Other themes: patient inclusion, family systems, emotional expression

Reference/ Authors Country	Aims	Study population	Data collection/analysis	Results Summary
		Marital status Single :0 Married:16 Widowed:3 Separated :1 **Number of children** **Level of education** Elementary school :8 High school :5 Technical college:4 University :3 **Primary cancer**: breast **Treatment**: Current		

Reference/ Authors Country	Aims	Study population	Data collection/analysis	Results Summary
		chemotherapy (35%) Post-chemotherapy 13 (65%) **Time since diagnosis/treatment**: 2.7 years		
Barthakur etal (2017)(132) India	To understand breast cancer survivorship trajectory from an Indian perspective and to understand the impact of the	**N** = 15 **Women** = 100% **Language**: English or Hindi speaking **Age**: 45-72 (57) **Level of education** Class X :1	**Methodology** Descriptive phenomenological approach. **Data collection** semi-structured interview **Analysis** Line-by-line reading was done to identify the areas of phenomena, statement pertaining to areas of phenomena was assigned meanings,	**Body image:** Impact on identity, surgery-related issues, hair loss, adjustments to clothing, and encountering difficult situations. **Sexuality** changes due to the treatment, partner's challenges and adjustments

Reference/ **Authors** **Country**	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
	diagnosis of breast cancer and its treatment on body image and sexuality issues	UG:4 PG :10 **Religion** Hindu :11 Islam :2 Christian :1 Zoroastrian :1 **Socio economic** **Occupation**: Employed:6 Homemakers :3 Volunteers :6 **Marital status**	Clusters of categories, broader themes, and domains based on identified statement were developed. Exhaustive description of phenomena was done based on integrated findings and provided to co researchers for and their feedback was incorporated to reflect the universal features of phenomena.	made, and attitudes held toward sexuality

Reference/ **Authors** **Country**	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
		Number of children **Primary cancer**: breast **Treatment**: Mastectomy 10 Lumpectomy 5 **Time since diagnosis/treatment**: 9.3 years		
Howard etal (2007) (133) Canada	To explore women's stories of breast cancer in order to uncover how	**N** = 12 **Women** = 100% **Language** English or Punjabi **Age**: 51 (range 34–63	**Methodology** Narrative analysis **Data collection** In-depth Interviews **Analysis** Narrative analysis strategies: close readings of	Four storylines that emerged were: Getting through a family crisis, Dealing with just another health problem, Living with never-ending fear and suffering, and learning a ''lesson from God.''

Reference/ Authors Country	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
	they made sense of their experiences	years **Level of education** Elementary school University **Religion** Hindu :1 Sikh:11 **Socio economic** **Occupation**: Employed:7 **Marital status** All married or widowed **Number of children**	the interviews focusing on women's stories of their breast cancer experiences. A summary of each woman's story was prepared to include the storyline she used. These summaries were compared and contrasted to identify themes and initial storylines. Women's stories were also compared with Frank's three illness narratives (i.e., restitution, chaos, or quest)	A minor theme, Breast Cancer as a Family Experience

Reference/ **Authors** **Country**	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
		Family Extended (Joint) **Primary cancer**: breast **Treatment**: mastectomy, radiation, and chemotherapy 11 reconstructive breast surgery 1 **Time since diagnosis** 10 months to 6 years		
Carlson etal (2013) (134) Canada	To explore the experiences and concerns of female south	**N** = 24 **Women** = 100% **Language**: Punjabi,	**Methodology** Thematic and content analysis. **Data collection**	**Universal Themes** ***Physical Impacts****:* Fatigue, Cognitive change, Loss of libido

Reference/ **Authors** **Country**	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
	Asian breast cancer survivors after treatment, to determine their understanding of follow- up care and to better understand their preferences for the content of a care plan. To understand the influence of	Urdu, English, Hindi **Primary cancer**: breast **Age**: 28-72 <44 Years: 6 45–54 Years :6 55–64 Years: 6 >65 Years:6 **Level of education** No school 3 Elementary 2 High school 12 College 5 University 2	Focus group and one to one interviews **Analysis** Thematic analysis was used to identify common threads and patterns in the women's experiences of breast cancer after treatment. It was performed simultaneously with data collection to identify recurring categories, emerging themes, and patterns Content analysis was used to systematically identify the preferences of women for survivorship care plan content by explicitly coding the data into categories after an initial line-by-line reading	Nerve damage and pain Reproductive or pregnancy issues **Psychosocial impact:** Body image, sexuality Depression Fear of recurrence and uncertainty Intimacy and relationships **Unique to South Asian women** Quiet acceptance Peer support

Reference/ Authors Country	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
	age, social situation and culture affect the experiences of SA BCSS after treatment, especially as they transition from oncology to community care.	**Religion** Sikh 17 Hindu 5 Christian 1 Muslim 1 **Socio economic** **Occupation**: Employed 7 Unemployed 8 Disability 2 Retired 6 No response 1 **Marital status**		

Reference/ **Authors** **Country**	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
		Number of children **Treatment**: Surgery 5 Surgery and chemotherapy:9 Surgery and radiation :3 Surgery, chemotherapy, and radiation :4 Hormonal therapy :7 No response :3 **Time since diagnosis/treatment**: 2-3 years		

Reference/ **Authors** **Country**	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
Nyblade et al (2017) (135) India	To explore the cause and manifestation of Stigma in breast cancer patients.	**N** = 59 **Women** = 100% **Language**: English, Kannada, or Tamil **Age**: **Religion** **Socio economic** **Occupation**: **Marital status** **Number of children** **Level of education** **Primary cancer**: breast **Treatment**:	**Methodology** Thematic analysis **Data collection** In-depth interviews **Analysis** The analysis approach used a combination of predetermined and derived themes for data coding. Coded data were reviewed to examine similarities and differences within each theme and between groups.	The three major themes were **Drivers** (causes) of stigma including Cancer as contagious, punishment death sentence the **manifestations** of stigma described, Isolation, Verbal Abuse, harassment, loss of employment, reduced marriage prospects and the **consequences** that follow stigma.

Reference/ Authors Country	**Aims**	**Study population**	**Data collection/analysis**	**Results Summary**
		Time since diagnosis/treatment:		

SA BCSS: South Asian Breast Cancer Survivors

4.5.7.1 Anxiety/Depression

About a fifth (21.5%) of women with breast cancer undergoing treatment had depression (124), in whom 22% was moderate to severe. A study of patients undergoing surgery for colo-rectal cancer, breast and head and neck cancer, showed post-surgical anxiety and depression was greater in patients with breast cancer (127). A case-matched control study showed that patients with breast cancer had higher levels of stress (measured by depression, anxiety and stress scale (DASS-21) than the normal controls (130). However, this paper did not describe how the controls were recruited or what matching criteria were used. Indeed, the summary description of group characteristics reported that the most common age group was 41–50 years in participants group and in control group was 0–40 years, which indicate they were not matched by age.

Depression was associated with poor quality of life (124) and stigma (126). Type of treatment was related to presence of psychological symptoms. A cross-sectional study of women following surgery for breast cancer, found having an anxiety disorder (p=0.03) and depression (p<0.01) was associated with stigma on univariable analysis although this relationship disappeared in the multivariable model where only levels of education (low; p=0.02) and type of surgery (breast conservation; p<0.001) predicted stigma (126). A study of psychological wellbeing following neoadjuvant chemotherapy for breast cancer showed that depression was more common in non-responders (70.5%) than responders (22%) with higher than average HAD scores (non-responders mean average 10.2 [range 4 to 20] *vs* responders mean average 5.6 [range 1 to 16]) (128). One study explored the relationship between type of surgery and HAD score and found no difference between women who had breast conservation or mastectomy (122). Lack of social support was also related to presence of depression, with those from nuclear families more likely to have depression compared to joint families (three generations) (57% vs 36%; p<0.05) (128).

4.5.7.2 Mental Health Component of Quality of Life

A wide range of factors were found to be related to the mental health component of quality of life across all the studies. These can be summarised as patient and disease characteristics, treatment-related factors and symptoms

4.5.7.2.1 Patient characteristics

The factors affecting the overall QOL were income (p = 0.03), religion (p = 0.005), patient's education (p = ≤0.001) (119, 121), self- (p = 0.004) (119, 121) and spouse-occupation (p = ≤0.001) presence of pain (p = ≤0.001) ,patient's age, marital status and social class (119). The emotional wellbeing of patients was directly related to the distance travelled to reach the treatment center (p=0.04), religion of the patient (p=0.006), marital status (p=0.002), education (p=0.04), self occupation (p=0.02) and spouse occupation (p=0.04) (121).

4.5.7.2.2 Disease characteristics

Overall QOL was affected by method of diagnosis (p = ≤0.001),previous treatment (p = 0.02), nodal stage (p = 0.01), presence of metastasis (p = 0.04) (121) composite stage (p = 0.005)(119, 121) and recurrent disease (121) while the emotional wellbeing of patients was affected by were nodal status (p=0.02), method of diagnosis (p = ≤0.001) and previous treatment (p = ≤0.001) (121).

4.5.7.2.3 Treatment-related effects

Chemotherapy (118) significantly reduced global QOL with poor scores *during* treatment. Women having adjuvant radiotherapy had more local symptoms in arm and breast and had worse social functions (p=0.02) compared with women not receiving adjuvant radiotherapy (118).

In young breast cancer patients (< 35 years), type of surgery was related to quality of life: those having had mastectomy reported overall good quality of life with better global health status (p=0.04) compared with those having breast conservation (125). The follow up period after treatment was seen to affect emotional well-being and body image scores with best scores in those who were 2 -5 years post treatment (119, 125).

After treatment, QoL improved with length of time since treatment; FACT-B score was reported as 89.83 ± 12.80 > 5 years post treatment, 85.75 ± 20.15 2-5 years post treatment and lowest, 79.06 ± 14.60, 1-2 years since treatment (119).

4.5.7.2.4 Symptoms

Among symptoms affecting quality of life , depression was associated with poor quality of life as described earlier (124), in addition poor quality of life was associated with distress due to hair loss (129).

4.5.7.3 Body Image and stigma

Stigma was more likely in women with worse body image scores (126). Stigma was independently inversely associated with educational attainment (p=0.01) and having had breast conservation rather than mastectomy (p = ≤0.001) (126). The association of stigma with BCS was an unexpected finding and it was felt by authors that it is possible that women who perceived high levels of stigma associated with the disease were more likely to have chosen BCS as they felt it was more normalizing route to have BCS or due to social construct of cancer in the developing countries, and also some increase in the cost of treatment associated with breast conservation, women who chose to have BCS were under social scrutiny and felt stigmatized. Conversely, in another study women who underwent breast conservation maintained a better body image through visit 1 (after surgery) (p = ≤0.001) and visit 2 (during adjuvant therapy) (p=0.055) compared with women who underwent mastectomy. However these differences disappeared by visit 3 (average 9 months after surgery) (118). Sexual role and performance concerns were fewer in patients who had a lumpectomy rather than a mastectomy (1.12 ± 0.44 and 1.38 ± 0.56; p<0.05) (122).

4.5.7.4 Concerns and coping mechanism

The predominant concerns among patients undergoing mastectomy and lumpectomy were, current illness, feeling upset or distressed, future, body image or disfigurement, sexual role and performance, and recurrence or relapse. Sexual role and performance concern were less in patients who had a lumpectomy compared with those who had a mastectomy (1.12 ± 0.44 and 1.38 ± 0.56; p< 0.05). In the lumpectomized group there was no concern regarding body image or disfigurement. Coping strategies employed were effective in resolving these concerns except the concerns regarding body image or disfigurement and recurrence or relapse in the mastectomized group. The coping strategies used were helplessness for body image concerns and talking to others, especially health professionals for concerns regarding recurrence. On comparing the resolution of concerns between lumpectomized and mastectomized groups ,there was no statistically significant difference between the resolution of concerns in the two groups except for sexual role and performance, where resolution in women treated with mastectomy was less than those treated with lumpectomy ($p<0.01$) (122).

4.5.7.5 Information needs

On evaluating the information needs of patients Kaur et al found that almost all patients felt they wanted to have more information about their disease, their chance of cure and life expectancy, possibility of disease affecting other family members, the duration of treatment, and the expense involved in treatment .This would help them to plan for the future (119).

4.5.8 Findings from qualitative synthesis

Out of the five studies, three were from Canada and rest from India. The two qualitative studies from India were aimed at evaluating the cancer stigma (135) and body image and sexuality (132). Thematic synthesis of the qualitative papers revealed two major themes; 1) Cultural context of disease experience and its impact on women and 2) Women's individual response to disease. A table showing the themes, subthemes, codes and quotes can be found in Appendix 2

4.5.8.1 Theme 1. Cultural context of disease experience and its impact on women

The cultural context in which the women experience their disease was broadly divided into the overlapping impacts of family, community and religion. Each had positive and negative influences, helping some to reduce the psychological distress while aggravating distress for others.

4.5.8.1.1 Community

Most Indian-heritage women felt strongly supported by their community. This was particularly evident in studies from Canada, where Indian women found their immigrant communities to be an effective support network which helped them to cope with disease and treatment. The women in all the studies were able to identify the positive aspects of the community which helped them to cope with disease and its treatment thereby reducing distress. Talking about their experience with others who understood their cultural context and to whom they could speak fluently was helpful. This created a challenge for ex-patriate Indian women living in Canada, whose culture remained Indian but where the language difference was a barrier.

> *For most women, this meant that they could share their personal cancer experiences within their own cultural and social context, in their mother tongue, making the exchange more meaningful and supportive. (Researcher, Canada) (134).*
>
> *Most women found that they could talk with family or community members who were already cancer survivors because they received hope from each other. (Researcher, Canada) (134)*

Some women felt that having a culture where you are expected to wear a particular clothing was in a way advantageous as wearing a saree or East Indian suits with dupatta was to conceal breast anyway, so that the loss of breast would be less noticeable. Notably women living in India felt that breast is expected to be covered so the loss is less noticeable.

> *One survivor also expressed the cultural expectation that breasts are to be hidden or covered which thereby reduced impact of the loss.(Researcher, India)(132).*
>
> *I wear East Indian suits. You want to look nice, but in my mind I know there isn't a breast here. Other people can't see that. I want to be normal, like a lady. (Patient, Canada) (134).*

However, some disliked the close nature of the community, unhappy with the invasion of privacy of patients by family, lack of hope given by community, or the pressure to be "socially correct". This negative effect was evident in both countries.

> *These women were not happy with the negative response they received from the "well-wishing" visitors because "they did not give person hounsla [hope] "they just come and disturbed you," and "the relatives say, 'Ha! How did it happen?' (Patient, Canada) (134).*
>
> One *woman who has cancer in our village, that lady who died, that time in communities some people scolded her and they separated her from the house. (Patient, India) (135).*

Several survivors had the experience of others wanting to see the scar. Few of them were not comfortable with it while few others were comfortable showing it to close relatives. As one survivor who also works as a cancer volunteer expressed, it was dependent on the context:

> *Some people have wanted to see it especially those who are very curious, I did not feel good at all about their curiosity as this is not a matter to be joked about, it is an illness. (Patient, India) (132).*

Patients in both countries perceived cancer-related stigma from the community. Some were worried that their diagnosis would affect the future of their daughters in terms of marriage prospects, while others were worried about the cultural implications of not bearing children immediately after marriage as was expected of them; an additional burden not faced by the Canadian-born non-Indian women.

> *Participants from all groups spoke about how childbearing and the addition of children to the family is a highly valued and emphasized role of women in South Asian culture and society compared with Western society—creating added pressures that make it harder to bearing the cancer diagnosis and treatment. (Researcher, Canada) (134).*
>
> *Would their daughters be eligible for marriage to good suitors? Breast cancer in the mother might mean that a daughter could have breast cancer as well, making matrimony with the daughter a higher risk for the future husband's family (Researcher, Canada) (134).*
>
> *You take our home care team, there are lots of times when family members will tell, 'Please don't park the auto right in front.' They are worried. Now what are they worried about? One is, will somebody else get it? But more importantly, there is a girl to be married in the family…It is not restricted to only the lower socio-economic strata. The guy could be a PhD from Harvard but he might have that fear. (Healthcare provider, India) (135).*

There was also ignorance regarding the nature of the illness and how it is spread among the women living in India, e.g., fearing cancer to be contagious, leading to social isolation, and delays in presentation to doctors.

> *I asked doctors and they advised not to fear and told that this is not contagious, even if you eat in the same plate other person will not get this, so it will not spread and you can move with all, without fear. Only after his words I got convinced and started to mingle happily.(Patient, India) (135).*
>
> *Other people think they should not share food, clothes and they should not share soap and also, they won't sleep with others. They should be separate only…I suffered very much and I thought I should not live, that is very difficult for me. (Patient, India) (135).*

Implications of being a migrant dealing with breast cancer in a new community had wider issues. Financial impact was a particular issue for Indian women in Canada because of restricted capacity to work due to illness. Being a migrant population, income from both partners was particularly important and the women found it increasingly difficult to work due to physical difficulties of treatment.

> *It is understood, however, that this concern is not unique to sa bcss, (south Asian breast cancer survivors) but applies to the migrant population who may be reduced to working under strenuous conditions when their family income depends on both spouses being gainfully employed. Two-spouse incomes are more central in an immigrant population in which vocational options may sometimes tend to be more physical in nature, with longer hours of employment. (Researcher, Canada) (134).*

4.5.8.1.2 Family

Family was described as a strong support system for many women helping them practically to go through treatment as well as providing psychological support.

> *The women constructed heroic stories of family members quitting their jobs to accompany them to appointments and treatments, taking over their household duties, and providing physical care. (Researcher, Canada) (133).*
>
> *In one instance, a woman recalled how her family refused to let her ''think about things'' related to breast cancer or ''feel sorry'' for herself, and pushed her to stay active. (Researcher Canada) (133).*

However, not all women had supportive families and the diagnosis of cancer sometimes led to a breakdown in relationships. In few it was due to the already existing problems in family life which worsened after diagnosis and others were due to lack of support from partners. Some children found it difficult to accept the change in appearance of women due to treatment.

> *However, several women had flirted with the idea of divorce because of the lack of support displayed by their husbands. One woman realized that negative conditions were already present in the relationship, but the significance of those conditions was heightened by the lack of support she felt after her cancer diagnosis and during treatment. At the time of the interview, she was considering a separation (Researcher, Canada) (134).*
>
> *Some family members they have neglected us… Before they will come very often but now it was reduced…They will not support me more. But I have lot of support for my friends. (Carer, India) (135).*

Several women described the experience of being required to continue with household and childcare responsibilities immediately post-treatment:

> *The members of family don't realize the weakness in the body after the cancer operation they think all the household work is my responsibility. (Researcher, Canada) (131).*

For some, already existing problems in family life worsened after diagnosis and others were due to lack of support from partners. Some children found it difficult to accept the change in appearance of women due to treatment.

> *One woman realized that negative conditions were already present in the relationship, but the significance of those conditions was heightened by the lack of support she felt after her cancer diagnosis and during treatment. At the time of the interview, she was considering a separation. (Researcher, Canada) (134).*

Family members sometimes found it difficult to accept or cope with the situation. They were concerned about recurrence and death but did not openly discuss this. Some patients had the additional responsibility of being brave to reassure their family.

> *One patient described how her teenaged daughter did not talk or eat after finding out about her breast cancer diagnosis.(Patient, Canada) (133).*
>
> *The women explained that family members took their illnesses ''hard.'' They cried and worried, and sometimes did not go to school or work because of their concern.*

> *One woman also indicated that her husband checked her pulse at night to see if she was still alive (Researcher, Canada) (133).*

Women described how their role in the family changed since their diagnosis and treatment. These affected their day to day functioning preventing them from fulfilling their role. A major role was being a mother and the thought of not fulfilling that role made some women non-compliant to treatment. The loss of self-esteem due to physical side effects also impacted their role in the family.

> *Participants from all four age groups complained of nerve damage and pain to various degrees, which got in the way of daily tasks and day-to-day living. Women were concerned by the effects on simple household tasks such as sweeping the floor or lifting heavy dishes. (Researcher, Canada) (134).*
>
> *Was distraught because she knew that she could not conceive children while on hormonal therapy, causing her grief as she struggled with adherence or nonadherence to hormonal therapy. (Researcher, Canada) (134).*

4.5.8.1.3 Religion

Religion and faith were important to many women, helping to accept disease, to cope or to change their lifestyle irrespective of country. Women tried to understand the reason behind the cancer diagnosis by attributing it to fate or 'karma' (134).This enabled them to accept it better but also had a downside of not going for treatment as "God has already decided the destiny" (131).

> *As one woman said: ''Nobody could change the time and cause of my death, it is God's will. So I avoided the chemo treatment (Patient ,Canada) (131).*

Some women felt that their faith was strengthened following the diagnosis, feeling closer to God in response to His "testing".

> *One deeply religious woman believed that as a ''true devotee of the Lord,'' God could teach her how to deal with problems in life, including breast cancer. She supported her convictions about the power of faith and her indubitable belief that she could ''cure herself'' through service to God. (Researcher, Canada) (133).*

However, others felt it was God's punishment for not being religious enough and then changed their life style and practices in accordance with their religion.

> *When I got cancer, it was like I was being punished because I did not wear my scarf [head covering] as a Muslim woman. Then I started wearing it, and for that I am grateful. I have always wanted to, but it wasn't the right time. (Patient, Canada) (134).*

4.5.8.2 Theme 2. Women's individual responses to disease

The second major theme was how women responded to the diagnosis and treatment and how they adapted ways to cope and to alleviate distress. There were a number of physical side effects side effects of treatment including fatigue, tiredness, pain, and arm swelling, some had cognitive difficulties. Some women were affected by it, however most women found practical adaptations to deal with it including change in lifestyle.

> *Women in all groups spoke of "having lower energy than I should have." Others identified fatigue as a loss of physical strength that drained the body of the physical capacity they had before cancer treatment. (Researcher, Canada) (134).*

4.5.8.2.1 Psychological response

Some women found that the breast cancer treatment was difficult to cope with by affecting their femininity i.e. loss of hair and loss of breast. People described the changes in their body and their desire to have a better cosmetic result or the use of wigs and prosthesis to address their body image issues.

> *What happens to us females is that it is so difficult when we don't have one breast. That thing can never be explained to anyone…(Patient, India) (132).*
> *Women felt that their body image, their sexuality, and their reasons for breast reconstruction were all tied into the identity of a woman who has to make decisions for breast reconstruction after reconsidering her personal need for feeling whole.(Researcher, Canada) (134).*
> *Several survivors also reported taking more care than before about their appearance: "When I go out, I take extra care. But… I have make-up on I try to wear nice dress. I have started buying more clothes than I did earlier… So I have something new and just to feel good. (Patient, India) (132).*

> *I wear East Indian suits. You want to look nice, but in my mind, I know there isn't a breast here. Other people can't see that. I want to be normal, like a lady. (Patient age 50,Canada) (134).*

Sharing experience with other breast cancer patients was helpful.

> *If people who have cancer are in each other's company, they come to know and understand each other, because they get hounsla [hope or encouragement] from each other. I will feel better if I talk with similar people who give me hounsla. (Patient, Canada) (134).*

Several women expressed concern about how their sexual life was affected, their partners found them less attractive, or they tend to lose interest in sex.

> *Few survivors voiced their concern about a lack of desire to engage in sexual activity and an inability to get aroused which was associated with vaginal dryness and pain. Moreover, one survivor with lumpectomy also expressed a change in her partner's overt sexual behaviour in the form of preference for the normal breast.(Researcher, India) (132).*

However, in some cases, however, the partners were very understanding and waited till they felt ready for sex.

> *It was really tough in the beginning. My husband was really good ... very supportive. He wasn't, you know, pushy or any of that stuff; he was very patient with me when it came to, you know, intimacy.(Patient, Canada) (134).*

There was an interesting observation from few women comparing sex life to animal life and is used for procreation only, some women found it very difficult to talk about their sexual life.

> *Another participant had extreme views that sexual life could be equated to "animal life" and it serves the function of procreation purposes. (Researcher, India) (132).*

Psychological symptoms were varied in women, some experienced severe shock, disbelief, depression and adjustment issues. Many women associated cancer with dying and were constantly living with the fear of death. This could be seen in the same women during different stages of disease and in some cases was a constant psychological response.

> *Younger south Asian women (<44 years of age) experienced depression related to reproductive issues associated with the cancer diagnosis, because the diagnosis changed the normal cycle of life (Researcher, Canada) (134).*

> *The women often left sentences unfinished and interrupted their own telling of their story with experiences of worry, fear, pain, and anxiety. (Researcher, Canada) (133).*
>
> *Depression, I used to get it a lot in my mind, in my heart. I used to feel like crying. My mind used to get upset. I am getting better now, but it still bothers me. (Patient, Canada)(134).*
>
> *Life is finished nothing is there after getting cancer….There is a belief among people that people will die if they get cancer. (Patient, India)(135).*

Few women however displayed more courage, were able to accept the situation with positive thoughts and were able to cope better.

> *When I was diagnosed with breast cancer I was frightened, but my family helped me realize that breast cancer was just like any other disease that could be treated. Now that my treatments are over and I am as healthy as I can be, I try not to think about breast cancer. It was just another health problem among other health problems that I deal with. (Patient, Canada) (133).*
>
> *I did all the treatment.... They did the operation; they did the surgery.... What is there to be scared of? You can't do anything about it; just accept it.(Patient, Canada) (134).*

4.5.8.2.2 Information seeking

Most women wanted information about their disease, treatment and side effects, which had both positive effect and negative impact on any psychological distress when they had difficulty in accessing information due to language barrier. Women described diverse ways in which they sought information about their condition like questioning medical professionals, talking to other patients, reading books as well as from internet.

> *One woman said: ''I read a lot about cancer from the books and the Internet. I was well informed after reading and gathering information.'' Another commented: ''I was constantly questioning the doctor.(Patient, Canada)(131).*

Some women used their illness as motivation to raise awareness among others and to talk about their experiences to reduce psychological distress in others.

> *I finished my radiation in May. I just felt I had to do something for other patients. (Patient, Canada) (134).*

Language was felt to be a major barrier to understand the information provided especially for migrant women and they expressed a desire to have written material in a regional language for better clarity.

> *Participants preferred a written, language-specific (especially for those who spoke only their own language) care plan in a booklet format.(Researcher, Canada) (134).*
>
> *They felt that they did not receive adequate patient support and counselling from the breast cancer care agency or their family physician, especially in their own language, which prolonged the depression.(Researcher, Canada) (134).*

For some women, this lack of communication, compounded by poor education, language barriers, and a culture where individual autonomy in health care decisions is not as emphasised as in western culture, had serious consequences:

> *One woman, who described herself as ''uneducated,'' indicated that she was not told that her entire breast would be removed: ''They may have told my daughter something in English but to me they just said there would be an operation.''(Patient, Canada) (133).*

A few women felt that the medical team looking after them were insufficiently supportive or lacked the communication skills needed to make them feel comfortable. Some also felt that the family were involved in decision-making more than they wished, and they were excluded thereby adding to their psychological distress.

> *As women struggled to try to make sense of their experiences, they recalled not fully understanding what they were told about their cancer treatments, even when translators were available, and that physicians often gave full explanations to their family members rather than directly to them. (Researcher, Canada) (133).*

Difficulty in gathering information unfortunately added to the uncertainties and worries about the future; the women were particularly concerned about any possibility of recurrence of the disease, metastasis or physical in capabilities due to treatment, although this was less of an issue for older women.

> *Although some sa bcss (south Asian breast cancer survivors) from all age groups shared their concerns about uncertainty and fear of recurrence, younger women (<44 years of age) were more emotional in their responses because of worry that the cancer might recur and because of the unknown future. Women in the middle age groups (45–54 and 55–64) were more concerned about what would happen to their children if the disease came back. The oldest participants (>65) were mostly not concerned about recurrence or uncertainty.(Researcher, Canada) (134).*

4.5.8.2.3 Coping and the barriers involved

The women described the various methods that helped them to cope with the diagnosis and treatment stage, they referred to hope, support from friends and other patients.

> *If people who have cancer are in each other's company, they come to know and understand each other, because they get hounsla [hope or encouragement] from each other. I will feel better if I talk with similar people who give me hounsla. (Patient ,Canada) (134).*
>
> *Everyone used to give me hounsla [encouragement or hope].... That's ok ... you are alright .. you'll be fine. Do your Paath [prayers].... I did a lot of Paath and went to the Sikh temple.... Everyone used to give me hounsla. (Patient,Canada) (134).*
>
> *Most women felt that sharing with others who had gone through similar experiences was more meaningful, thereby providing social support that would enhance quality of life for south asian women who felt shy and who had language barriers. (Researcher, Canada) (134).*

Some also described how they resorted to practical solutions to deal with their problems and cope with their situation including breast prosthesis, wigs etc.

> *Others either shaved their heads before the chemotherapy sessions began and had wigs made out of it or as one participant said: "I bought a couple of wigs off the net and I would go around in my blonde avatar. Actually got a blonde (laughs) just to kind of cut off your nose to spite your face kind of thing…"(Patient, India) (132).*

> *Adjustments for those undergoing mastectomies involved using substitutes such as prosthesis, padded bras, and pads. The use of prosthesis on an everyday basis was convenient, but its weight was a concern and others would use pads made out of cloth. (Researcher, India) (132).*

There were instances were women described feelings of fear, anxiety, panic and social isolation which prevented them from coping with the situation.

> *The women often left sentences unfinished and interrupted their own telling of their story with experiences of worry, fear, pain, and anxiety. (Researcher, Canada) (133).*

> *Some participants described the experience of social isolation and dependence on family members (Researcher, Canada) (134).*

Interestingly the effect on finances were mentioned from the studies from Canada and not from India. Being a migrant population, income from both partners was particularly important and the women found it increasingly difficult to work due to physical difficulties of treatment.

> *It is understood, however, that this concern is not unique to sa bcss,(south Asian breast cancer survivors) but applies to the migrant population who may be reduced to working under strenuous conditions when their family income depends on both spouses being gainfully employed. Two-spouse incomes are more central in an immigrant population in which vocational options may sometimes tend to be more physical in nature, with longer hours of employment (Researcher, Canada) (134).*
>
> *Along with being worried and fearful about recurrence, the women drew attention to their financial difficulties because they were unable to work due to residual physical pain and weakness. (Researcher, Canada) (133).*

Indian women living in Canada were exposed to a culture which has different expectations as regards to the role of women in family, where women were expected to make contribution to society through employment, politics and this is different to what they see at home and this need to be kept in mind while looking after them. A diagnosis of breast cancer is not just confined to a woman's life alone, rather if affects her immediate family, her religion and the wider community where she lives. This can affect her both positively and negatively. All these influences will dictate how she responds to the diagnosis and treatment. Positive influence can help her to accept it, cope with it better and make practical adaptations in her life. On the other hand, the negative influence of her cultural context can aggravate the psychological distress. These can lead to mental health issues as well as non-compliance with treatment.

4.5.9 Critical Interpretive Synthesis (CIS)

CIS combined findings in relation to i) mental health and ii) stigma and body image (see Table 10). Although Indian women had significant depression and anxiety with similar rates to those in other populations, this was framed by their culture which remained similar in both Indian and Indian migrant communities. Indian women in India and in migrant communities experienced their community, family and religion as both supportive and as causes of distress, sometimes sufficient to cause refusal of treatment. Those in migrant communities had additional sources of distress: difficulty in accessing host-country community support and further reduced participation in decision making due to language barriers and financial distress, if the disease or treatment stopped a necessary second income. In addition to the language barrier, support groups for breast cancer women in Canada were seen as not culturally relevant or congruent with the Indian migrants' needs.

Stigma and body image were related and amplified by the foundational role of women in Indian society as wife and mother and poor knowledge about the nature of cancer. Fears that cancer was transmissible led to social isolation, and whole families became stigmatised in terms of the marriage prospects of the daughters or sisters. Core beliefs about feminine roles meant that the impact of breast cancer on sexual function, sexual attractiveness, and ability to bear children, and roles of homemaker and provision of care for children, in-laws and husband was serious. Even for Indian women in India, experience of the response of family and community was not always seen to be culturally congruent for the individual women concerned, preferring societal expectations to personal experience.

Table 10: Critical Interpretive Synthesis (CIS)

Psychological concerns	Relevant findings from quantitative studies	Relevant findings from qualitative studies	Synthesised findings
What are the psychological concerns of Indian women with breast cancer?	Anxiety/Depression, body image issues, stigma, factors affecting mental health component of quality of life	Women reported significant psychological distress both helped and aggravated by their community, family and religion	See below under the separate concerns
Mental health	• 21.5 % of patients had depression • Higher levels of anxiety and depression than: ○ normal controls, ○ those after surgical procedure for other cancers, ○ those responding to chemotherapy, ○ those from joint families. • Prevalence rates similar to studies	Overall, support from community, family and religion reduced distress and helped patients to cope in both home and migrant communities • However, social expectations have negative impact by increasing pressure: ○ to be socially correct, ○ to have children immediately after marriage; fear of infertility prevented	• Indian women have significant depression and anxiety with similar rates to those in other populations. • Indian women in India and in-migrant communities experienced their community, family and religion as both supportive and as causes of distress, sometimes sufficient to cause refusal of treatment. Those in-migrant communities had additional sources of distress, including:

Psychological concerns	Relevant findings from quantitative studies	Relevant findings from qualitative studies	Synthesised findings
	from other populations • Emotional wellbeing was directly related to: ○ distance to reach the treatment center, ○ patient’s religion, marital status, education, ○ patient and spouse occupation, ○ extent of disease, ○ method of diagnosis, ○ cancer treatment, e.g., type of surgery. • Poor quality of life also associated with depression and distress due to	some from having chemotherapy. • Though faith supported most, others: ○ practised ‘passive fatalism’ thereby refusing any treatment, ○ believed disease was God’s punishment for religious error, causing additional distress. • Family were most involved in decision making and where women felt excluded, this added to distress. Lack of information in a language they understand, lack of education, difficulty in gathering information	○ difficulty in accessing host-country community support and further reduced participation in decision making due to language barriers ○ financial distress, if the disease or treatment stopped a necessary second income

Psychological concerns	Relevant findings from quantitative studies	Relevant findings from qualitative studies	Synthesised findings
	hair loss.	added to the uncertainties and worries about the future adding to their distress. For the migrant population in Canada, income from both partners was particularly important and the women found difficulty in working due to physical difficulties of treatment adding a "financial distress".	
Body image and stigma	Worse stigma was associated with poor body image scores, low levels of education and breast conservation surgery	• A diagnosis of cancer led to stigma through ○ reduced marriage prospects ○ a belief that cancer was infectious • Stigma led to social isolation	• Stigma and body image were related and amplified by the foundational role of women in Indian society as wife/mother and poor knowledge about the nature of cancer. • Breast conservation, unlike most other studies, was associated with

Psychological concerns	Relevant findings from quantitative studies	Relevant findings from qualitative studies	Synthesised findings
		and delays in presentation to doctors. - Women felt that the loss of breast and loss of hair diminished their feminine nature and core role in their society; cultural dress (which allowed the loss of a breast to be less noticeable), good wigs or prostheses helped to address their body image issues.	greater stigma perhaps due to social scrutiny of an “unnecessary expense” and fears of recurrence.

4.6 Discussion

Indian patients suffer similar psychological concerns to women of other cultures including adverse mental health, stigma and body image issues. However, the psychological distress suffered by Indian women is framed by their cultural experiences and expectations. The review identified particular challenges for Indian migrant women, who not only ‘carry their culture’ to a host country but face significant further challenges in accessing culturally acceptable healthcare following migration.

For migrant women in Canada who had limited acculturation, complexities such as family structure, religion and community affected adversely, particularly in terms of decision-making and the role of women in households and society. Aspects of cultural competence (by the service provider) and cultural congruence (related to the patient’s perception of care received) are apparent and highly relevant in patients experiencing “otherness” aggravating distress (77). This is seen not only in-migrant communities where culturally competent care may be challenging, but also in Indian communities where within their cultures, individual women may not receive culturally congruent care and assumptions are made by clinicians and families about culturally competent care.

India is traditionally a highly religious country, both spiritually and culturally. Commonly, families have a patriarchal, extended structure, with social roles prescribed based upon factors such as age, gender and community influences. The review reported data from ten states out of the total twenty-eight, there is variation in cultural, social, religious and geographic backgrounds among each state. Some states are predominantly urban and developed, in contrast to few having more rural and underdeveloped areas (136). Though majority of Indians practice Hinduism, it is a minority religion in eight states of the country. However, similarities still remain in the joint or extended family system which is mentioned in some of the sacred Hindu books and has been going on in the land for centuries and consist of number of married couples and their children who live together in the same house (51). On marriage, a girl leaves her ancestral family and becomes a part of the joint family of her husband. Immigrant women living in Canada, however lacks the support from the extended family system that they depended on in their country of heritage which can have an impact on how they cope with the cancer diagnosis (137). Family responsibilities and obligations are the key motivators of caregiving within immigrant South

Asian families(138, 139), and women often takes the role of a nurturing parent who is revered and respected similar to the Indian epics which portray women as bound by tradition, diligent , self-sacrificing, self-denying, and yet powerful (57). My review found that family was a powerful source of support and it influenced women positively and negatively. The support was in the form of providing physical care, helping in household duties as well as encouraging them to think positively. A qualitative study examining the experiences and responses of family members of immigrant Punjabi women diagnosed with breast cancer found that family members made significant sacrifices to support relatives with breast cancer and accepted considerable disruptions to their personal and work lives (140). Some women, however, felt the need to support the family members emotionally as they couldn't cope with the shock of the diagnosis for the loved one. Women also faced the loss of their major role in the family of being a mother and the thought of not fulfilling that role made some women non-compliant to treatment. Indian women grow up in multi-generational households where the decision-making power rests with the male household members, initially fathers, then husbands and then the adult son. This contrasts with patient autonomy and shared decision making in Western cultures where patients have priority in treatment decisions.(141) Exclusion from decision-making, exacerbated by language barriers, was an evident cause of psychological distress of Indian women in Canada (131). Interestingly, a recent Indian survey showed that the majority of patients wanted full disclosure about their cancer, its treatment and prognosis even if this was poor, in contrast to their family carers few of whom shared this information believing it to be harmful (142). In addition to the conventional roles and responsibilities associated with being docile wives, dutiful daughters-in-law, fostering mothers, and self-sacrificing caregivers, many of the migrant women in Canada were expected to hold full-time employment and take responsibility for most of the domestic chores which was in contrast to their practices in India where women often have access to domestic help and support of extended family, and if they were well educated they were not expected to do physical work (137). Some women in the review felt that the families were not understanding and supportive enough as they still had to continue with all the house hold and child care responsibilities post treatment (131).

In breast cancer survivors of various ethnicities, more acculturated migrants were found to be more proactive in their medical treatment by taking responsibility for their care, avoided isolation and having a positive attitude (143). My review highlights the additional issues facing immigrant Indian women; difficulties in accessing information, accessing support other than family, and exclusion from joint decision-making in stark contrast to the non-migrant women they observe at the clinic (134). Migrant women also face distinct challenges where a breast cancer diagnosis limits their ability to manage the household and contribute financially to the family. Mental health issues in migrants are recognized, including the challenges faced because of language and cultural differences; the effect of culture and society in shaping of symptoms and illness behaviour on diagnosis, coping and treatment; effect of employment, social status and integration, differences in family structure and process affecting adaptation, acculturation and intergenerational conflict (72, 73).

Extended family and community are always considered as strong sources of support for Indian women (139), traditionally the community is seen as an extended family and societal responsibilities of each individual are prescribed in the Vedas which are the holy book of knowledge. In addition to familial duties, an individual also has responsibilities to the welfare of the community (57). To maintain the community connections in the country of migration women are seen to develop links with services through their social networks, which included relatives, friends, community or church associates, and professionals (144). However there is also a stigma related to cancer as well as any health related problems in the community and women believed that it is important to maintain the appearance of a healthy family with a strong lineage to ensure their daughters are married on time so they tend to keep the diagnosis of breast cancer as private as possible (145). In contrast, my review found women who were willing to talk about the diagnosis with peers, and to hear from people with a similar diagnosis and appreciate the psychological and emotional support from such a discussion (131, 134). However few women did describe the stigma associated with cancer diagnosis and the negative effect of community where people visited only to be socially correct and were keen to be kept away from them (134). Immigrant women also felt the need for a common language or having someone in health care system to talk to them in their own language as few women were not well versed in

English (131). They also talked about having peer support groups to share their unique cancer stories within their own cultural and social context, in their mother tongue, making the exchange more meaningful and supportive (134). This is similar to the needs of Chinese immigrant women where 80% of participants in a study expressed interest in programs tailored for Chinese cancer patients, particularly information based potential services like about financial and social assistance, and general healthcare (143).

For migrant families, a lack of extended family or wider community system may affect how migrant women cope with cancer (137). Lack of social support has been identified as contributing to depression in Indian breast cancer survivors living in the UK, along with other patient-related factors like younger age, previous psychological problems and non-cancer related difficulties (17).

Family and community expectations may also influence the treatment options available to women as well as their autonomy to make informed treatment choices. There is a deeply embedded tradition that Indian women are expected to conceive within one year of marriage (59), and women may be stigmatised if they remain childless, either voluntarily or involuntarily (61).

Choice of treatment type also had an impact on subsequent depression or anxiety aggravated by exclusion in decision-making and levels of support. Breast conservation, was associated with greater distress than mastectomy in one study (126), perhaps because of more fears about recurrence. Irrespective of the type of treatment, the women in my review were significantly affected by the loss of breast and loss of hair, though cultural dress enabled them to feel the loss of a breast was less noticeable. Symbolic interactionism helps us to understand that woman learn meanings and symbols through social interaction which is essential to expression of thought. Women often consider their hair and breasts as symbols of femininity and womanhood, loss of hair secondary to chemotherapy is often associated with loss of femininity, sexuality, attractiveness and womanhood (146) while loss of breasts as part of treatment embodies loss of femininity, beauty, and motherhood (147).These convictions can affect their decision making particularly in relation to treatment choice (148). Although in general, breast conserving surgery was associated with reduced stigma (118), in keeping with other work (149, 150) women who chose to have conservation may have felt under social scrutiny, seen as an unnecessary expense, highlighting the conflicting pressures women must navigate in order to make an informed treatment choice.

Culture and religion influenced women's understanding of cancer and access to appropriate information. Poor understanding about the cause of breast cancer led to isolation and depression. 'Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred' (151). Religion, one type of expression of spirituality, is a set of organized beliefs about God that is shared within a community of people (152). There are a number of studies which corroborate the role of spirituality and prayer in helping patients from diverse cultural backgrounds accept the cancer diagnosis, find inner meaning and peace, and positively pursue cancer treatment despite fatigue or pain (152-155). A diagnosis of breast cancer can be distressing and shocking to the women and they tend to turn to religion and faith to understand the reason behind the cancer diagnosis and also as a method of acceptance and coping. Religion can help people attribute meaning to situations, provide support and consolation and help to regain the sense of control apparently lost when faced with an adverse situation (156). Previous studies in breast cancer patients and survivors have shown that 85.4% of the women reported that religion helped them cope with their illness (157) and they turned to religion hoping for guidance from God through the illness and for support from other members of their faith community (158). Religion as a coping strategy has also been reported as used by Indian patients diagnosed with depression living in the UK (159). The women in the review are seen to attribute the cause of their cancer to various metaphysical beliefs like *Karma* (131, 133, 134), *kismet* (133), and *God's will* (131) which is in keeping with the traditional Indian society metaphysical beliefs, that karma, God and spirits, are thought to be important causes of life's events like disease and suffering. This is in contrast to the western culture where they believe that the causes of diseases are found in the physical and social world and also do not believe in reincarnation (160). It is seen from studies that patients who attribute disease to God's will showed greater perceived psychological recovery and have a credible and socially acceptable explanation for their illness (161). Thus, it can be considered as an effective coping mechanism for patients faced with a life changing diagnosis

However, women from two studies described '*passive fatalism*' (131, 134) in which they felt that their diagnosis was beyond their power, so were not keen to pursue with treatment, this is in accordance with the South Asian culture which believed that life events are beyond their control. This should be watched out for in our patients as they tend to be non-complaint with treatment and would need additional support from family and medical professionals explaining to them the need for treatment.

4.7 Strengths and limitations of this study

This systematic literature review was conducted and reported according to the PRISMA process,(107) but as with any systematic review, it is possible to miss relevant studies. The additional search involving EBSCO database gave a number of useful papers published from India unavailable elsewhere.

The questionnaires used in the observational studies in the systematic review had been validated in India [DASS21 (162)] or translated and validated in regional languages like Malayalam [HADS (163),PHQ-9 (164), FACT-B (165), WHOQOL-BREF (166)], Marathi [PHQ-9 (167), EORTCQLQ-C30 (118)], Hindi [EORTCQLQ-C30 (118)], Tamil [EORTCQLQ-C30 (168)]and Telugu [EORTCQLQ-C30 (168)].

Only five qualitative studies were found, with only two conducted in India. Even after excluding the two studies at most high risk of bias, the quality of the observational studies was poor in many aspects highlighting the need for high quality research in this field which includes work done in India. Critical Interpretative synthesis was used to combine the results from both quantitative and qualitative studies.

4.8 Implications for clinical practice

Clinicians must be aware of the range of issues contributing to the significant psychological distress experienced by Indian women with breast cancer. Cultural issues relating to individuals, families and communities both helped and contributed to depression and anxiety. Therefore, the culturally competent clinician will assess the patient as an individual – whether in the West or in India. Unless this is done, the risk of cultural incongruence will remain with serious psychological consequences for the patient. Even in India, the clinician must not assume that they know all the culturally relevant influences, and must also allow for differences in regional language spoken, especially in tertiary hospital settings. Early support to reduce the impact of diagnosis and treatment decisions and side-effects, with access to appropriate language is important - especially so for immigrants or those accessing healthcare out of Indian region/state.

A family-centred approach to care, but one which includes the woman in decision-making will help overcome barriers women face in India and elsewhere. Migrant Indian women had additional stigma to their western counterparts, and thus careful discussions are needed with individuals regarding treatment choices and accessing support, including access to wigs from their own hair. The importance of motherhood and parenting should be kept in mind for young breast cancer patients. Religion and spirituality are important for coping and chaplaincy services tailored to the needs of women should be an integral part of clinical services. Clearly important for Indian women, culturally competent and congruent care is important for all people, regardless of their culture or heritage. Future research should also focus upon the specific concerns of women from other cultural backgrounds, with particular attention paid to the distinct needs of migrant communities.

4.9 Implications for future research

Our review highlights how cultural background can influence psychological outcomes in cancer care, with particular challenges for migrant communities. As international migration increases, so too does the complexity of delivering culturally congruent care. Culturally congruent care moves beyond cultural competence, to address ‘cultural distress’, caused by the *additional* challenges of accessing appropriate health and supportive care in the host country. For example, research among Caucasian women with breast cancer shows group therapy improves their psychological outcomes,(169, 170) yet migrant Indian women in Canada often declined the support offered by local cancer agencies.(133)

Findings identified by this review are highly likely to have relevance for other medical conditions and populations. Migrant Indian women in Canada expressed the need for a healthcare professional to talk to them in their own language as few women were fluent in English.(131) Peer support groups, in their mother tongue, to share their unique cancer stories within their own cultural and social context make the exchange more meaningful and supportive.(134) The same issue is described with immigrant Punjabi women who were reluctant to discuss health concerns outside of their family network, feeling more comfortable if family members accompany them when accessing health services and support groups.(137, 145) Similarly, Chinese immigrant women would prefer programs tailored for Chinese cancer patients.(143) Future research should seek to identify the particular challenges faced by migrants with different healthcare problems and from different cultural background in order to inform the delivery of culturally congruent care.

4.10 Summary

This chapter described the findings of the systematic literature review and qualitative synthesis. The synthesis of the review shows that although Indian women had significant depression and anxiety with similar rates to those in other populations, this was framed by their culture which remained similar in both Indian and Indian migrant communities. Indian women living in India and Canada experience a range of psychological morbidities in relation to breast cancer diagnosis and treatment which profoundly affect their role in the family and wider community. Culturally competent and congruent care including excellent and accessible communication and information giving is important to both prevent and alleviate distressing symptoms whether in India or as part of an immigrant community.

In **Chapter 5**, I will discuss the findings from patient interview study conducted among breast cancer patients in India.

5 INTERVIEW STUDY

5.1 Introduction

Chapter Four described the findings from the systematic literature review and qualitative synthesis which showed that although Indian women had significant depression and anxiety with similar rates to those in other populations, this was framed by their culture which remained similar in both Indian and Indian migrant communities. In this chapter I describe the methods used, the findings and a discussion of the findings of the semi-structured patient interview which was designed to answer the following research questions:

1. What are the psychological concerns of women of Indian heritage receiving treatment for breast cancer in relation to breast cancer and its treatment?
2. What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?

5.2 Rationale for choice of methods

To answer the research questions and gain an understanding of the psychological symptoms faced by Indian women with breast cancer undergoing treatment, a qualitative methodology was used. In social research, the power of language is often used to clarify the meaning, thus personal description has great importance (90). The research interview is an important data collection strategy which is used in qualitative research. An interview is a method of collecting data whereby the interviewer interacts with the participant and the responses are collected verbally. This would involve a more direct interaction between the researcher and the participant than questionnaires. There are various types of interaction between a researcher and participant. Hence in qualitative interviews, much interest is given to the interviewee's point of view. Qualitative interviewing is usually flexible and it follows the direction taken by the participant, allowing the emphasis to change based on any new issues that emerge. This is known as an iterative approach where the data collection continues on to analysis and back until the description of experience is comprehensive and saturated (171). The structured interview, which is sometimes called a standardized interview, is one of the ways of administering a survey research instrument and involves the administration of an interview schedule by an interviewer (79). All the interviewees are given the exact same questions thereby receiving the same interview stimulus. However, this was not chosen because it would not give the participants flexibility to talk about their individual issues or have an in-depth discussion about their psychosocial concerns. Other data collection approaches could have been used for the patient study, such as a focus group discussion. This is a type of group interview where the communication between research participants is important to collect data, and they are encouraged to talk to one another: asking questions, exchanging stories and commenting on each other's experiences and points of view (172, 173). The advantages of using focus group methodology are that it could encourage participation from those who are reluctant to be interviewed on their own as well as those who feel they have nothing to say could engage in the discussion generated by other group members. To answer the research question two, I have used both the interview and focus group data collection approaches. Interviews were used to understand the views experienced by individual women who had undergone treatment for breast cancer, rather than focus group discussion as some women might find it difficult to express their psychological concerns and talk about sensitive issues and their experiences in front of others (173). I allowed a family member to be present at the interview (non-participatory) if specifically requested or required as a pragmatic decision; to help the participant feel comfortable, or where this was a prerequisite for consent. However, I used focus group discussion, as described later (see Chapter 6), when opinions from oncologists, nurses and members of public were sought.

In-depth or unstructured interviews are one of the key methods of data collection used in qualitative research where the researcher does not influence the scope and depth of the participants response and allows the individual to define their world which is important for grounded theory methodology where little is known about the subject area or problem (174). As there is already a considerable body of literature about psychological concerns of women with breast cancer in general, and some knowledge about the concerns of Indian women, grounded theory approach has not been used here. For patients, I chose semi-structured interviews as opposed to other qualitative methods as it is a commonly used approach in qualitative studies where there is already prior knowledge of the subject and so a grounded theory approach is not appropriate, and gives an understanding into the thoughts and behaviours of the participants. The interview guide was developed using open-ended questions based on the current literature and expertise of the student and supervisory team. This was to elicit in-depth answers about patients’ experience during cancer diagnosis and treatment, their manner of coping and how they made sense of the disease.

A purposive sample of patients with a wide range of specific characteristics (age, living alone/with others, socioeconomic status, level of education, number of children, marital status) was selected from those who were referred from the Department of Oncology, who gave informed consent to take part in the study, to gain maximum variation in responses and experience. The purposive characteristics aimed to result in a population with maximal variation with regard to issues which may affect patients’ experience. Sampling methods used in qualitative research are theoretical sampling in the context of grounded theory which is usually developed by snowballing technique, and convenience sampling where available participants are recruited by means of accessibility (175). Neither of these methods were used in my interview study as it would not provide me with the wide variation in participant characteristics, I needed to provide rich data. However, convenience sampling was used for focus group discussion as described below. The patients were interviewed on their own usually, but in some situations the carers wanted to stay with them as they were very much involved in the care of the patient. In one instance the patient was unaware of the cancer diagnosis and the carer insisted on being present. However, the carers only provided prompts regarding treatment details if patients were not able to provide them.

5.3 Research setting and study governance

I was involved in preparing the research protocol and presenting it to the ethics committee along with the departmental head (CS). The informed consent and the topic guide in regional language was modified and submitted again before approval was obtained. Approval was obtained from the Ethics Committee and Scientific committee of Amrita Institute of Medical Sciences and Research Center prior to recruitment and institutional approval was gained from the hospital. (Appendix 11) As the approval was given prior to postgraduate school registration and patient interview data collection was starting at the point of registration (1st October 2015), the necessary approvals were confirmed to be in place by the supervisory team and submitted for information as part of the HYMS submission for the focus groups (submission form included in Appendix 14)

- Patient interviews:
    - Ethics Committee and Scientific committee of Amrita Institute of Medical Sciences and Research Center (approval obtained 03/08/2015)
    - Institutional permission (approval obtained 30/08/2015)
    - HYMS ethics committee informed, with approval letters included as part of focus group submission (submitted for approval 11.12/2015)
- Focus groups:
    - No Indian ethical approval required
    - HYMS ethics approval received (REF 15 21; 17/12/2015) (Appendix 12)

The study was performed in accordance with the 1964 Declaration of Helsinki and its later amendments.

5.4 Interview methods

My personal contribution was in the i) concept and design of the study, ii) writing of the protocol and topic guide, and gaining necessary governance permissions, with the support of my Indian supervisor (Dr Chitra Venkateswaran), data collection and analysis with the support of both supervisors, and additional mentorship from Dr Ann Hutchinson from the Wolfson Palliative Care Research Centre with regard to the qualitative analysis, iv) writing and interpretation of findings with support from my supervisory team.

5.4.1 Setting

The interviews were conducted in a tertiary hospital in the South Indian state of Kerala (October 2015 to January 2016).

5.4.2 Participants and eligibility criteria

5.4.2.1 Inclusion criteria

All adult patients with breast cancer undergoing treatment and agreed to take part in interview who

1) Are able to give written informed consent.
2) They should be able to understand and speak Malayalam.
3) Able to take part in an interview

5.4.2.2 Exclusion

Those patients who are unable to participate in an interview due to physical or cognitive impairment

5.4.3 Development of the interviews

5.4.3.1 Design

This qualitative study used in-depth semi-structured one-to-one interviews allowing for the cultural context of South India. The range of experience and cultural expectations even within the same hospital, could make it difficult for some women to express their psychological concerns freely and talk about sensitive issues and their personal experiences in front of others hence the interview methodology was applied.

5.4.3.2 Eligibility, invitation and consent

Eligible patients attending the Medical Oncology department of Amrita Institute of Medical Sciences and Research centre were invited to take part by their usual clinician during a routine appointment. From the patients with breast cancer attending the department of Oncology for follow up, a purposive sample, aiming for approximately 20 of patients with a range of specific characteristics (age, living alone/with others, socioeconomic status, level of education, number of children, marital status) was selected, to gain maximum variation in responses and experience and allow examination of convergent and divergent experience.

Interested participants were given detailed written information (see Appendix 3 Participant information Sheets) and consent taken by the researcher (SD). Written consent to interview was sought after any of the participant's questions had been answered. The consent forms were both in English (Appendix 3) and Malayalam. (Appendix 4) Audio-recordings of all interviews were made. Informed consent included for use of anonymized quotes for publication purposes.

5.4.3.3 Data collection and management

I interviewed the participants in a private room without interruption at a time that was convenient to them when they came for clinical review at Oncology. The participants were interviewed on their own unless there was a particular reason for the carer to be in attendance (non-participatory apart from giving factual information). A research observer (CV) was present during the interviews, taking field notes to record any observations, for example, about the body language of participants. A family carer could be present if requested. Sociodemographic data were collected at the beginning of the interviews.

The interviews (duration 30 to 45 minutes) were audio-recorded, verbatim transcribed, translated into English (SD) and back-translated (CV) to ensure fidelity to the participants' experience. The purpose of translation to English was to publish in English, but also to allow the non-Indian researcher (MJ) to participate in the analysis thereby helping to address some of the potential challenges in reflexivity as SD and CV were both staff working in the Department at the time of the data collection and both from the culture involved. MJ however, works in UK clinical-academic environment and therefore is able to view the service and culture – both in terms of similarities and differences - from a distance.

Interviews were conducted in Malayalam (regional language) to obtain rich, comprehensive and uninhibited stories and used a topic guide (Appendix 5) based on research team expertise and the literature. As my systematic review was not complete prior to data collection, the initial topic guide was informed by the findings of my informal scoping, and then added to as emerging findings from the systematic review became apparent. The participants were asked broad open-ended questions about their experience of being diagnosed with cancer, with particular emphasis on mental health, how they went through treatment, their coping strategies, the change in their role and family expectations and faith and spirituality as a coping mechanism. The transcripts were read and checked for accuracy, and any new topics emerging from initial interviews were incorporated into future interviews. Data saturation (175) was considered adequate when no new codes were seen, and convergent stories predominated.

To preserve confidentiality, names and contact details collected in a patient demographic sheet were stored in a locked cabinet. The audio-recordings were stored in a password protected laptop and were then immediately erased from the recorder used in interviews. The recordings were permanently deleted after 5 years of data collection. All transcripts were anonymised and given unique identifier with no personal details to identify the patient.

NVivo 12 software, a computer-assisted qualitative data management program, was used to code, store, and organize data.

5.4.3.4 Ethical considerations

The ethical concerns considered during the interview process includes participant burden, gaining consent, maintaining confidentiality and management of any psychological distress arising because of the interview. Participants were interviewed in a quiet private room during one of their routine visit to the hospital thereby minimising their need to travel for the interview. The interview lasted approximately one hour, and breaks were offered as required. It was made clear that the participant could withdraw from the study or end the interview at any point if they chose. The interview started with open questions enabling participants to relax and then was followed by direct questions relating to their mental health concerns and coping in response to the diagnosis of cancer. The interview ended with a question probing their experience of the interview process. The researcher, who is a trained palliative care physician, monitored for any psychological distress during the interview process and was equipped to manage, if any, including referral to appropriate clinical services, but none of the participants needed any additional help.

The consenting process was also considered important throughout the study. The primary physician obtained verbal consent from the patient to talk with the researcher prior to being approached by the researcher. The researcher gave the participant information leaflet in the regional language and obtained informed written consent. The participants had opportunity to ask questions of the researcher. The consent form asked for permission to use audio recording as well as use of anonymised quotes for publication purpose use of data for future studies. No monetary reimbursements were offered to the patients or carers.

5.5 Sample size considerations

It was anticipated that 15 to 20 participants would be sufficient (176) but planned to recruit until data saturation was indicated by no new emerging codes. Given the focussed nature of the research question, we also anticipated that we would achieve “information power” from this number (177).

5.6 Analysis

Qualitative analytic approaches can be roughly divided into two; those that arise from a particular theoretical or epistemological position or a board theoretical frame work examples of which include conversation analysis (178) interpretative phenomenological analysis (179) and discourse analysis (180) and those that can be applied across a range of theoretical and epistemological approaches like thematic analysis (113) which is a flexible and useful tool which provide a rich, thorough and intricate, account of data. Thematic analysis which is a technique for recognising, examining and recording patterns (themes) within data was used in my research due to its flexible nature; this would enable women to be heard directly rather than through further interpretation as their voices are less central in healthcare decision-making in the Indian culture. The type of thematic analysis I used was reflexive (181), to fit best with my aim of ensuring the women’s voices were heard. This approach also helped me to study a relatively homogeneous group whilst allowing for variation in experience within that group. Though data collection did not use a theoretical framework, a theoretical framework of “cultural distress”(77) influenced our analysis. The analysis was done by data familiarisation by reading and re-reading, line by- line coding of all transcripts, discussion to describe developing patterns of commonality (themes, or convergence), agreement of analytic themes through further discussion ensuring distinct themes with consistent data (90).

Thematic analysis was used, moving through the stages of familiarization with the data, identification of a thematic framework, indexing the data using the thematic framework, arranging the data into charts, mapping and interpretation of the data (90). Though the interview guide and initial data collection was influenced by the researchers’ general knowledge of the literature without use of a theoretical framework, a theoretical framework of “cultural distress”(77) influenced the analysis. The systematic literature review (Chapter 4) showed that Indian women with breast cancer, even in India treated by Indians, may not receive culturally congruent care and assumptions may be made about what culturally competent care means for an individual. I chose this because the woman’s voice is less likely to be central in healthcare decision-making in the Indian culture. It was felt to be crucial to enable this voice to be heard as directly as possible rather than through further interpretation. The approach also fitted the need to find a relatively homogeneous group whilst allowing for variation in experience within that group. Again this is consistent with what is known of symbolic interactionism; (82) the treatment decision-making process of women is in the context of the meaning they have for breast and hair as symbols of femininity and their core role in their society.

Interviews and field notes were checked line-by-line for accuracy before analysis began. English data were analysed in a step by step fashion: i) familiarisation with the data by reading and re-reading, ii) line-by-line analysis (coding) of the observed beliefs and concerns of each participant with development of agreed codes, iii) coding of all transcripts, iv) discussion between SD and MJ to describe developing patterns of commonality (themes, or convergence) v) agreement of analytic themes through further discussion between SD, CV and MJ (182). All three researchers independently coded the initial interviews and agreed codes through discussion, whilst allowing that new codes could be found, SD then completed the coding of all interviews. Codes were then sorted into broader themes after discussion with the MJ and checked to ensure that data within themes were consistent, and that the themes were distinct from one another.

5.7 Findings

5.7.1 Study participants

The interviews took place between October 2015 and January 2016. Twenty participants were recruited to interview; sociodemographic and clinical characteristics are described in Table 11. Out of the 20 participants (median age 56 years; 42 to 74), 14 were accompanied by a carer (husband) during the interview at the request of the patient and one carer (daughter) insisted on being present as the patient was not aware of the diagnosis. The stage of disease at diagnosis and treatment provided are given in Figure 2 and 3. None of the participants withdrew from the study or asked the interview to be terminated.

Table 11: Sociodemographic characteristics and Clinical characteristics of participants

Variable	
Age	**Range of age (in years), median -** (42 to 74) 56
Education School level Graduate level Not known	**Number (%)** 10 (50%) 9 (45%) 1 (5%)
Economic Status Middle class Upper middle class	**Number (%)** 19(95%) 1 (5%)
Marital Status Married Widowed	**Number (%)** 17 (85%) 3 (15%)
Religion Hindu Muslim Christian	**Number (%)** 16 (80%) 1 (5%) 3 (15%)
Main Carer Husband Son	**Number (%)** 16 (80%) 2 (10%)

Variable	
Daughter	1 (5%)
Daughter-in-law	1 (5%)
Carer lives with patient	**Number (%)**
Yes	19 (95%)
No	1 (5%)
Patient aware of the diagnosis	**Number (%)**
Yes	19 (95%)
No	1 (5%)
Carer aware of the diagnosis	**Number (%)**
Yes	20 (100%)
No	0 (0%)

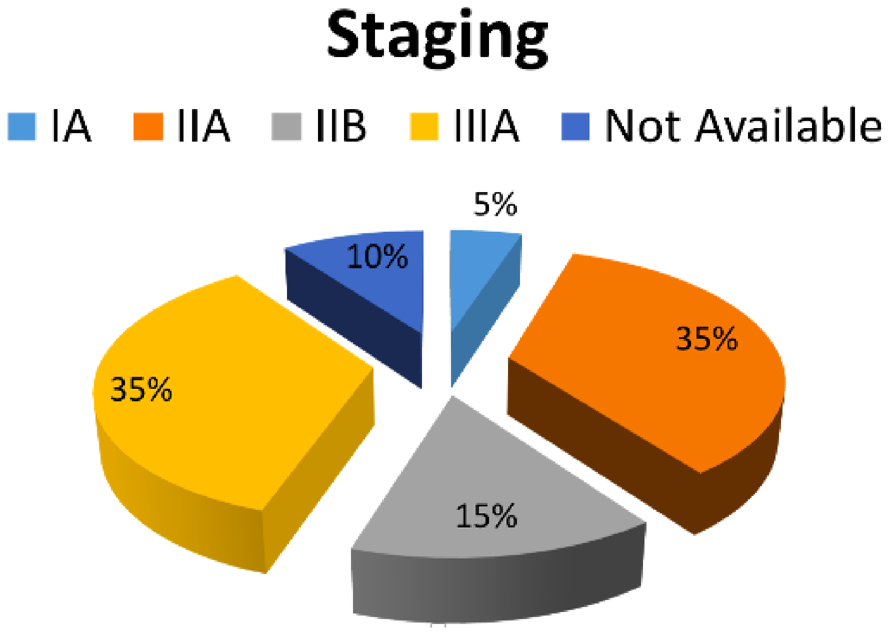

Figure 2: Stage of disease of participants

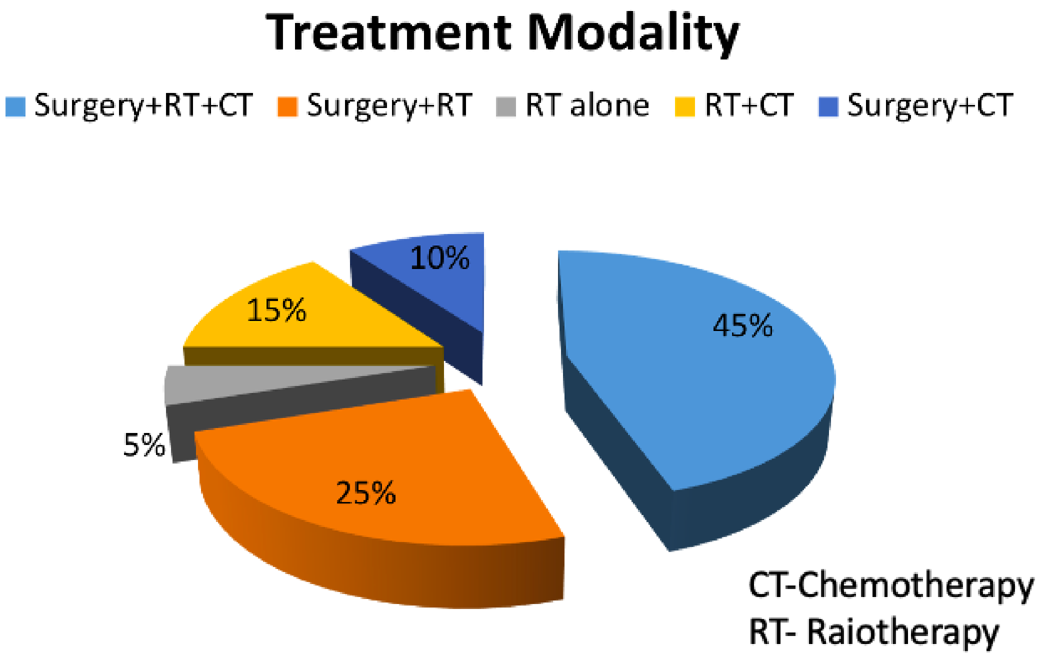

Figure 3: Treatment modality provided.

5.7.2 Findings from the thematic analysis

Three major themes were generated: 1) Far reaching psychological distress of patients to disease and treatment 2) Getting on with life 3) Influence of their support system. The major themes, subthemes and codes are described in Table 12**.** The complete list of quotes from the study are given in Appendix 6

Table 12: Themes, subthemes and codes.

Major themes	Sub themes	Codes
Far-reaching psychological distress	Anxiety	Anxiety, fear, uncertainty, worries about future Anxiety in relation to: Effect on function, Inability to do physical activity, Change in routine habits and Impact on sexual function. Surprise, unexpected,
	Depression	Sleep issues, Loss, grief Lack of interest

Major themes	Sub themes	Codes
		Loss of hope
	Other psychological response	Guilt, Blame, Shock, Anger, Inability to talk about problems Distress due to Physical side effects of treatment symptoms, Alopecia, scarring, skin changes, Lymphedema, Treatment experience, body image
Getting on with life	Making sense of the disease	Disease perception, understanding, knowledge by patient
	Actively seeking information	Seeking knowledge Utilisation of resources
	Role of medical professional	Role of medical professionals
	Practical aspects	Access to care, transport Economic, Financial lack of resources
	New way to live normal	Rationalisation Information Intellectualization Pragmatism, stoicism, acceptance Positive thinking Maintaining normal Practical, active, adaptation, personal life style change Keeping busy
	New future	Responsibility for people

Major themes	Sub themes	Codes
		Action: warn others Raising awareness Positive thinking: Resilience Caring for self, hobbies Emotional resilience Facing up to the future Downwards comparison
Support system	Family and friends	Role of family in decision making Relationship with husband Family changes, role in family Feeling of burden to family Role of friends
	Faith	Prayer Faith, spirituality, faith fatalism Bargaining with God
	Community	Perception by community Lack of empathy from professional Social stigma Social isolation Invasion of privacy Preference of female doctor

5.7.2.1 First theme: Far-reaching psychological distress

As reported in the literature review in Chapter Four, women from our study also described a range of emotions which included shock, disbelief, anger, guilt about the delay in diagnosis, anxiety, depression, uncertainty, social isolation, physical inability and loss of independence during treatment and living in fear of recurrence. Some women became moved during the interview, reliving the days of diagnosis and found talking about it difficult, although valuable. Worries about role changing, ’who is going to look after me’, ‘who is going to look after my children’ were expressed by many women. Another major concern was the uncertainty ‘not knowing whether this is going to come again’, living in constant fear of recurrence.

5.7.2.1.1 Anxiety

Some women, due to their pre-existing beliefs about breast cancer and its causes, had been convinced that they would never get the disease and were shocked at the diagnosis.

> *In my family in all these years there is a history of heart attack, my father’s father had it. I was expecting that since I am a bit overweight (laughs) I would be getting that and I never thought that I would get cancer’ (Participant 17; aged 40-50)*
>
> *I have been told that people who eat non-vegetarian food or smoke or take drugs get illness like cancer, I don’t do anything, I eat pure vegetarian food and still I got this so I felt upset about that (Participant 10; aged 60-70)*

Lack of familiarity with medical terminology by some led to delay in understanding and accepting the diagnosis. When the terms were explained in the consultation, this added to their shock.

> *I never thought it is going to be this, I was convinced that I will not get this disease, somebody mentioned the word carcinoma and I didn’t know that it meant this, I always thought the word was cancer, also there was a mention of malignancy in mammogram, I didn’t know that was cancer either. So, when doctor told me the result, I said I didn’t understand. Then he explained that it is the first stage of cancer: then I was really shocked’ (Participant 7; aged 40-50)*

Many were worried about the impact of having cancer on the future of their children, who were 'too young' at diagnosis and 'still in school'; the younger mothers in particular expressed distress at the risk of not being with them as they grow up.

> *My children were not settled, my son was studying a course in Engineering, thinking all that (voice breaking), and younger son is studying in school. Husband has retired from work. Thinking of all that made me sad (Participant 15; aged 50-60)*
>
> *My main thoughts were, my children are still young, I have a husband, I am the one who looks after everything in house…(Participant 14; aged 50-60)*

In addition to the anxiety in relation to their children and family responsibilities, they had many anxieties about the process and personal effects of cancer treatments.

> *But when chemotherapy started, I had lots of issues, I was alone in house with nobody to help me as I am used to doing things on my own, my mind was always tensed thinking 'how did this happen to me, 'oh, it has happened to me' and I keep thinking about other people dying. I am normally an anxious person and I worry about small things, and I had problems with depression in past and I had got treatment for that. That was all completely cured, now I don't have any problems. (Participant 13; aged 60-70)*
>
> *So, I was anxious and especially when chemo started and I had problems I was worried whether I would be able to complete it till the end, there was so much difficulty, it took nearly 10 days for me to get up and sit on the bed. (Participant 16; aged 40-50)*

Fear of not coping with physical symptoms of the disease and treatment was significant, in relation to how symptoms would affect their ability to function. Household work tended to be the sole responsibility of women, so being physically unable to fulfil that role would add to their distress. They feared that their symptoms would become overwhelming, forcing them to discontinue treatment which added to their anxiety about disease recurrence.

Most of the women shared concerns about the possibility of disease recurrence; many believing that cancer was by nature incurable and that recurrence was inevitable. In addition to getting information from their treating doctor, they also had a range of information sources of varying accuracy (media, other patients etc.) available to them in the house or while attending oncology follow-up. This anxiety added to already high levels of vigilance about any further symptoms leading them to seek medical advice and the reassurance of a "negative test" to help them to move forward.

> *I keep worrying about whether the disease will come again. I listen to doctor talking on radio and they say it could come again; some doctors say after some time it could come again. Here also when I see other patients, they say they had it before, and it has come back second time. But my test is negative in arm pit so I am bit relieved'. (Participant 11; aged 40-50)*

In general women experienced a decrease in or lack of sexual desire after treatment due to physical symptoms of fatigue in conjunction with the hormonal treatment with accompanying reduced libido, vaginal dryness and worries about infection. A few older women reported abstinence prior to the diagnosis due to already declining health and did not attribute lack of sexual activity to the cancer.

> *I haven't had any contact since the diagnosis, mainly because I am too tired and fatigued to do it and my husband is accepting that. He doesn't have any problem with that'. (Participant 16; aged 40-50)*

Despite the effect on sexual activity, most of the women reported that their relationship with husband was not adversely affected; however, a few felt a need to satisfy their partner's desire despite their lack of interest. Differences in desire for sexual activity between husband and wife could cause problems sometimes compounded by incorrect health beliefs.

> *I have some problems with my bladder and have difficulties sitting down, so I can't clean myself properly, husband is still keen on having sex, so it is a problem, also if we don't have physical contact he might develop some prostrate problems, so I am worried about that. I am worried that I would get some infection if I don't clean it properly Then he does it himself. It is mainly due to my bladder problem, also I don't have any interest in it anymore. So, this is the main problem now, husband is very much interested in having sex and I am not. Then husband said we could use condoms. (Participant 12; aged 60-70)*

5.7.2.1.2 Depression

Most women experienced low mood and other depressive symptoms mainly in response to what was often seen as a terminal diagnosis. The words sad, disappointed, tearful and loss of confidence were used to describe their emotions. A few had had psychiatric review; one woman described how she cried throughout the mental health consultation.

> *So, when I saw Dr C for the first time, I did not say anything, I was crying throughout the consultation. My husband did all the talking; I was sitting and crying there all the time (Participant 7; aged 40-50)*

One woman described how she had no desire to live longer but carried on for the sake of family. The realisation that she was the emotional and practical lynchpin of the family added to her distress when envisaging their family life without her.

> *Still, I don't know whether it is due to my age, but I don't have the desire to live longer also. But thinking about my children and husband, if something happens to me, they will not be able to bear it. I have enough of my life, I am fed up of life .(Participant 12; aged 60-70)*
>
> *‘Of course, when I was diagnosed with this disease- because all say this is a terrible disease- I started thinking that I am doomed for a life time that my near and dear ones will undergo great mental suffering, because it has always been me who stood as a pillar that supported our family. That caused me great pain. Even now I am in that pain’ (Participant 2; 60-70)*

For many, the physical effects of the disease and treatment led to depression.

> *So, during chemotherapy, when I am alone in house, I become upset thinking about lot of things and had problems with all the medications. I lost my appetite, I am not able to go out of the house, I started losing my hair. I became more and lower in mood (Participant 13; aged 60-70)*
>
> *During chemotherapy I felt that I was suffering especially when I was so tired and lying down, I felt, why this did happen to me. Also, at that time I didn’t feel like eating any food, and my family will be forcing me to eat, they cook different types of food and*

> *give it to me. Also, I couldn’t taste any food so I couldn’t eat and felt upset (Participant 11; aged 40-50)*

5.7.2.1.3 Other psychological responses to disease

Some women experienced a sense of guilt and regret at having not done what they should have done; especially breast self-examination, consulting a doctor earlier on when they developed symptoms or doing more frequent mammogram as indicated. These women had higher educational qualifications and were more affluent.

> *No nothing has changed. (Low voice) Only now the doctor here was telling that if I had come to this hospital two years back when I first detected swelling, I could have been treated by oral medicines (Participant 5; aged 70-80)*

> *If I had come earlier the chemo would have been avoided, it had become 2 cm about 1.5 to 2cm, if I had come earlier maybe if it was less than 1cm... (Participant 17; aged 40-50)*

Some women responded with anger and frustration at the diagnosis, physical symptoms during treatment, or their inability to do their routine physical activities.

> *So, I was getting angry frequently, I am not able to rest all the time, when they [children] go to school I am fine and I can rest at that time’ (Participant 17; aged 40-50)*

> *I was also very angry initially, when I reached home after chemotherapy due the discomfort in my body, I used to get very angry and I used to speak angrily with all my family. I used to answer back to my family members, so my husband was angry with me. (Participant 9; aged 50-60)*

Some anger was directed at family members but originated from the frustration the women experienced at being unable to fulfil their role as the wife and mother. This was true even for the women in employment showing how Indian women perceive themselves as wife and mother first, before any professional commitment. The women’s patriarchal upbringing is likely to make it difficult for them to accept the idea that men in family could take responsibility for housework.

Women found it difficult to talk about their problems with their immediate family or friends may be due to lack of opportunities, or due to fear of being judged, or because they didn't have anyone who would listen to them. There was a lot of stigma associated with a cancer diagnosis and women were reluctant for this to become public knowledge.

> *Like I am able to talk to you also openly, but normally I don't talk to anybody, or I don't open up easily. I don't talk to others because they don't retain what we tell them, they interpret in their own way. They also exaggerate and speak to others like that. So, I don't talk to others much, I was born and brought up in urban area and now I live in rural area and it is difficult to deal with such people (Participant 14; aged 50-60)*

> *I don't talk about my distress to others; I feel that I have to suffer my problems. Also, nobody asks specifically--- and I always say there is no problem, everything is ok I don't have any problem, I am taking treatment---. (Participant 11; aged 40-50)*

Talking freely about their experience was not something which women expected or felt able to do, some commenting during the interview that this was helpful. Participating in the interview made few women realise their capabilities about opening up about themselves.

> *I am glad that I talked to you as I realise that I am able to talk about my disease and answer the questions in detail. I didn't realise that I would be able to talk like this. I am glad I did it. (Participant 16; aged 40-50)*

5.7.2.1.4 Distress due to physical side effects of treatment

Women described how side effects of chemotherapy and radiotherapy including nausea, vomiting, and lack of appetite, fatigue and hair loss was distressing. Women tended to respond by staying in the house which led to social isolation which aggravated the situation.

Changes in their bodies due to hair loss, loss of breast, lymph oedema, swelling of hands due to frequent intravenous access as well as scaling of skin were major concerns. Almost all the women interviewed were concerned about the hair loss and were affected by it.

Women in Kerala are renowned for their long, thick black hair of which they are very proud as a symbol of beauty and femininity. Losing hair was a cause of serious distress.

> *I lost a lot of hair, I had long and thick hair, so I was very sad when I lost my hair, my hair was not even grey, it was still black in spite of my age. Now it is coming back, and I*

> *am getting more grey hair now. All people used to comment on my long black hair but now everything is gone. My daughter had got a wig for me, I used it a couple of times when I went to temple, but when I used it, I felt strange, so mentally I was not comfortable in using that. (Participant 12; aged 60-70)*

Some women were ashamed of hair loss and a few thought that the hair loss would be perceived as an indicator of disease severity by others.

> *'That disease might not be a good cancer and is likely to be risky, but I only have to be ashamed of hair loss, but in front of people they think that hair loss is an important indicator of disease severity (laughs). (Participant 17; aged 40-50)*

> *The facial expression of people changes and they keep staring and I become upset that I am being singled out in front of other people. Now I am ok and my only thought is when to remove my head scarf and walk around freely. (Participant 17; aged 40-50)*

Some women found that the loss of hair affected their ability to participate in their usual social interactions or attend religious gatherings at which it is inappropriate to cover your head.

> *If it is in temple then definitely there will be questions about why I have covered my head. Even people who know us would say "Oh you have lost all your hair"? Then we will have to explain everything. So, I don't go to temple but pray in the house, prayer is the one that leads me forward. (Participant 16; aged 40-50)*

> *Also, I did not want to go to church as there are a lot of people of our acquaintance in church so I am the only one with hair like this, so I said I will only go to church once my hair grows back to my church. But I go to other churches where nobody knows me. (Participant 13; aged 60-70)*

> *No change in faith since diagnosis but not able to go to temple now as I don't want to wear this head scarf and go to temple. I go to temple that are very near our house, but not to very large and famous temples where a lot of people come daily (Participant 10; aged 60-70)*

Whilst artificial hair was helpful for some, others reported the difficulty in getting used to artificial hair both by themselves and their family.

> *I had brought a wig, but you see I have a grandchild and I was worried what will the kids think If they see me wearing that and I wore it once, but I felt uncomfortable wearing that in front of kids even though they didn't say anything. So, I have not worn it since. (Participant 18; aged 50-60)*

Some clinicians failed to recognise the importance of their hair to the women affected. One woman mentioned a particularly difficult conversation with a doctor who dismissed her concerns.

> *I discussed it with doctor (not DrP) and he was saying "Oh you will lose all of it" jokingly. He didn't give importance to it (nervous laugh) I used to care for my hair a lot---- and I already had short hair –then--- I got used to it. Now I am upset that it is not growing back and every day I keep checking to see whether it is growing back. (Participant 18; aged 50-60)*

With regards to mastectomy, women were affected differently, some women felt that the removal of breast caused disfigurement and affect their personal image whereas others were not bothered by mastectomy as long as the disease was cured.

> *No, I was not upset about that, I am not young, I am now old, I also know that there are new methods to cover that. But I don't need any of that, I am now old and I was not upset by that (Participant 10; aged 60-70)*

> *Then they said about breast reconstruction, but then I felt I am 60 years old now, so what is the point now? So, I agreed for mastectomy. (Participant 13; aged 60-70)*

Age appeared to be a factor that affected their decision making, older women did not feel any need to have a breast reconstruction surgery, which would also have been more expensive compared to mastectomy. A few women were bothered about the disfigurement attached to mastectomy and were keen to be careful about appearance while sitting down.

> *But when we do lumpectomy alone there would be a gap and so should do flap. I agreed to flap, as doctor explained that when mastectomy is done and later, I might become upset or irritated on seeing my body, he said it might or might not happen. When we look at our body in future, I should not regret the decision. In my mind I know what happened but at least in front of others it won't be evident. If they look at my face they wouldn't know about it will they? (Participant 16; aged 40-50)*

> *I had total mastectomy and I am a bit upset about that, especially when sitting down there is some disfigurement, so I have to be very careful about appearance while sitting down. (Participant 12; aged 60-70)*

5.7.2.2 Second theme: Getting on with life

The second major theme was “getting on with life”. Once they overcame the initial shock of diagnosis, women tried to make sense of the disease, by actively seeking information and with the help of medical professionals, and their practical adaptations. Many found a new future and a new way to live normally, but for a few of them this was not possible all the time.

5.7.2.2.1 Making sense of the disease

The women tried to come to terms with the situation by attempting to make sense of the disease. Most women had a good understanding of the different modalities of available treatment and the indications for each which had been explained to them by the medical professionals looking after them. This was important in being able to move forward.

> *I know about the treatment; I believe it is to prevent recurrence. Radiotherapy is done to burn any residual tissue left behind. I did not have any problem during radiotherapy. I did not have any concerns or worries about radiotherapy. (Participant 10; aged 60-70)*
>
> *My understanding is that surgery has completely cured it and chemotherapy also helped in the removal, if anything is left behind then radiation is to destroy the cells by burning them. (Participant 12; aged 60-70)*

5.7.2.2.2 Actively seeking information

To understand more about the disease and treatment and to be better educated, the women took an active role to gather information by asking medical professionals, reading books and leaflets, and watching television.

> *I read about things, I try to be bold and brave in the situation rather than thinking I have a terrible disease. I gather information as much as possible, now there are lot of printed material available which are good sources of information. I am not scared*

> *about reading and getting more knowledge, especially there are lot of misconceptions among people. (Participant 14; aged 50-60)*

One woman felt comforted in the knowledge that breast cancer is different from other cancers with a better cure rate; she was able to get solace from this fact.

> *Prayer, studying, reading more about it, else I was in a shocked stage, but knowing that it is different from other cancers, I hope it is true, if it is detected in primary stage there is 98% chance of cure, the doctor also reassures me that good cure rate with surgery at early stage and results look positive. (Participant 17; aged 40-50)*

5.7.2.2.3 Practical aspect

The cancer diagnosis caused a significant financial burden to many patients as they have to find the resources for treatment. Often it was a joint effort by immediate family members to share the costs.

> *Because I was thinking that we would have to spend lot of money, then my son said, mother you should not think like that, money is not an issue, the important thing is to get recovered from the disease. (Participant 6; aged 50-60)*

Often the participants lived far away from the treatment centre and the treatment might have to be compromised to accommodate travel.

> *Initially doctor said I need 16 doses of chemotherapy and then because I had problems in travelling and my son couldn't take time off work and come all the time, so we discussed it with doctor and changed it to eight. (Participant 10; aged 60-70)*

5.7.2.2.4 Role of medical professional

Most women understood the cancer treatment well, having had good explanations from their medical professionals, felt that their treating doctors were supportive, helping them to come to terms with the diagnosis and accept the treatment. This was unexpected and welcomed compared with the previous experience of medical care for many. The terms used by them include 'relief', 'consoling', 'reassured' and 'supportive.'

> *Also, the consulting doctors are a relief; Dr V and Dr B are very good at explaining things and we can ask them anything. Some doctors we can't ask anything. (Participant 14; aged 50-60)*

> *So, the doctor reassured me a lot, was very consoling, he was like a brother to me. I had worries about this hospital; we didn't know much about it as we have never visited here before. It was the first time we had come to this hospital. But after seeing the doctor we were very satisfied with all the care and decided not to go anywhere else. (Participant 13; aged 60-70)*

5.7.2.2.5 New future: Responsibility for others

Women felt that it was their duty to warn others, to create awareness so that the disease can be detected at early stage. Having gone through the diagnosis and all the treatment they appreciate the stigma and 'sorrow' associated with the disease and wouldn't want another woman to go through that

> *I pray that nobody else would get this disease, whatever we say that we are not upset; this disease is a great sorrow for everyone. So, whenever anybody or my colleagues call me to talk about this and I ask them and I advise them that even when they see any small swelling, I ask them to check it out so that nobody develops into this disease. (Participant 16; aged 40-50)*

5.7.2.2.6 New way to live normally

Few women were able to make positive adaptations in their life because of their experiences and support provided by the treating physicians, they developed more confidence, gathered more information about their disease and treatment and also resorted to new hobbies, all these helped them to cope with their illness.

> *No, it is more hobbies like looking after my plants and vegetables, cooking my favorite recipes, doing things around the house that I like, watch my favorite programs on TV. I try and do things I enjoy so that I don't become upset thinking about my disease. (Participant 13; aged 60-70)*

5.7.2.3 Theme 3 Influence of their support system

The third major theme was the "influence of their support system" strongly based on family, friends, faith and the community which affect them positively as well as negatively. The family, friends and faith were a positive influence, but women did not feel supported by community. Due to the stigma associated with the disease women did not feel up to discussing the issues with the community nor did they get any support from it.

5.7.2.3.1 Family

Women felt supported by immediate family, who were taking time away from work, and accompanied them for hospital appointments, provided financial support, stayed at home and helped in all physical work. Some women felt that the illness strengthened family relationships and attachment.

> *The support I have at home, the support from my children, I think the greatest thing is the support I get from my children. They tell me, mother you need not do all these, not even know all these, you just sit there in peace, all other things we will do. That I need not worry about money and all. That kind of support my children are giving. (Participant 6; aged 50-60)*
>
> *Family was very supportive; my sister-in-law has come from Abu Dhabi to look after me, so that she can accompany me while I go for radiotherapy. Sometimes my husband comes with me and some days she accompanies me, someday she stays at home to get my kids ready for college every day. Before that my husband's sister who is in Bahrain, came over during chemotherapy and stayed for the entire time. They all have been very supportive. (Participant 20; aged 50-60)*

However, where family members were unable to increase support due to other commitments, tensions could arise. Some felt worried about the family especially about their partners not coping and managing the household work in their absence and about the future of their children.

> *My husband is finding it very difficult to cope, especially taking time away from work and we try and manage between ourselves especially my son and brothers; but they also have family and so can't spend lot of time with me. Also, my son has exams now, so it is difficult to take time off. But when I think about my husband, I am a bit upset. (Participant 14; aged 50-60)*

On occasion, the accepted patriarchal structure of the family caused serious concern. An example is seen here where a woman was not involved in the decision for her to have breast reconstruction.

> *I didn't know about this decision. Once I was in the theatre, they discussed with my husband about it, and he said to go ahead with reconstruction. But now I feel they shouldn't have done the reconstruction as it is causing me more discomfort as I can feel the tissue more prominently and I feel a pull or stretch at my shoulder when I lift my hand. (Participant 3; aged 60-70)*

5.7.2.3.2 Faith

Faith was a major source of support for most, helping the women to cope with their illness. As seen from the demographic data, most women in the study practiced Hinduism, with Christianity and Islam also represented. Women described faith as a family affair, praying together, and reading spiritual books together. Some believed God had enabled them to have an early diagnosis due to detection of lump at initial stage and having lumpectomy as opposed to mastectomy.

> *God has planned something for me, and it will happen like that. God doesn't do anything without a plan, also if something happens to me then God will provide for my children. I have faith in God. I go to temples, take part in religious ceremonies, so I believe that God wouldn't let anything bad happen to me. (Participant 14; aged 50-60)*

The impact of hair loss on religious observance participation was therefore felt badly as described above. Women spend time following rituals, but loss of hair affected this greatly, some women avoided going to worship places especially churches and temple.

> *I am able to face others and speak with confidence to others and to you because of my faith. I believe that the disease will be completely cured by treatment. I used to visit temples but I don't do it anymore, mainly due to my hair. Muslims can wear purdah over head but both Christians and Hindus people will notice if we cover our head. (Participant 16; aged 40-50)*

However, for some women their faith was seriously challenged; believing that the cancer was sent as a punishment from God leading to bewilderment and sense of injustice over the diagnosis.

> *I do not ever think that I have cancer. There is no cancer in my body. Even now I think this should not happen to me. We have not wronged anyone. We have only helped others, if not by way of money, through our physical support. Even now I do not believe that there are cancer cells in my body. (Participant 1; aged 70-80)*

For others, faith acted as a barrier to accessing treatment resulting from 'faith fatalism' where they believe God has already decided their fate. The relatively common belief that that cancer in particular was a disease that equated to God's punishment also led to stigma.

> *I used to go to temple all the time even before I had this illness and I used to pray all the time. But now since the diagnosis my faith seems to have decreased. I light the lamp and pray but I don't spend a long-time chanting prayer as I used to do. I used to spend lots of time in prayer before the illness. For the past few days, I have been thinking about that actually, but I don't know the reason for my change in behaviour. (Participant 3; aged 60-70)*

> *For all my illness in past I have never consulted a doctor or had any treatment, and I used to do all the jobs at home. I believe God is looking after me and curing me, I didn't have to go to any hospital. So, I believe that it is God's grace that is looking after me and will continue to do so. (Participant 8; aged 50-60)*

Religious observance also could impact on other issues, for example, the belief that breast self-examination should not be done during the time of visiting sacred temple denotes the underlying belief that the examination is somehow wrong and unholy.

> *Then since the gynaecologist checked me, I didn't think this was going to happen, else I would have been more cautious, I was also observing a penance as I was going to visit a sacred temple. So, I did not do breast self-examination during that time, but my doctor had checked me and said everything was clear. (Participant 12; aged 60-70)*

5.7.2.3.3 Community

The immediate community appeared to be adding to the distress of the women, they preferred not to talk about disease to others for fear it would be exaggerated; women felt particularly under scrutiny and felt harassed. The well-wishers, who visited, despite acknowledged good intentions, worsened their apprehension by asking questions, discussing misconceptions about the treatment making the women unable to decide.

> *Not really harassing, but they will ask me, "Oh, you have cancer? What happened? Are you undergoing chemotherapy?" Even if somebody is not undergoing chemotherapy treatment, they will say, she is. So, we get mentally disturbed. (Participant 1; aged 70-80)*
>
> *Then they began to ask questions implying that my condition was very serious and I am bedridden and whether I needed any help. I have always been active ever since surgery and doing all my work, so I felt upset that people are seeing me as one with a terminal illness, so I avoided telephone calls and avoided them. (Participant 17; aged 40-50)*

Most of the women had no-one other than immediate family to talk to, they clearly didn't have any support groups. There was also the added stigma of cancer diagnosis and the desire of everyone to keep the diagnosis to immediate family and not let others know about it.

5.8 Discussion

This qualitative study of twenty participants with breast cancer from a tertiary centre in Kerala, the first of its kind from the State, gives voice to the far-reaching psychological distresses faced by women undergoing treatment, and the experiences which helped or hindered them through the process. Most previous Indian studies of this subject used quantitative methods (183). Women experienced their diagnosis and treatment in the context of a prevailing societal attitude regarding the role of women as wife, mother, and the carer of older in-laws. Although the women in this study expressed distresses common to women from Western culture, the distress was amplified by this core expectation. Thus, a disease of a female organ and symbol of such womanhood, with treatments which further affected body image, sexual function, and ability to perform care of house and relatives, undermined a perceived primary purpose, even in more highly educated and employed women. However, despite the societal pressures, most women found their families and faith a source of strength although some had unsympathetic, or less flexible home situations. For some, faith was expressed unhelpfully, restricting access to self-care and acceptance of cancer treatments. The almost uniform importance of faith and faith practices also magnified the impact of some of the effects of treatment, such as loss of hair. Erroneous health beliefs and misinformation were common playing a role in delayed diagnosis, the psychological distress on learning of the diagnosis, and societal stigma associated with a disease that some thought could be contagious. Compassionate and honest information from professionals was greatly valued and helped ameliorate distress, but the women were not always able to participate fully in clinical decision making. Support groups were lacking, leaving those without strong family support with little help.

India does not have a population-based organised breast screening program at national level (184), and for the few programs that are available in various hospitals have identified barriers for women to use them including absence of symptoms, apprehensions about screening test, pre-occupation with family problems, practical difficulties, lack of approval from spouse, forgetfulness and being too busy (183). Nearly half of the breast cancer patients are diagnosed at advanced stages contributing to increased mortality (185). Some women in my study expressed their surprise at getting a cancer diagnosis, as according to their health beliefs, convictions, and dietary habits, they were convinced that they would not get cancer. Women often presented late for diagnosis due to being too busy to look after their own health, poor recognition or knowledge of symptoms, false belief that a strong family history was necessary and misdiagnosis by health providers (186). One woman in my study, from Hindu background, described not doing breast self-examination as part of maintaining penance while visiting temples. In another study most Catholic women reported breast self-examination to be embarrassing suggesting influence of religious doctrine on health beliefs (187), though in a separate study Muslim women did not feel that breast self-examination was against their Islamic beliefs (188).

Religious coping in response to illness can be both positive, providing comfort and reassurance and negative, with painful spiritual struggle or doubt (189). Most women in my study depended on faith to help them come to terms with the diagnosis and to cope. This is in keeping with previous studies showing spiritual beliefs and practices are central to coping (152-156) especially in ethnic minorities (28). However, some women considered their cancer as “God’s punishment” which increased stigma and resulted in ‘faith fatalism’ which proved as a barrier to accessing treatment, consistent with previous studies (131, 134).

Women expressed a range of psychological concerns: anxiety, depression, fear of disease recurrence, worries about their children and worries about change in role in family. This is similar to the distress experienced by all women where prevailing concerns include overall health, physical concerns, cancer recurrence or metastases, psychosocial concerns about children and burdening the family, and body image and sexual health concerns (28). However, our findings indicate that these women experienced these concerns in the context of a perception that their *primary purpose* in society was as wife, mother, home-maker and care-giver. Even for educated employed women in our study, and in Kerala – an Indian state viewed as affording higher status for women and known to have matrilineal descent among Nayar Hindus (43)- the primary distress was related to their inability to perform this role rather than loss of their employment. Traditionally Indian women have a strong commitment to their immediate family, which includes their husband’s families, friends and the religious community (190). Family is usually considered more important than a career (191), and women’s wishes are expected to conform to family traditions, honour, and welfare (192). Working women also bear the primary responsibility of child rearing (193). Putting career ahead of family risks social censure and there is pressure to conform (194). However, this strong sense of family commitment was the most important support system for women.

Indian collectivist families promote interdependence rather than the ‘individualism’ of Western societies (141, 195, 196). The women in my study described how immediate family provided practical support like accompanying for hospital appointments, taking time away from work to help with childcare and housework and assisting with personal care tasks such as bathing or brushing their hair, which was difficult after surgery. Indian women grow up in multi-generational households where the decision-making power rests with the male household members; initially fathers, then husbands and then the adult son. Key decisions about treatment may be made by the oldest male relative or even by the whole family, but excluding the person being treated (196, 197). Exclusion from decision-making, exacerbated by language barriers, was a cause of psychological distress of Indian women in Canada (131). A recent Indian survey showed that most patients wanted full disclosure about their cancer even if prognosis was poor. In contrast, few of their family carers shared this information, believing it to be harmful (142). As long ago as 1979, 83% of Indian women who underwent mastectomy wanted more information prior to surgery (116). Although the women in our study largely had a good experience of their doctors, many Asian clinicians still believe that complete disclosure is undesirable and would increase patients' distress (198). Therefore many Indian cancer patients treated at cancer centres are unaware of the "true nature" of their cancer diagnosis from a clinical perspective (199). In a survey of South Indian patients attending radiotherapy only 62% were aware of their disease, of whom only 45% had been told by their doctors (200). One of the patients in the study was unaware of the diagnosis and the family member was present throughout the interview to ensure that she would not be 'accidentally' told about the diagnosis by interviewer.

Most participants raised body image issues due to loss of hair and of breast surgery. Alopecia has been reported as one of the most distressing and traumatic disease related events that the patient will experience and is a constant reminder of the disease itself (201-203). Hair loss can lead to loss of self-confidence, low self-esteem and heightened self-consciousness (204). It is particularly difficult for Kerala women to cope with hair loss as long hair is prized as a traditional feature of 'Kerala-ness' (205). A major hypothesis of symbolic interactionism is that meaning arises out of the process of interaction between people, resulting in probable ways of acting. Most women saw hair loss as a barrier in accessing support including social or religious gatherings and found artificial hair to be a poor substitute. Women were able to express how the changes in these symbols affected their life and so using the approach of symbolic interactionism help us to gain better understanding of the thoughts and experiences of women. However, despite this commonly acknowledged cultural issue, some clinicians failed to recognise how deeply hair loss affected women and were unsympathetic despite working within the same culture. Previous work has shown dissatisfaction with the doctor in 40% patients partly due to the doctor's underestimation of the distress of hair loss (204).

Women were affected differently by mastectomy; some women felt that the removal of breast caused disfigurement and affected their personal image whereas others were less concerned, perhaps feeling that this was most likely to effect a cure. Age appeared to be a factor that affected their decision making consistent with a study among Guajarati speaking Indian women living in the UK who felt that their appearance didn't matter as long as they are alive and healthy (206).

Most women felt that talking about their problems would be useful but did not have a "right person" to talk to. They found study participation provided an outlet for their thoughts. Indian women generally prefer to seek socio-culturally acceptable informal care (207) though this was not perceived to be helpful to the women in our study. Although most of the women had some psychological distress, few were referred to psychological services. Those that were referred found this useful. Referral rates for psychiatric/psychological services for cancer patients (even in institutions where such services are available) in both India and the West appear to be equally low (183). This may be due to the increased stigma related to mental health diagnoses and physicians' general reluctance to refer.

Significant financial burden was experienced by some families as a result of cancer diagnosis and subsequent healthcare; a situation previously described in another Indian state (208). In India healthcare expenditure constitutes almost 5% of gross domestic product (GDP), out of which public funding is only 0.9% and about 71% comes from out-of-pocket on receipt of care (209). A study on the evaluation of economic burden of cancer on Indian households showed that cancer-affected households as compared to with households with similar socioeconomic and demographic characteristics but not affected by cancer, experienced higher levels of outpatient visits and hospital admissions and increased out-of-pocket health expenditures per member controls (210). Financial concerns have been shown to affect the health seeking behaviour of middle class families, as well as for women without financial autonomy and decision-making power who depend on men as providers(207).

5.9 Strengths and limitations

This is the first qualitative study among breast cancer patients from the state of Kerala and involved twenty participants with a semi-structured interview guide allowing discussion of various topics and flexibility. There are limitations of all interview approaches; as participants reconstruct the past from their memories, the results could be biased due to the intersubjective nature of the interview, and the participants might try and answer in a socially acceptable way or attempt to answer in a way they think the researcher would prefer. However, despite these limitations, as the study is trying to elicit the deliberate description of the past and reconstruction of events by the patients, the use of the interview is justified to answer the research question about experiences the patients had during their treatment phase. The interviews were in-depth, in their regional language, allowing detailed answers from the participants. They were all pleased with this opportunity to voice their experience. However, due to the diverse nature of the culture of country the data cannot be considered representative of the South Asian population, and neither was this a purpose of this qualitative study. However, there were many similarities to the experiences of Indian women elsewhere, with added Kerala experiences to the picture. Most women interviewed were from the upper middle class although some from more deprived strata were included.

The presence of a family carer in most interviews may have caused reticence of the participant to share their concerns completely openly. However, the data show that detailed accounts of the adverse, as well as positive, aspects of family, friends and society were freely reported.

5.10 Clinical and research implications

Although not designed to be generalizable, these experiences resonate with the systematic review (see Chapter 4) of Indian women in two other Indian states and Indian Canadian migrants. There are important messages to clinicians caring for Indian women with breast cancer anywhere in the world. Clinicians must understand the prevailing societal attitude in which these women live; as wife, mother, the carer of older in-laws and the importance of hair loss. Even where the woman lives in another country, these values are often still in place. Women greatly appreciated compassionate information from professionals but were not always able to participate in clinical decision making. A family-centred approach to care, which includes the woman in decision-making, is needed. Clinicians need to understand and empathise with the body image issues women face especially associated with hair loss and proactively help to reduce the distress. There is an increasing need to refer to psychological support services for those who need them. The importance of motherhood and parenting should be kept in mind for young breast cancer patients. Culturally congruent support groups are needed. Faith is important for coping and tailored chaplaincy services should be an integral part of clinical services and explored particularly for women refusing or with poor adherence to cancer treatments.

5.11 Summary

This chapter described the methods and findings from the patient interviews conducted with breast cancer patients undergoing treatment in India. I explored the psychological concerns related to disease and treatment in relation to prevailing societal attitudes regarding the role of women as wife, mother, and the carer of older in-laws. Hair loss caused particular distress. Family and faith were key support systems for almost all the women although was also causes of distress for some. Chapter 6 will discuss the methods and findings from the focus group discussion among health care workers and members of public.

6 FOCUS GROUP STUDY

6.1 Introduction

Chapter Five described the methods and findings from the interviews conducted with breast cancer patients undergoing treatment in India. The psychological concerns related to disease and treatment were explored and analysed through the lens of cultural distress; women described their distress in relation to the prevailing societal attitudes regarding the role of women as wife, mother, and the carer of older in-laws. Hair loss caused particular distress. Family and faith were key support systems for almost all the women, although also was a cause of distress for some. In this chapter I will present the methods and findings from the focus group study of health care workers and members of public. The primary objective was to

1 To investigate the cultural context in which Indian women with breast cancer experience their disease and treatment through understanding the general awareness of healthy volunteers of the impact of breast cancer on Indian women in the community.

2) To understand the factors which aggravate or ameliorate (including solutions to address or prevent) the psychological concerns including those arising from their Indian cultural context.

6.2 Rationale for methods used

In order to answer the question about the cultural context within which Indian women living in India experience the psychological concerns in relation to breast cancer and its treatment a focus group approach was used. Here, I am interviewing healthy volunteers about their awareness of breast cancer in community and how they perceive any change in the role of women with breast cancer in the community. Focus groups, as mentioned earlier, are a form of group interview that explicitly uses group interaction as a method to collect data from participants. Here the researcher introduces the topic and has an interview guide but the data is generated by participants talking to each other, exchanging stories and commenting on other's contribution (172). Focus groups were initially used in market research in 1920s (173) and later in 1946 Merton and Kendall described ‘focused interview' with groups (211, 212). They aim to explore the subjective experiences of participants in relation to predetermined research questions and have defined certain standards for interviewing including gaining explicit experience of participants and their views about the topic under investigation, using a detailed interview guide. The topic guide is developed based on the research questions and aims and objectives, data obtained from literature review previous and the experience of the research team. Focus group methodology helps the participants to explore and elucidate their thoughts and ideas with each other which is not possible in one-to-one interviews, also helps the interviewer to get answers to the series of open-ended questions in the words of participants. Since the discussion involves interaction between participants and moderator it collects a wealth of interactive data which distinguishes the focus group from the one-to-one interview (213). Communication between the participants is important because this can highlight their cultural values, while analysing the satire, agreement, dissent and other narratives used in a group will identify shared and culturally sensitive common knowledge making focus group particularly useful for cross cultural research and work with ethnic minorities (172). The main focus group discussion helps to draw upon participant’s approach, view point, experiences and responses which are more likely to be revealed via the interaction in a social gathering, in a manner which is not achievable by other methods like, observation, one-to-one interviewing, or questionnaire surveys. While individual interviews are good at gathering personal experiences and attributes, focus groups obtain a diversity of views and emotional processes within a group context (211). Our aim was to explore the understanding of the community regarding breast cancer, its diagnosis, treatment and how generally women cope with the diagnosis and this was facilitated with five focus groups with doctors, nurses, church members in each and two groups with volunteers.

6.3 Research setting and study governance

Ethical approval was sought from Ethical and scientific committee of Amrita Institute of Medical Sciences and Research Centre; ethical approval was given for interviews. The Committee provides Institutional approval for the hospital focus groups, but decided that the community focus groups did not need approval. Subsequently a research protocol for the whole focus group study was submitted to the Hull York Medical School Research Ethics Committee, UK, and approval obtained prior to data collection. The study was performed in accordance with the 1964 Declaration of Helsinki and its later amendments.

6.4 Focus group methods

My personal contribution was in the i) concept and design of the study, ii) writing of the protocol and topic guide, iii) gaining necessary permission, iv) data collection and analysis, and, v) writing and interpretation of findings, all with support from my supervisory team.

6.4.1 Setting

The focus groups were conducted in the South Indian State of Kerala in a single tertiary hospital, a single Christian church, and a community palliative care unit volunteer group (October 2015 to January 2016).

6.4.2 Participants and eligibility criteria

6.4.2.1 Inclusion criteria

1. Adults (18 and over) working in the Department of Oncology (Medical, Surgical or Radiation Oncology) at Amrita Institute of Medical Sciences and Research Centre (Doctors and nurses)
2. Adults (18 and over) belonging to the volunteer network attached to the Palliative care unit in the Community.
3. Adults (18 and over) attending the local Christian church.
4. Able to give written informed consent.
5. Able to understand and speak Malayalam or English
6. Able to take part in an interview

6.4.2.2 Exclusion criteria

Unable to participate in focus group discussion due to physical or cognitive impairment

6.4.3 Development of the focus groups.

6.4.3.1 Design

A qualitative study was conducted using thematic analysis (113) as a theoretically flexible approach (See Chapter 3). Five focus groups (one group each of doctors, nurses, and members of a local church's women's group and two groups of volunteers working with palliative care patients) gave data. Doctors and nurses were selected to get in-depth understanding of the perceptions of a health care worker with regard to breast cancer and separate groups of doctors and nurses were chosen to allow the nurses to speak freely given the strong clinical hierarchy in India. Experiences from lay people were obtained from trained palliative care volunteers who are part of a neighbourhood network programme in palliative care (214). Convenience sampling was done for all the groups. A faith group is important because faith is such an integral influence in the state and the church group was selected as convenience sample as it was the local church of the researcher (SD).

6.4.3.2 Eligibility, invitation and consent

Potentially eligible participants were approached from: i) Department of Oncology; doctors and nurses, ii) Department of Palliative Medicine; community-based volunteers, and iii) members of a local church’s women’s group.

Convenience samples among doctors and nurses working in Oncology were obtained. Doctors were invited by SD, and nurses by the Director of Nursing. Email reminders were sent to doctors. Those who were willing to participate were asked regarding their date and time of convenience. Members of the church group were invited through the parish priest through announcement during the Sunday mass. Interested participants were requested to stay back after the morning mass. Community volunteers were invited by palliative care staff.

Interested participants were given detailed written information (see Appendix 8 and 9 Participant Information Sheets). Both the Information Sheets and consent forms (Appendix 10 and 1) were in both English and Malayalam (regional language). Written consent to interview was sought after any of the participant’s questions had been answered and included consent for audio-recording, use of anonymised quotes and use of data in future research. Consent was taken by the researcher (SD) prior to data collection.

6.4.3.3 Data collection and management

Five semi-structured focus groups of approximately 45-60 minutes were conducted (SD, with co-facilitator CV) using a topic guide (see Chapter 3 for detail in its development) to explore understanding of breast cancer, experiences of patients regarding diagnosis and treatment, and psychological impact. **(**Table 13**)**

Table 13 Focus Group Discussion Topic guide.

1) Could you please tell us more about your general understanding of breast cancer?

2) Would you like to share any experience of people diagnosed with breast cancer?

3) Could you please tell us more about your concepts of treatment experience?

4) Could you please talk about the psychological aspects of the disease and treatment?

5) Could you elaborate on your general understanding about difficulties patients could face?

6) Could you tell us more about your general ideas about role of women in family, role reversal, body image issues?

7) How do you think communities could support women with breast cancer?

8) Any further comments?

Doctors and nurses were interviewed separately in the room adjacent to the outpatient department and Oncology ward respectively at a convenient time for all the participants who expressed an interest to attend. Two separate groups of palliative care volunteers were conducted in the community on the same day to ensure maximum participation. The church group was conducted on a Sunday, and even though both men and women were invited, only female participants attended. The groups were selected applying the concept of 'applicability' thereby ensuring that participants have something to say on the topic , has a broad knowledge of the study area and are willing to talk to the researcher (215). A research observer (Athul Manuel) , who was a staff member working in the department of Palliative Care, was present during the interviews in the community taking field notes to record any observations, for example, about the body language of participants. Sociodemographic data was collected prior to the interview. Clinicians' groups were conducted in English and lay groups in Malayalam, audio recorded and transcribed. Those in Malayalam were translated into English (SD) and back-translated (CV). There were no study withdrawals. Translation enabled the data to be published in English, allowed the non-Indian (MJ) researcher to contribute to the analysis through which the potential challenges of reflexivity were addressed (both SD and CV are from the culture involved and worked in the department at the time of data collection). MJ, the research supervisor, who has extensive experience working in both clinical and academic environments in the UK, provided a different perspective to the data from a distance.

The lead researcher (SD) introduced the focus group participants, explained the purpose of study, discussed the etiquette and options for study withdrawal, as well as summarized the discussion at the end. The participants were asked broad open-ended questions about their understanding of breast cancer, encouraged to share the experiences of their friends and relatives who have been diagnosed with breast cancer with particular emphasis on diagnosis, treatment and psychological symptoms.

To preserve confidentiality, names and contact details collected in the participant demographic sheets were stored in a locked cabinet. The audio-recordings were stored in a password protected laptop and were then immediately erased from the audio-recorder. The recordings were permanently deleted after 5 years of data collection in January 2021. All transcripts were anonymised and given unique identifiers with no personal details to identify the participants.

NVivo 12 software, a computer-assisted qualitative data management program, was used to code, store, and organize data.

6.4.3.4 Ethical considerations

The ethical concerns considered during the focus group discussion include gaining consent, maintaining confidentiality and anonymity; and risk of harm that can arise to the participants in the process. Since it is an open discussion with topics and themes emerging during the conversation it could be difficult to always control the content of the discussion. The efforts to address these ethical concerns were made through the introductory briefing where the information regarding the discussion was provided with suitable level of detail and clarity, emphasised the ground rules regarding disclosure, reiterated the public nature of focus group and stressed on the need for confidentiality and anonymity. Guidance on subjects that might be unsuitable was also provided and the groups were told about the aim of the focus group was to discuss the health problem rather than finding any solution thereby managing the participants' expectations. In addition, the Participant Information Sheet was provided in the regional language and informed consent taken. The consent form asked for permission to use audio recording as well as use of anonymised quotes for publication purpose use of data for future studies. No monetary reimbursements were offered to the participants or carers. The participants also had opportunity to ask questions of the researcher before data collection started.

The moderator (SD), a trained palliative care provider, throughout the discussion ensured that each participant had an opportunity to contribute to the discussion without being under pressure to do so if unwilling and monitored for any psychological distress during the process. She was equipped to manage distress, if any, including referral to appropriate clinical services, but none of the participants needed additional help. The discussion lasted approximately one hour, and breaks were offered as required. It was made clear that the participant could withdraw from the study or end the interview at any point if they chose. The interview started with open questions enabling participants to relax and then was followed by direct questions relating to the subject with invitation to share experiences. The moderator also stayed on the room for a while after each focus group to give individual participants the opportunity to address any issues or concerns.

6.5 Analysis

Transcripts and field notes were anonymised and checked for accuracy. Data were subjected to thematic analysis (113) using 'cultural task analysis' (94) as a lens, which describes how cultural nuances like patriarchy and role of women in family can affect how they experience the disease (95, 96) and make decisions with regards to treatment. Although this theory contrasts the mindset of the West (America) and the Far East (Japan), we found it relevant in the context of South India also. The following steps were conducted: i) data familiarisation, ii) line-by-line coding; SD, CV and MJ independently coded a group transcript and agreed a code-list, whilst allowing new codes to present, iii) coding of all transcripts (SD), iv) discussion (SD, MJ) to describe developing patterns of commonality (themes, or convergence) and v) agreement of analytic themes through further discussion (SD, MJ) - ensuring distinct themes with consistent data.(113) Analysis was performed continuously; issues raised influenced subsequent group discussions**.**

6.6 Results

6.6.1 Study participants

Characteristics of the 45 participants are summarised in Table 14. The median age was 50 with about 77 % were female, 88% were married, 64% belonged to Christian faith.

Table 14: Sociodemographic characteristics of participants

Variable	**Number**
Age	**Median age (range) in years-** 50, 33-81
Sex	**Number**
Male	10
Female	35
Number in each group	
Oncologists	5
Nurses	10
Church members	16
Community volunteers	14
Education	**Number**
High-school	13
Diploma	6
Graduate level	12
Post-graduate	7
Not known	7

Marital Status	**Number**
Married	40
Single or widowed	3
Not known	2
Religion	**Number**
Hindu	11
Christian	29
Muslim	4
Other	1
Number of years of experience for clinicians	**Median (range)in years-** 25, 9 to 35

6.6.2 Findings

Three major themes and seven subthemes were generated from the data: Psychosocial issues related to diagnosis, psychosocial impact of cancer treatment and coping with diagnosis. The findings are presented below each theme with illustrative quotes. The complete list of quotes from the study is given in Appendix 14.

6.6.2.1 First theme: Psychosocial issues related to diagnosis

6.6.2.1.1 Recognition of psychological distress

All groups felt that the psychological symptoms in women can start at diagnosis or any time during treatment. They can be triggered by various factors including treatment-related body image changes on their sense of womanhood, fears of social stigma and thoughts of being abandoned by their spouse.

> *When disease is diagnosed, instead of seeking treatment, she will decide to keep the disease a secret, also that is a private part of my body, even my husband will reject me, such a fear. All this is part of a social stigma, what people have imposed on women saying a woman should be like this. The stigma in Indian culture is a major factor in this. (Volunteer2;3 Age 40-50)*

These fears could affect behaviour and relationships, with sometimes extreme consequences, aggravated by insufficient information or opportunity to ask questions. Whilst some doctors acknowledged the need to address these symptoms, and that they did not assess psychological distress systematically, most considered psychological distress would settle with tumour-related treatment alone.

> *There was a lady who was behaving abnormally at home, jumped into a well. It was a cancer in the curable stage, even then patient became like that, because of incomplete information. Then finally she got admitted and was managed when she became well enough to share her story she said' don't laugh I will tell you the reason, I was told I will lose my hair, when the doctor said like that, I thought why should I live with no hair, my husband liked my hair and married me. (She had a lot of hair) (Nurse1 Age 50-60)*

> *…tend to kind of prioritise and take care of the medical aspects and leave all the rest of it thinking that it will sort out on its own. (Doctor2/Male/40-50)*

If there were persistent psychological concerns, doctors felt unable to provide mental health support due to a perceived lack of time and an apparent choice to believe it is not their responsibility; these issues are just 'part of their [patient's] life'. However, some commented that a dedicated team to provide psychological support, or trained personnel to help them through the process of explaining the various modalities of treatment to the patient would help them address these issues better.

> *they think these issues are a part of life, because most of them, they are alone, their family goes out to work so there is no one to talk to them, family just ensures that they are well at home when they come back but do not ask how they feel when they are alone. (Doctor 4 /Female 40-50)*

Nurses acknowledged that short consultation times did not permit doctors to go into detailed support, but they felt doctors could improve their communication within their current resources. For example, one extra sentence, e.g., to reassure that hair would regrow following chemotherapy, or to ask the nurse to arrange support from another patient, could help the patient significantly.

> *…surgeon can only answer in one word, a detailed conversation is not possible there, so when they ask, "Will I lose my hair doctor?' They say yes, they can only answer that. But if they add one more sentence like 'don't worry it will come back' it might be more reassuring to patient. (Nurse 1 Age 50-60)*

> *Then she had chemotherapy, radiation, lost all her hair and then she became very upset mentally. All these are the things they say, lot of mental stress, losing hair so much, when they have their shower and see the hair falling like water, they can't bear it. (Church1 Age 60-70)*

6.6.2.1.2 Delayed diagnosis

Clinicians were concerned that cancer is usually detected at an advanced stage, due to the lack of universally accessible screening programmes. This also concerned the lay groups who felt that such a screening system was a public health priority.

> *Generally, breast cancer is something which, in most, maybe western countries it is screened and detected and screening is high but in India there is no organised screening. (Doctor1 Male/50-60)*

> *Now these things like mammography, just like when health workers used to collect samples from houses for filariasis etc., in a similar manner, with the support of the social leaders, government should make it compulsory that after 35 years, all women should do mammogram. (Volunteer 1; 8 Age 40-50)*

They had witnessed suffering due to late presentation and called for screening to be available, irrespective of ability to pay. Women also tended to ignore or hide their health needs because of reluctance to be examined by a male doctor and/or putting the needs of their families above their own.

> *Today's Indian woman is of the habit of living for others. She thinks my life is meant for others. So, she will hide the disease thinking other will have to suffer for me.* (*Volunteer2; 3Age 40-50)*

> *Initially many people hide the disease. Only after it spreads and becomes unmanageable, it is communicated and then the situation will be beyond cure. (Volunteer2; 1 Age 50-60)*

> *Because of that people who lives in villages don't know we can identify or do breast self-examination or the treatment and its complications, they don't know anything about that. (Nurse 4 Age 40-50)*

Stigma and false beliefs regarding cancer aetiology and diagnosis can stop women from seeking care. Most families still practiced arranged marriages and news of cancer in a family can seriously affect the marriage prospects of their daughters. Delayed diagnosis may also be because the family are unable to afford the investigations or time away from work. Sometimes they must travel miles to attend an affordable cancer hospital, taking considerable time off work, thereby adding to their financial worries.

> *One of the biggest problems is stigma; many people are worried that if the news gets out, it is going to affect my daughter's marriage, my family in general. (Doctor 5/Male 50-60)*

> *To avoid such treatment from expensive private hospitals, people take some effort and struggle but go to regional cancer centres to get treatment, even if the travel is so difficult, people tend to go like that. Because they know that expense will be too much if they go to nearby places. (Church 5 Age 60-70)*

This can sometimes affect treatment decisions as women tries to hide the news of cancer recurrence from community by refusing treatment.

> *Her second breast was also diagnosed with the disease. So now though the doctor has told her chemotherapy was enough, she is not doing it. The single reason being, if she loses her hair again, the society will come to know of her disease again, that problem is haunting that family, she is ready to die but not ready to give up her hair… (Volunteer2; 3 Age 40-50)*

6.6.2.2 Theme 2: Psychosocial impact of cancer treatment

6.6.2.2.1 Experience of treatment

There were concerns regarding the lack of national standard guidelines for treatment delivery. The doctors felt that breast conservation may not be offered assuming that women are not bothered by how they look, or the traditional Indian dress will cover any cosmetic disadvantage due to mastectomy.

> *The next thing is, of course surgery is usually the first line of treatment once the patient is diagnosed and I don't think that it is either breast conservation or reconstruction is offered as often as it should be. A lot of people are reluctant to come forward for surgery because of the fear of losing the breast. (Doctor1 Male/50-60)*
>
> *Our culture is totally different, or like somebody wearing a saree, it is not very obvious, she does not have one breast, I think it does not make much of a difference. (Doctor 3, Female 50-60)*

However, the lay groups felt that breast removal does affect the women psychologically and highlighted the need for counselling. They considered *"long hair and breasts as the yardsticks of womanhood"*. They also mentioned the crucial role of women in the Indian family and how there is a "*disruption of the rhythm of family in all aspects."* Clinicians were very aware of and concerned about the financial impact of cancer treatment on the families of their patients.

> *Most of the women feel great mental agony when breast is removed. Before surgery, all are given a psychological counselling now. That does some good. Some patients do plastic surgery after the removal surgery. But only those with money can afford that. (Volunteer 1; 8 Age 40-50)*
>
> *I have known many who cannot reconcile with the removal of their breast. That is more prevalent among younger women around 30-35 years of age, than old women. Old women do not have that much difficulty. (Volunteer 1; 8 Age 40-50)*

Treatment side effects and body image issues are a major concern. Some patients develop lymphoedema, which the nurses felt could have been avoided/ameliorated by regular exercise and better post-operative care, but which would carry additional costs for the family.

> *Also, if it is working women financial issues also come and job-related issues so they will postpone the treatment till the job issues are sorted and settled." (Doctor 5, Male 50-60)*
>
> *Post operatively patient develops lymph oedema; again, this is due to lack of information. Lymphoedema is very disabling, they are free of disease for 8-10 years and they live with 15kg of one limb. (Nurse5 Age 60-70)*

Women are considered to be in charge of the day-to-day activities of family and expected to look after others and this role reversal adversely affects the entire family. The deep-rooted patriarchy practised in the families prevents them from envisaging husband taking up the role of women.

> *If women have an illness, it is an issue from the start because that woman would have been the main person in the family, then there is a disruption of the rhythm in all aspects, taking care of children, husband, so it is very difficult. (Volunteer 1; 5 Age 60-70)*
>
> *So, when they become ill, the total structure of the family is affected, they can't do anything, so the kid's studies will be affected, husband's work is affected. Husband is not able to go to work, so the income of the family is affected. So, the total structure of the family is getting changed. (Nurse 1, Age 50-60)*
>
> *In Kerala most women in house have an important role, right from getting up in the morning, cooking, getting kids ready for school, looking after husband, some husbands if they are lazy (laughing in background) right from getting their shirt ironed and ready to wear, feeding them, and getting their bags ready and giving it to them so that they can go for working. (Nurse 10, Age 60-70)*

6.6.2.2.2 Experience of Medical care

The lay groups expressed mixed opinions about the empathy and communication skills of the doctors that they have encountered. One member from the church group described how the "*doctor gets angry when asked any questions*" and complaints to the hospital management were apparently unaddressed.

> *The hospital management said he is an elderly doctor, when he becomes busy with lot of patients, he is not able to manage things and so gets angry. (Church 8 Age 40-50)*

> Participants were very vocal about the financial gain of private hospitals, perceiving this to be to the detriment of patients.

> *To be quite honest this is all a business to make money. Even when doctors know that the patient is going to die soon, they still give radiation, chemotherapy do all treatment and get money.* (*Church 14 Age 60-70)*

They also reported lack of empathy and compassion from doctors except those working in palliative care. The community-based volunteers worked with a public health palliative care unit felt that the government funded hospitals had improved and were satisfied with the care they had witnessed.

> *Another experience is even if patients are diagnosed with cancer the doctors don't behave in a compassionate manner with them. I know about an experience, if we ask anything to doctor, he immediately loses temper and will not explain things to us. He would say 'The patient is 80 years old, what more do you need, how long should she be alive? (Church 8, Age 40-50)*
> *Compared to doctors from other specialities those working in palliative care shows more love and compassion People working in palliative care are very caring and I have personal experience, they have at least a bit more compassion. We need more people like that.* (*Church 5, Age 60-70)*

> *Here (public hospital) the treatment is very good. We do not have anything to complain. All the doctors and nurses, attenders, chemo ward staff, volunteers, are very good. I had gone to a private hospital before coming here. What I feel is, here we have better treatment than even that. All patients get equally good treatment. That government is doing all these things. Many people do not know. (Volunteer 1; 8 Age 40-50)*

6.6.2.2.3 Solutions

Note, solutions also related to some aspects of Themes 1 and 3 but are presented here. Solutions were suggested at several levels:

6.6.2.2.3.1 National

Screening programmes and public health education would address public perception that breast cancer was usually incurable and encourage women to present earlier. Implementation of national cancer treatment guidelines would improve confidence that management was not primarily profit driven.

> *…similarly, government should ensure adequate screening services for asymptomatic people then it will be more useful in detecting the disease. (Volunteer 2; 1 Age 50-60)*

6.6.2.2.3.2 Service

Increased resources to employ other clinical disciplines trained in mental health support such as social workers. Access to basic mental health and communication skills training for all clinicians, and development of peer support groups/buddy systems would also be helpful. Inter-disciplinary team working, currently rare, would address some of the unhelpful role self-perceptions (e.g., "it's not my job") perpetuating unempathetic consultations by doctors. In addition, earlier integration of palliative care services can help in identification of symptoms, provide psychosocial support and help in better patient communication.

> *I think what's best you could do is probably just have people to provide inputs, have somebody who is always available on call to support, because all that they, I realize, , most of the time, twenty people who call, about ten or twelve of them just call for reassurance like this is nothing wrong, this is alright, (Doctor 5, Male 50-60)*

> *I still feel the best way to address it is to get people who have gone through it, show them the photograph, talk to them and make them talk. 'I have also gone through this hair loss and my hair is grown back'. That confidence cannot come from any amount of preaching, it has to be actually talked to with the person who has gone through it. (Doctor 5, Male 50-60)*

6.6.2.2.3.3 Individuals

Timely, frank and honest conversations with the patients and family were needed. Lack of time was recognised as a challenge, but should not be seen as an excuse to abdicate responsibility. The need for doctors, in particular, to have an understanding of the impact of treatment side-effects, and to show empathy was highlighted. For example, acknowledgement of the distress due to hair loss, and reassurance of re-growth would be a simple and non-time-consuming.

> *Will I lose my hair doctor?' They say yes, they can only answer that. But if they add one more sentence like 'don't worry it will come back' it might be more reassuring to patient.* (*Nurse 7, 40-50)*

6.6.2.3 Theme 3 Coping with diagnosis and treatment

6.6.2.3.1 Response to illness

Some women adapted to their different circumstances, finding ways to continue with their lives relatively undisturbed.

> *There was an author and college lecturer who used to go to college and say, I am a cancer patient, keep an eye in newspaper for my obituary. So, the students only knew about it when she spoke about that. Else she was not looking like a cancer patient. (Nurse 1, 50-60)*

However, others were greatly affected by the disease and treatment. They would also be affected due to the stigma of cancer diagnosis preventing them from discussing with other patients or affected by the side effects of treatment including fatigue.

> *Also, after staring chemotherapy we will really be fatigued, then we have to take rest and the whole family needs to support them, else they the patient would be low in mood and lose all hope. Also because of the mental strain they will continue to go downhill. If the family are very supportive then the patient would get better quickly. (Church 9, 70-80)*

The distress caused by a cancer of such a key female organ, the distress related to breast surgery and its impact on the spousal relationship, in the context of the role of the Indian woman, was appreciated.

> *There was a patient who had breast cancer and had surgery, but her main concern was whether her husband would abandon her. As one of her breasts is removed, she was concern that her husband would leave her. The patient used to talk to me about it and cry about that. (Nurse 7, 40-50)*

6.6.2.3.2 Sources of support

Family, children, motherhood were seen as a strong motivation, a means of coping and provided something to live for and the reason to undergo treatment, with an implied obligation to undergo treatment for the sake of the family.

> *it is good for her children's sake point of view… if she becomes depressed, same thing is going to affect children when they grow up if they ever have to face this again. (Doctor 1, Male, 50-60)*

In general, doctors viewed Indian women as self-sacrificing and nurturing mothers who ignore their own health while they look after the family. Faith and religion were seen as strong sources of support by all participants irrespective of their own religion, with an assumption that faith would make patients stronger and help them think positively, though a thought was shared about woman refusing surgery in view of 'organ being given by God which cannot be cut' similar to faith fatalism.

> *…automatically become more religious, pray to God more (Nurse 10, 60-70)*

> *then socially like neighbours, people whom we interact with are all very compassionate to cancer patients, they provide them with whatever assistance they can. With all that these patients cope. Then they all have acceptance and they accept it as their fate. (Nurse 3, 30-40)*

However, some women feel unsupported by family when unable to carry out their expected role due to illness and feared spousal abandonment.

> *Sometimes they are worried if their husbands will leave them and go away, they have to spend a lot of money for their treatment, or they are worried about their kids and them wasting a lot of money. "They have just started their life and they are spending a lot of money for my treatment". "it is better to die'. There are people who say like that. (Nurse 4. 40-50)*

This may be complicated by cultural expression, or lack of expression, of emotion. Indian men rarely demonstrate emotions openly which may then be misinterpreted as being unsupportive.

> *Probably it is so much easier in western countries to voice out your love or concern which is probably still a taboo in our country. I don’t think there are too many husbands who go around saying, “No, don’t worry. I love you; I am still here.” I don’t do it, so I don’t know how the patient’s might be doing it. (Doctor 2, Male, 40-50)*

6.6.3 Congruence and dissonance between professional and lay groups

In general, professional and lay groups agreed that psychological distress was significant, affecting treatment choices and responses to the disease. Both lay groups identified the vicious cycle of late presentation and stigma associated with erroneous health beliefs as being aggravated by the lack of national screening and public education programmes. (Table 15) All groups were quick to identify family and faith as strong sources of support. However, all admitted that these could also cause significant distress.

The main differences between the professional and lay groups centred on responsibilities and solutions. The doctors recognised the distress although, apart from some exceptions, did not address this, denying responsibility, skills or time. Their solutions were more time and additional trained staff. Other participants felt that the doctor did have an important role in providing empathic communication, and nurses felt that even small changes within resources would make a big difference to patients. Lay groups were suspicious of financial motivation for treatment, with poor confidence that treatment provided was standard, aggravated by poor information giving by doctors. However, clinicians were themselves distressed at the financial burden placed on patients and their families by treatment costs.

Table 15: Areas of agreement, disagreement, or silence between the groups

Subtheme	Doctors	Nurses	Community volunteers	Church members
Recognition of psychological distress	Agreement			
	All groups recognised psychological distress, and identified similar causes			
Delayed diagnosis	Agreement			
	All groups felt delayed diagnosis aggravated distress around diagnosis, and fed erroneous public understanding about cancer, including surrounding stigma, which led to a vicious cycle of late presentation.			
Experience of treatment	Disagreement			
	Acknowledged side-effects could be distressing, and sub-optimally managed Concerns about financial "toxicity" of treatment		Suspicions that treatment options were driven by hospital profit, and pharmaceutical companies rather than patient benefit Lack of national guidelines leading to variable treatment	
Experience of medical care	Agreement			
	There was uniform agreement about the care provided by palliative care team for symptom control, empathy and psychological support.			

	Disagreement			
	Recognised care was disease-focused and felt lacked skills and time to manage mental health	Doctors communicated poorly and could do better especially around expressing empathy regarding hair loss.	Poor opinion of medical (doctor) care, particularly about communication skills, information giving and being open to questions	
Solutions	Disagreement			
	More resources, health care workers with mental health training e.g., social workers, earlier integration with and access to palliative care services Better training and time in clinic	Better communication skills for the doctors even within resources, although agreed more resources and a system which valued person-centred care would be helpful	Further research is needed regarding the cause of the cancer, e.g., dietary issues	Cancer treatment should be free, which may also encourage early presentation
	Agreement			
	National screening programmes for all; national public education programmes; National clinical guidelines to manage			

	the cancers; cancer should be a government priority		
Response to illness	Agreement		
	All groups agreed that the distress caused by the cancer of a female organ in relation to body image and disfigurement had profound effects on the relationship with spouse, sense of self and role. This was especially because of the importance placed on women as wife, lover, home-maker, mother and carer of the elderly in the Indian culture.		
	Disagreement		
	Doctors felt that the impact of loss of breast etc. was less of an issue for Indian women because of national dress	Nurses highlighted the impact of lymphoedema especially, which is not hidden by national dress	Lay groups both felt that loss of the breast was felt as keenly as in Western cultures, if not more so, by Indian women, given the importance of her almost sole role in the family.
Sources of support	Agreement		
	Family and faith were considered as strong sources of support by all groups. However, all also could see that the family and faith centred society was a cause of distress in some, particularly when faith practices were disrupted, and family expectations not met and families did not accept the women’s needs, or where interpretations of faith fed into erroneous health beliefs and stigma.		

6.7 Discussion

When viewed through the lens of the 'cultural task analysis'(94), the cultural nuances within which an Indian woman experiences her breast cancer strongly affects her psychological experience. This was particularly seen in relation to patriarchy, also visible within the clinical teams, the role of women and family and faith. Significant distress affected how women presented with and responded to breast cancer, accessed support and navigated family role changes. A vicious cycle of erroneous health beliefs, late presentation and a lack of national screening programme was identified. Family and faith were considered a major support by all, but the impact of breast cancer on a woman's primary role in the home was particularly hard, adversely affecting the whole family. Therefore, although the family provided support, it also caused distress if the woman, or those around her, felt she was unable to fulfil her priority role, aggravated by a lack of displays of reassuring affection from male relatives. A range of solutions were suggested, from national programmes of education and screening to better care – especially regarding empathic clinical communication skills, and local peer "buddy" support. Nurses and lay groups felt doctors could communicate better even within time constraints, but doctors – good examples of care notwithstanding – were constrained by a bio-medical focus, lack of time and other team resources, e.g., social workers, appearing to choose to view the women's distress as the women's responsibility.

Diagnostic delay and late presentation (about half of newly diagnosed breast cancers in India(216, 217) contributes to a worse prognosis and a belief that breast cancer is incurable. These fuels delayed presentation and diagnosis. The lack of an organised screening program (218) was seen as a key factor in this vicious cycle in addition, the reluctance of women to participate in screening programs implemented by government due to their responsibility for domestic chores of extended family as well as treatment decisions being taken by other members of family (219) Indian women, particularly older women(220), despite reporting poorer health than men, have lower rates of healthcare utilisation, with fewer hospitalisation and outpatient encounters (221). In spite of all advances in medical care a large number of people still believe that cancer is infectious and attribute social stigma to the diagnosis that they are not willing to come for screening to avoid getting a positive diagnosis (222). Indian women living in rural and peri-urban neighbourhoods have poor knowledge of breast cancer, with a minority practicing self-examination and none presenting for clinical breast examination(223). Immigrant Indian women living in the West who are more educated and acculturated appear to engage better with the breast cancer screening services (224, 225). National programs to increase awareness with affordable (free to patient) screening would foster early presentation.

Treatment related body image issues have been mentioned by both groups including distress caused by loss of breast, loss of hair and lymphoedema. The fact that "*long hair and breasts*" are considered as *"the yardsticks of womanhood"* even by the community throws light to the importance of symbols in the life of women. The interpretation woman attributes to other mastectomized women can contribute to the delay in the early detection of breast cancer (226). Stigma was highlighted by all, contributing to delayed diagnosis, affecting how women coped with the disease, affected treatment decision and from other work, a lack of active involvement during medical encounters or decision making (227). Women usually have arranged marriages, and have repeated reminders of the importance of the birth of a first child within the first year of marriage (228). These philosophies can affect the health-seeking behaviour of women, with some refusing treatment because of fears of infertility and stigma, with hair loss seen as a "hallmark" of cancer. Women appear to be particularly vulnerable to social stigma, and seems to be a factor in treatment delay in other conditions like tuberculosis (229)**.**

The patriarchal culture influences the way women respond to illness (54). This is consistent with reports from patients of the interview study. Incomplete information and the lack of opportunity to ask questions, have been noted; women are usually accompanied by a 'male carer who did all the talking' and remained passive during consultations (227). Exclusion from decision-making was a cause of psychological distress of Indian women in Canada(131), exacerbated by language barriers and 83% of Indian women who underwent mastectomy wanted more information prior to surgery in a study done as early as 1979 (116). Our doctor participants considered that a well-informed patient coped better, but prevailing attitudes keeping doctor at top of a hierarchy, seems difficult to change and even suggestions from nurses (often women) similar to ones from our study regarding communication, may neither be given nor received easily.

The collectivist family (195) was considered as a strong source of support. However, consistent with my review and interview study, a "two-edged sword" was described whereby some women felt 'unsupported' and worried particularly about 'spousal

abandonment', aggravated by a cultural reluctance of Indian men to show emotion. Similarly, faith practice is described as a major source of strength and resilience consistent in various other cultures (28, 152). However, as with my findings from review and patient interviews, previous work, issues in relation to faith can also be a cause of distress.
My study gives insight into the experiences in both the public and private healthcare sector; the clinicians were employed in a private institution, volunteers were attached to a government community team, church members had mixed experience but mainly accessed private care. Majority of patients in the country rely on private health care as shown by a cross-sectional study among patients randomly selected from tertiary cancer hospital in public sector located in major cities of five states in India where one-half of patients reported private health facilities as the first point of contact and majority of them faced financial problems in treatment (230). Church group members raised concerns about the influence of financial drivers for institutions, aggravated by the lack of national treatment guidelines, and the poor quality of medical care regarding compassionate communication and information giving. Reports of corrupt and irrational practices including referrals for unnecessary investigations and practice of non-evidenced based treatment for commercial gain are widely known in medical circles, but public dialogue on this is lacking in India (231, 232). Another study of clinicians' perspectives described the medical encounter as both 'authoritarian' and 'consumerist', although power incongruities in the doctor-patient relationship are variable and subject to change (227). However, there were pockets of good practice in the clinicians' data as shown from study of women with breast cancer receiving care from the same private hospital as the clinicians in my interview. They reported mainly good, compassionate care from their oncologists, but found this surprising, and in contrast to previous poor medical encounters.

The need for better communication, particularly by doctors, was emphasised by all. This appears to be both an individual and system issue, with no priority given at institutional level to communication skills training, or inclusion of suitably skilled team members (such as social workers). Cultural differences in communication are recognised and the paternalistic, hierarchical communication style in South East Asia is common, but not well received by patients (233). Poor communication is reported elsewhere, for example, in chronic non-communicable disease management clinics (234). Communication skills training is recognised as necessary for clinicians but there is no structured programme, and limited availability (235). Lack of effective communication and poor doctor-patient relationships lead to patient and carer dissatisfaction and is associated with litigation (236), and even violence against doctors in the country (237, 238). Consultation models (239) which cater to disclosure of concerns, ideas and expectations by patients should be a part of ‘gathering information’ within the communication framework and exemplify a patient-centred approach (240). In response to a universal call for a change, the undergraduate medical training in the country has recently been amended to a competency based curriculum with the aim to introduce Attitude, Ethics and Communication module (AETCOM) as a longitudinal program over the duration of the course (241), which was led by palliative care professionals. A similar nationwide approach to post-graduate training would build on this, but issues around professional identity culture and funding priorities at individual institutions would need to be addressed. Of note, none of our participants mentioned communication skills training as a solution.

Both the groups commented on the need for a dedicated team providing psychosocial support, communicating with patients regarding disease progress and treatment modalities, identifying and managing potential disabling symptoms like lymphedema, and overall providing compassionate care. Early integration of palliative care is now known to improve the health related quality of life and provide better symptom control (242) the American society of Clinical oncology (ASCO) has released position statement and guidelines on the early integration of Standard Oncology care and Palliative care for any patients with metastatic malignancy or those with high symptom burden (243). Care provided by palliative care teams was seen as good, and earlier integration of palliative care into breast cancer care could help in improving symptom burden, providing psychosocial support and also provide education and training for oncology staff in psychological distress identification, assessment and basic management, as well as advanced communication skills training, in the absence of a national post graduate programme

Religion was considered to be a support system by most of the participants. The strong religious practices evidenced in the country from prehistoric times, closely intertwined with cultures, caste system, family life, was felt to be a major source of strength and resilience in keeping with other studies in various other cultures (28, 152).These different cultural nuances to which the Indian woman is exposed can influence her psychological processes and decision making capacity which is evidenced through the framework of 'cultural task analysis'(94).

6.8 Strengths and limitations

This qualitative study from Kerala, explored the understanding of clinicians and non-clinicians on the subject, enabling interpretation of clinicians' views in the light of lay public opinion. The study captured experiences of public and private health care settings, from both upper and lower socio-economic groups. These data will not be, and are not intended to be, representative of the whole South Asian population. However, the findings are likely to be applicable to Indian women elsewhere, such as the experiences of accessing medical care, and the principle need to be cognisant of the woman's cultural context when providing breast cancer care can be extrapolated to the rest of the country, and to migrant Indian women who often "take their culture with them" (Chapter 4). Lay volunteers have some clinical experience, and so will not be totally representative of lay voices with no experience. However, this experience is firmly rooted in the community rather than hospital. The inclusion of only one Christian church is a limitation, however, Kerala State is recognised for its inter-faith harmony and understanding of other faith cultures. Further, the participants were almost all women. However, this study aimed to highlight the experience of women, in a culture where this voice is typically less prominent. Men were represented in both professional and lay groups, but we recognise that we have fewer direct accounts of men's experiences. Of note, men were invited to the church group as well as women, but only women attended. Although this may indicate that the topic is viewed as a "women's problem only", the data we generated clearly indicated how this "woman's problem" affected the whole of family life and society. In this study the experience of breast cancer patients was reported by individuals who did not experience the illness themselves but will be synthesised (see Chapter 7) with the data from women with experience presented in Chapter 5.

6.9 Clinical and research implications

The findings from this focus group discussion echo those of systematic literature review (Chapter 4) and the interview study (Chapter 5). The clinicians and lay people are aware of the psychological distress faced by women going through a life changing diagnosis and are calling to address them. An appeal for a screening program and public education, particularly in rural communities, was voiced; surely a priority for this prevalent cancer. Post-graduate communication skills training for doctors and nurses, prioritised by institutions, facilitated by earlier and stronger links with palliative care teams, would help address a lack of effective empathic communication, and the identification, assessment and basic management of psychological distress. A greater emphasis and understanding of multi-disciplinary team working, with resources to include social workers and earlier integration and availability of palliative care is needed. Culturally tailored community support groups and/or patient "buddy" systems can provide women with psychological and practical help.

6.10 Summary

This chapter described the methods and findings from the focus group discussion conducted among health care professionals and members of the public. Indian women with breast cancer are seen by varying members of their clinical and lay communities to experience widespread psychological impacts. These are amplified by the patriarchal context within which they live, which extends into clinical practice. Family and faith provide a strong support structure, and are a cause of distress, as core roles and expectations are challenged by this disease of womanhood. Poor education, late presentation and lack of universal screening lead to a vicious cycle of stigma aggravating distress.

In Chapter 7, I will synthesise the findings from the literature review, patient interview and focus group studies

7 THESIS SUMMARY SYNTHESIS AND DISCUSSION

7.1 Introduction

The overarching aim of the thesis was to identify and gain an understanding of the psychological concerns of women of Indian heritage with breast cancer living in India or anywhere in the world in relation to the diagnosis and treatment, and to elaborate on the aggravating or ameliorating factors.

Chapters **four to six** presented the findings from i) my systematic literature review of the psychological concerns of women of Indian heritage in relation to breast cancer treatment living anywhere in the world, ii) my qualitative interview study of Indian women living in India undergoing breast cancer treatment and iii) my focus group study of health care professionals, community volunteers and members of the public.

This chapter will bring together the findings from each study in relation to the research questions addressed in this thesis.

7.2 Research questions

The questions arising from the research aim were

1. What are the psychological concerns of women of Indian heritage with breast cancer receiving treatment, in relation to the diagnosis and its treatment?
2. What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?

7.3 Integration and summary synthesis of findings

The key findings from each of the questions are summarised in Table 16 and form the basis for this discussion. In the table, I present my findings from each study in relation to the research questions with a synthesis of the findings, and then bring together to summarise the overall findings. Table 17 shows how I have used triangulation (244) to look for agreement, partial agreement, silence, and dissonance between the findings from each study. In the following text I bring together the overall findings in relation to my thesis aims.

Table 16: Key findings from research questions

Questions	Systematic literature review	Patient interview study	Focus group discussion.	**Summary**
What are the psychological concerns of Indian women with breast cancer living in India, or anywhere else in the world, in relation to breast cancer and its treatment?	• Indian women suffer similar psychological concerns to those of other cultures, including adverse mental health, stigma and body image issues. • Distress is framed by patriarchal cultural experiences and expectations which both aggravate and ameliorate.	• Indian women living in India experienced the similar psychological concerns to women from the West including anxiety, depression, fear of disease recurrence, worries about their children, worries about change in role in family and body image issues due to loss of hair and breast. • Distress was amplified by the core expectation regarding the role of women as wife, mother, and the carer of older in-	• Professional and lay groups agreed that significant distress was experienced by women which can affect treatment decisions and how they responded to having breast cancer. • Distress caused by the cancer of female organ in relation to body image and disfigurement had profound effects on the relationship with spouse, sense of self and role.	• Psychological symptoms faced by Indian women are similar for women all around the world, and Indian women everywhere have particularly strong symptoms related to with predominantly issues related to body image and stigma. This is framed by their patriarchal cultural expectations, which may be complicated by erroneous health beliefs, lack of information, language barriers • The disease being a cancer of female organ affected

		laws. • For these Keralan women, loss of hair was a particular distress	• Doctors felt that the impact of loss of breast was less of an issue for Indian women because of national dress so didn't opt for breast conservation; the lay groups disagreed	the core role of women as daughter, daughter in law and within society and how they think of themselves from an Indian culture and relationship with spouse and this aggravated the distress as they felt unable to fulfil their role.
What are the influences which aggravate or ameliorate these psychological concerns including those arising from their Indian cultural context?	• Indian migrant women not only 'carry their culture' to a host country, but face further significant challenges in accessing culturally acceptable healthcare • For Indian women (both home and migrant), family structure, religion and community were major	• Families and faith were sources of strength. • Faith helped them to come to terms with the diagnosis and to cope. • Compassionate and honest information from professionals was greatly valued and helped ameliorate distress. • Some women had	• Family and faith were considered a major support by all. • However, some felt that family was a "two-edged sword" whereby some women felt 'unsupported' and worried particularly about 'spousal abandonment', perhaps	• Family and faith were generally accepted as the main source of support, felt across all groups both in home country and abroad. • In addition, community was also thought to be helpful by most women. • However, there were instances where due to

	influences • Such factors may be supportive to women, but may also be particular causes of distress • Aspects of cultural competence and cultural congruence are relevant in this situation, both for “home” and “migrant” women.	unsympathetic or less flexible home situations which aggravated distress. • Some women considered their cancer as ‘God’s punishment’ which increased stigma and resulted in ‘faith fatalism’ which proved as a barrier to accessing treatment • Hair loss was a barrier in accessing support including social or religious gatherings, and felt that artificial hair was a poor substitute. • Some clinicians failed to recognise how deeply	due to the cultural reluctance of Indian men to show emotion. • All groups felt delayed diagnosis aggravated distress around diagnosis, and fed erroneous public understanding about cancer, including surrounding stigma, which led to a vicious cycle of late presentation. • Doctors communicated poorly and could improve, especially around expressing empathy for hair loss. • Family and faith	unsympathetic families or worries about spousal abandonment, the families aggravated their distress. • A few women also expressed faith fatalism which aggravated their distress, others couldn’t practice faith due to body image issues which was not helpful. • Women in India felt that clinicians could be more empathetic as some failed to recognise how deeply hair loss affected their distress. • Delayed diagnosis due to lack of organised screening can aggravate the distress

		hair loss affected women and were unsympathetic despite working within the same culture • Most women felt that talking about their problems would be useful but did not have a ‘right person’ to talk to.	centred society was a cause of distress in some, particularly when faith practices were disrupted, and family expectations not met and if families did not accept the women’s needs. • The lay groups felt that it was their job to support women with cancer, be it through emotional or financial support and felt that community should stay together.	around diagnosis and also affected public understanding about cancer. Screening should be accompanied by public health education to break the vicious cycle of delayed diagnoses and erroneous health beliefs. • Earlier access to, and better availability of, palliative care services may support oncology teams to better identify psychological distress, and support/educate with regard to communication skills

7.3.1 Thesis aim.

To identify and comprehend the psychological concerns of Indian women with breast cancer living in India or anywhere in the world in relation to the diagnosis and treatment and the factors which aggravate or ameliorate the psychological concerns.

7.3.1.1 Psychological distress in the context of a patriarchal culture

All my studies found that the psychological symptoms experienced by Indian women were similar to women from other cultures: shock, disbelief, anger, guilt, anxiety, depression, social isolation, fear of recurrence, worries about their children, worries about change in role in family and body image issues due to loss of hair and breast. However, whilst the issues are similar at first glance, Indian women seem particularly affected given the context of the societal expectations placed on them primarily as wife and mother. Breast cancer affects a female organ; a primary symbol of womanhood. Breast cancer treatments further adversely affected body image, sexual attractiveness and fertility, and the ability to take care of the house and relatives. This undermines their perceived primary purpose, even in more educated and employed women. In many parts of India, especially the rural areas, cultural, social and economic factors still preclude girls from getting only a basic education preparing her only for matrimony, motherhood and caring for family (245). This is assumed to be different in Kerala; an Indian state viewed as affording a higher status for women (43). However, even in my Keralan studies, women's primary distress was related to their inability to perform the role of wife, mother, child rearing and care for family – often extended – members, rather than any loss of employment. Keralan findings were consistent with the traditional view of families being more important than careers (190, 191) (193); those who do not conform and prioritise their career risk social censure (194).

Indian women usually have arranged marriages with explicit expectations and repeated reminders of the importance of the birth of a first child within the first year of marriage (228). These philosophies can affect the health-seeking behaviour of women, with a few refusing treatments because of the fear of loss of fertility and stigma (all the family daughters will now be unmarriageable), with hair loss, again, being seen as symbolic of the cancer patient. In my interview and focus group studies, I identified a vicious cycle of erroneous health beliefs, late presentation due to a lack of an available-to-all national screening programme, meaning that breast cancer was always perceived as incurable.

Concerns about alopecia were particularly apparent in the Kerala studies where women reported that this distress was not always recognised by their oncologist. Keralan women take pride in their long hair, which is considered by some as a traditional feature of 'Kerala-ness'(205). Most women in my interview study saw hair loss as a barrier in accessing support from the community and found artificial hair to be a poor substitute. Interestingly, in my focus groups, doctors, unlike the other groups, felt that the impact of loss of breast was less of an issue for Indian women because of national dress and saw this as a reason why many didn't opt for breast conservation. Other participants considered that the low rate of breast conservation was related to social censure for choosing an expensive and "unnecessary" procedure.

My literature review found that migrant Indian women face additional challenges due to language and cultural differences to the host country, effects on employment where second incomes were important in the migrant context, social status and host integration. This, in turn, affects their adaptation, acculturation and causes intergenerational conflict. Exclusion from joint decision-making due to language barriers can be a problem (134); women may find it more challenging than male immigrants to learn a new language (246). Mental health appeared better in migrants who perceive themselves to be accepted by the host country, and if the host country understood their culture and language (247).

7.3.1.2 The impact of family

All studies agreed that the family was both an important positive and negative factor for all women. The review showed that in addition, for migrant families, a lack of extended family or wider community system adversely affected how migrant Indian women coped with cancer (137). The patriarchal structure of family unit carried over to the migrant country which had a strong influence in decision making and sometimes can aggravate the distress felt by migrant women when they felt excluded from the process (131). A number of barriers impair the role of migrant women in treatment decision-making which included language difficulties, poor health literacy, the complexity of healthcare systems, degree of acculturation, cultural expectations of the doctor's role and the role of the family (248-250).

Immediate family was generally supportive, managed to take time off work to accompany during hospital appointments, assist in day-to-day chores and provide financial support. However, where family members were unable to increase support due to other commitments, tensions could arise. Some felt worried about their partners not coping and managing the household work in their absence and about the future of their children.

Even for Indian women in India, the response of family and community was not always seen to be culturally congruent for individual women concerned, preferring societal expectations over personal experience. Open displays of affection from male relatives were unusual in this culture which thereby increased worries about ‘spousal abandonment.’ The impact of breast cancer on a woman’s primary role in the home was seen by lay groups as particularly hard, adversely affecting the whole family. Therefore, although the family provided support, it also was a cause of distress if the woman, or those around her, did not feel she was able to fulfil her priority role.

7.3.1.3 The impact of faith/religion

All my studies agreed that faith was as a strong source of support to ameliorate distress and many women drew positively on their faith as a coping mechanism and source of spiritual support, spiritual beliefs and practices are reported as central to coping (152, 156) especially in ethnic minorities (28). Most women in the study depended on faith to help them come to terms with the diagnosis and to cope. Religion can provide positive and negative support to those with illness either as reassurance or as spiritual struggle (189). This view as a source of strength and resilience is consistent in various other cultures (28, 152). The strong religious practice is closely intertwined with cultures, caste system and family life in the country from prehistoric times. Significantly, alopecia prevented some women from attending social or religious gatherings cutting them off from a valuable means of support.

However, again, all studies described challenges e.g., how ‘passive fatalism’ (131, 134) could adversely treatment adherence. Some women interviewed considered their cancer as “God’s punishment” reflecting society stigma and led to – in a few - in ‘faith fatalism’ which proved as a barrier to accessing treatment, consistent with previous studies (131, 134).

7.3.1.4 The impact of health services and the community

Women were greatly helped by empathic and honest information from professionals; effective communication from health care professionals is known to alleviate distress (251). The women interviewed felt that their oncologists in general provided good support, surprisingly so for some who compared their experiences favourably with previous encounters with doctors. However, the lack of empathy by some clinicians, in spite of working in the same culture, about loss of hair and breast aggravated the distress – the doctors should have understood, but did not. This is similar to the findings from a study which assessed and compared perceptions about the impact of cancer and chemotherapy among health-care providers and patients, which found that patients gave highest impact score for hair loss but was greatly underestimated by physicians (252). The literature review and focus groups included comments – particularly from the lay public and nurses – that the communication skills of doctors were suboptimal and added to the distress. Doctors, in general, saw the distress but felt addressing this was beyond their training and resources – in contrast the nurses felt that even the addition of a short sentence of acknowledgement would be very effective in helping the women. Interestingly, no group identified the need for communications skills training for doctors; instead, solutions provided by the doctors were for additional members of staff to cover this shortfall.

Most women felt that talking about their problems would be useful but did not have a “right person” to talk too. They commented that study participation provided a welcome outlet for their thoughts. Previous studies have indicated Indian women generally prefer to seek socio-culturally acceptable informal care (207). The lay participants were vocal about the need to support these women as a community with both psychological and financial means. However, the women in our interview study found that the immediate community aggravated their distress and were not keen to discuss their problems with them due to stigma. Although most women had some psychological distress, few were referred to psychological service and those that were, found this useful. Referral rates for psychiatric/psychological services for cancer patients (even in institutions where such services are available) in both India and the West appear to be equally low (183).

Diagnostic delay and late presentation in around half of newly diagnosed breast cancers in India (216, 217) contributed to a worse prognosis, and a general belief that breast cancer is incurable, in turn, fed into delayed presentation and diagnosis. The lack of an organised screening and educational program (218) was seen as a key factor in this vicious cycle. It has been seen that Indian women, particularly older women, are less likely to seek appropriate and early care for disease (220). Even though they report poorer health than men, they have lower rates of healthcare utilisation, with significantly lower rates of hospitalisation and outpatient encounters (221). Additionally Indian women living in rural and peri-urban neighbourhoods are reported to have poor knowledge of breast cancer, with only a minority practicing self-examination and none presenting for clinical breast examination (223). Immigrant Indian women living in the West who are more educated and acculturated appear to engage more with the breast cancer screening services (224, 225). National programs to increase awareness and financially viable screening program targeting people in low socioeconomic groups would contribute to a cultural shift in the knowledge and attitude of women and enable early presentation.

7.4 Psychological distress and the role of palliative care

The easing of suffering or distress is an essential purpose of palliative care. The overall burden of cancer diagnosis and treatment is referred to as distress, which is defined by the National Comprehensive Cancer Network (NCCN) as, “Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its symptoms and its physical treatment” (253).Identification of psychological suffering and distress in a timely manner during treatment is important to enable the physician to offer the help and support to alleviate the patient’s suffering and prevents non-compliance with treatment. A survey conducted among Canadian oncologists and specialist nurses in Oncology showed both groups being aware of the common occurrence of psychosocial problems in women with breast cancer; however, physicians were less likely than nurses to offer these women psychosocial support before problems were identified (254). A palliative care approach includes assessment and management of psychological as well as physical symptoms, and can be incorporated into care from diagnosis. It is therefore important that the patient’s experience is understood, psychological concerns identified and appropriate support provided.

7.5 Summary triangulation of the literature review, interview, and focus group data

My triangulation looking at areas of agreement, partial agreement, dissonance and silence to compare my findings in the systematic review, interview study and focus groups is shown in Tables 17.

All studies agreed that although breast cancer affected women psychologically in similar ways to women all over the world, this distress is significantly framed by patriarchal cultural expectations which are a part of the day-to-day life of the women since birth. The major psychological distresses including cancer-related stigma (affecting the whole family), body image issues, worries about role loss, which may be complicated by erroneous health beliefs about the transmissibility and inevitable incurable nature of breast cancer, and financial stress. Women particularly suffered from their perceived inability to fulfil their culturally expected role of a daughter-in-law, wife and mother because of their cancer of a female organ and treatment-effects (e.g., alopecia, mastectomy, infertility, vaginal dryness) which symbolised loss of their primary purpose.

The major support for the women was perceived to be family and faith. However, these support systems can themselves prove as a source of distress in instances where motherhood became a ‘two-edged sword’ and women worried about spousal abandonment, the patriarchal nature interfering with decision-making and faith fatalism aggravating distress. Hair loss as a major stressor is not addressed appropriately or adequately by clinical team.

In my studies, there was dissonance about the experience of medical care and community support. Some women reported supportive clinical care while others had their distress aggravated due to poor communication and a lack of patient-centred and involved care. Lay groups had mixed experiences of medical care, but often poor. Whereas the lay groups highlighted the importance of community support, the women themselves were ambivalent, saying that the community could be judgemental and aggravate stigma.

Only the two primary studies provided suggested solutions to the problems identified; the review of existing literature being silent on the topic. In particular, late diagnosis, lack of

Table 17: Factors which ameliorate and aggravate distress

Factors which ameliorate distress		Systematic Literature review	Interview study	Focus groups
	Agreement	Family Faith	Immediate family supportive Faith was a major support system	Family, children and woman hood as a strong motivation Faith and religion a major support system
	Partial agreement	Sharing experience with others helped	Talking about problems helped	
	Dissonance	Experience of medical care: unable to get information due to language barriers Felt not supported by health care professionals Community greatly supported the migrants	Most women understood the cancer treatment well, having had good explanations from their medical professionals Actively gathered information Community not supportive due to stigma, women felt	Recognised care was disease-focused and felt lacked skills and time to manage mental health. Doctors communicated poorly and could do better especially around expressing empathy regarding hair loss.

			under scrutiny and harassed.	The lay groups felt that it was their job to support women with cancer, be it through emotional or financial support and felt that community should stay together
	Silence	No response on solutions	Solutions: Warn other women, create awareness for early detection. Practical changes in life, new hobbies	Solutions: screening programs, improve resources, communication skills

Factors which aggravate distress				
	Agreement	Poor knowledge about the nature of cancer Family Body image: hair loss Loss of role as a mother and wife can lead to non-compliance Financial impact on migrants	Hair loss as a barrier in accessing support including religious support Hair loss causing body image issues Inability to perform the role of wife and mother Side effects of cancer treatment Patriarchal nature of family excluded from decision making Financial impact on family members	Treatment-related body image changes on their sense of womanhood Fears of social stigma and being abandoned by their spouse. Concerns about financial “toxicity” of treatment

	Partial agreement	Exclusion from decision making Community expectation of fertility Faith: passive fatalism	Faith fatalism, punishment from God	Exclusion from decision making due to patriarchal culture
	Dissonance	Experience of medical care: lack of communication, compounded by poor education, language barriers Breast conservation was associated with greater stigma due to social scrutiny	Mastectomy can worsen body image concerns as opposed to conservation.	Mastectomy can worsen psychological symptoms
	Silence	Delayed diagnosis was not mentioned in the review Lack of information: language barriers Stigma: fears that cancer is	Delayed diagnosis due to not performing self-breast examination Treatment and diagnosis had an effect on sexual life	Delayed diagnosis due to lack of screening program, self-sacrifice, poor knowledge about breast cancer from women of rural

		transmissible led to social isolation Lack of extended family in migrants aggravated distress Treatment and diagnosis had an effect on sexual life		areas Lack of time from doctors to provide psychological support Effect on sexual life not discussed

public understanding of cancer and subsequent fear of recurrence was highlighted by the lay focus groups. They suggested this would be address by organised screening programs free to all. Unsurprisingly, only the review highlighted the additional issues faced by migrant women. Also – only the studies which included the women's voices made any mention of the adverse impact on sexual satisfaction.

Of note, no participant suggested communication skills training for clinicians as a solution to distress caused by lack of empathy.

7.6 Strengths

The systematic literature review looked specifically for studies of Indian women identified the gap in literature especially regarding qualitative data from Indian subcontinent. The robust search identified papers published from India unavailable elsewhere. A critical interpretive synthesis approach was used to for the mixed-method synthesis of the qualitative and quantitative papers thereby producing new and more. The questionnaires used in the observational studies in the systematic review had been validated in India and few were translated and validated in regional languages. Qualitative research has an important role in both forming new theory and modifying existing theory. Although my aim was not to form new theory (using established theory), my research could develop theory depending on finding applicable knowledge.

The qualitative interview study and focus groups were able to provide an in-depth understanding about the psychological symptoms of Indian women with breast cancer from the perspectives of patients, clinicians and laypersons. I was able to capture the experiences of those from both public and private health care settings, thereby giving voice to women from both upper and lower socio-economic groups, and to interpret the views of clinicians in the light of lay public opinion. Both the qualitative studies were first of its kind from the state of Kerala in South India. Although I did not aim to develop new theory, I was able to use existing theory to inform my analysis, and show its relevance in my study population.

The quality of the observational studies identified from the literature review, especially the work done in India, was poor in many aspects highlighting the need to build capacity for high quality research in this field. The overarching use of symbolic interactionism, and various frameworks including cultural distress (77) and cultural task analysis (94) used for interpretation of data enabled us to understand how the distress experienced by women are closely related to culture (and arising from cultural incongruence even in India), affects their behaviours and responses and that this culture travels with the women to the country of migration. This is important to understand given the great size of the Indian diaspora in the world.

7.7 Limitations

As my data collection was done in India during my out of program from training year, I had to complete the data collection before my return back to the UK, I was not able to conduct a sequential thesis with each study fully informing the subsequent studies. The SLR was not therefore complete when my interview data collection started and thus the earlier data collection was not informed by a full understanding of the gap in literature. However, I did already have an impression, from my initial reading, that there were a few qualitative papers. This was confirmed when my SLR was completed. My SLR was complete in time to inform the analysis of both interviews and focus groups. Although I was not able to complete my interview data analysis prior to conducting my focus groups, I had completed the data collection, and, due to familiarity with the interviews, was aware of key issues that informed my focus group topic guide.

The systematic review will be limited by the known challenge of finding all relevant publications; there may be key papers that were not included. The main limitations of the included papers related to i) the poor methodological quality of the observational studies - although the measures used for depression, anxiety and stress were validated in an Indian population and ii) the small number of qualitative papers.

I designed the patient interview study after attending a basic qualitative methodology course in India along with the help of local mentor (CV). I could have further benefitted with training and mentorship in the UK at that time, which were provided once I had registered as a post-graduate student at HYMS.

My decision to interview some participants with a family caregiver present was pragmatic. Although in most instances it was helpful (relaxing the patient, useful prompts from the family member) it also risked potential problems (restricting the participant in what they felt they could say in front of a family member; the family member restricting what the interviewer could say). However, overall, it facilitated rather than hindered, participation, and despite concerns that participants may have felt constrained, detailed accounts of the adverse, as well as positive, aspects of family, friends and society were freely reported

The results of the interview study might be influenced by my personal bias and assumptions as I am from the same culture as the women in study but this was minimised by discussion of the findings with the supervisor based in UK and from a different culture, who helped in analysis. In a few of the interviews, the carer was present in non-participatory role which could nevertheless have prevented the participant from discussing her concerns in full. Due to the diverse nature of the culture of the country the data from a single state cannot be generalised to the South Asian population, but much is applicable.

Most women interviewed were from upper middle-class families attending private hospital; however, the focus groups were able to give the perspective from volunteers working in the public sector. Concerns about loss of career and second income of family were not mentioned by women in the study, though this is different in women living other states which were volunteered to me in response to the published paper. Interviewing a church group gave a disproportionate representation for the Christian community although voices from people of other faiths were included.

7.8 Clinical and research implications

These are important messages to clinicians caring for Indian women with breast cancer anywhere in the world. Clinicians must be aware of the range of issues contributing to the significant psychological distress experienced by Indian women with breast cancer. They should be trained in the assessment, and management of common psychiatric disorders in patients with cancer using clinical practice guidelines developed by the Indian psychiatric society (255) as well as NICE guidelines (256). The issues should be understood in the context of their prevailing societal attitude of women as wife, mother, and the carer of older in-laws. The importance of hair loss and risk to fertility should be particularly recognised and acknowledged. Even where the woman lives in another country, these values are often still in place. Migrant Indian women carried additional stigma to their western counterparts, and thus careful discussions are needed with individuals regarding treatment choices and accessing support, including access to wigs from their own hair.

Cultural issues relating to individuals, families and communities both helped and contributed to depression and anxiety. Therefore, the culturally competent clinician will assess the patient as an individual – whether in the West or in India (e.g., the Indian physicians – unlike the lay groups – failed to recognise the impact of loss of a breast). Unless this is done, the risk of cultural incongruence will remain with serious psychological consequences for the patient. The NICE guidelines recommends identifying and addressing the needs of groups who may have difficulty in accessing or face stigma while using mental health services including people from black, Asian and ethnic minority communities. Through the mental health gap action program (mhGAP), WHO aims to increase the coverage of key mental health interventions in low and middle income countries which has a large proportion of global mental health burden (257).

Even in India, the clinician must not assume that they know all the culturally relevant influences and must also allow for differences in the regional language spoken, especially in tertiary hospital settings. Cultural congruence involves efficient collaboration between health care provider and patient, cultural competence is a quality that is thought to be progressing constantly. However the care offered might not be perceived by patients and families as adequate as they bring their own values, perceptions and expectations to each health care encounters (258).

There is also an issue regarding culturally acceptable behaviour and culturally appropriate behaviour. For example, it appeared “normal” that doctors were paternalistic and didactic in their practice with little expectation that patients would express their concerns and preferences, or that these would be considered (culturally acceptable, but not appropriate). Another example is that although it may not be surprising to my participants that a clinical decision would be taken with male family members only, this approach was recognised as aggravating women’s distress.

Early support through the impact of diagnosis and treatment decisions and side-effects, with access to appropriate language is important - especially so for immigrants or those accessing healthcare out of Indian region/state. There is an urgent need for screening and early cancer detection services as well as education to overcome the stigma and erroneous health beliefs, so women present earlier.

Women greatly appreciated compassionate information from professionals but were not always able to participate in clinical decision-making. A family-centred approach to care, but one which includes the woman in decision-making will help overcome barriers women face in India and elsewhere. The importance of motherhood and parenting should be kept in mind for young breast cancer patients. Culturally congruent support groups are needed. Religion and spirituality are important for coping and chaplaincy services tailored to the needs of women should be an integral part of clinical services particularly for women refusing or with poor adherence to cancer treatments. Clearly important for Indian women, culturally competent and congruent care is important for all people, regardless of their culture or heritage.

Future research should also focus upon the specific concerns of women from other cultural backgrounds, with particular attention paid to the distinct needs of migrant communities.

In addition, my thesis is only a first step in understanding the psychological concerns of Indian women with breast cancer. Further research is needed to extend study into women living with advanced breast cancer, no longer having any treatment, or those now in remission. They are likely to have overlapping concerns, but also others which relate to their disease status.

7.9 Overall summary of thesis

The overall aim of this research was to understand more about the psychological symptoms faced by Indian women with breast cancer during treatment and to identify the aggravating and relieving factors of the same.

I found that psychological distresses were common, and similar to women living in the west, but were experienced within, and aggravated by, a common culture of Indian women where symbols of femininity are heavily imbued with societal role expectations. Family structure, religion and community appear to both protect against and cause distress in relation to an expected core role and male dominance particularly in decision-making. Stigma aggravated by erroneous health beliefs about the transmissibility of cancer, and the vicious cycle of late presentation limited the support that the womens' close communities could provide.

The psychological impact was predominantly in relation to body image issues related to loss of breast and hair experienced within their core role of wife, mother and family caregiver. Even within India, women might not receive culturally congruent care, and this, often accompanied by poor communication aggravated distress. Distress was magnified by financial concerns particularly in immigrant communities where a second wage was often crucial, and in India where payment for treatment may tip the family into poverty. The patriarchy often extended into models of healthcare with most doctors being men working within a predominantly biomedical model where poor communication and lack of empathy aggravated distress. The theoretical perspective of symbolic interactionism (52) was pertinent in showing how the loss of symbols of femininity including breast and hair affected the life of women and allowed a better understanding of their thoughts and experiences.

7.10 A COVID-19 post-script

The data collection of the theses was from the period 2015 to 2016. In December 2019 there was the first reported case of coronavirus disease 2019 (COVID-19), caused by the novel severe acute respiratory syndrome coronavirus (SARS-CoV-2), and which was declared a pandemic by World Health organisation in March 2020 (259). Subsequently it was clear that several areas of healthcare including infant and maternal health, immunisation, and non-communicable diseases was severely affected by the pandemic (260, 261). India had its first positive case of COVID-19 reported from the State of Kerala on January 30th, 2021 (262). Nation-wide lockdown was instituted by the Government of India in response to the pandemic which affected the travel between the states as well as travel to cancer treatment centres. In addition, some cancer centres were partially or completely transformed to COVID-19 treatment facilities. Data from a cohort study conducted among 41 cancer centres in India showed a considerable impact on the cancer services with either complete cessation of cancer screening services or functioning at less than 25% of usual capacity at more than 70% of centres (263). This will have a substantial impact on the cancer stage at presentation and outcomes especially in areas where screening services are minimal.

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8 APPENDICES

8.1 Appendix 1 List of excluded studies

Study	Reason	Study	Reason
Bapsy etal (2016) (264)	Conference abstract	Kanagalingam etal (2015) (265)	Conference abstract
Basu etal (2010)(266)	Conference abstract	Kaur etal (2016)(267)	Conference abstract
Bergerot etal (2018)(268)	Not Indian	Khubalkar etal (1999) (117)	Poor quality
Bose etal (2012)(269)	Conference abstract	Maurya etal(2015) (270)	Conference abstract
Bourdeanu etal (2010)(271)	Not Indian	Mishra etal (2012) (272)	Conference abstract
Chander etal (2011) (273)	Conference abstract	Patel etal (2010) (274)	Conference abstract
Check etal (2019) (275)	Not Indian	Patel-Kerai etal (2017) (276)	Not Indian
Cheung etal (2012) (277)	Not Indian	Ramu etal (2015) (278)	Not research question
de Souza etal (1979)(116)	Poor quality	Singh-Carlson etal (2014) (279)	Conference abstract
Duxbury etal (2016) (280)	Conference abstract	Singh etal (2015) (281)	Conference abstract
Fiszer etal (2014) (282)	Review	Sharma etal (2014)(283)	Conference abstract
Fu etal (2017)(284)	Not Indian	Yoo etal	Review

		(2014)(30)	
Jeffe etal (2004) (285)		Not Indian	

8.2 Appendix 2 Table showing the themes, subthemes, codes and quotes of systematic literature review

Themes	Subthemes	Codes	*Quotes*
Cultural context of disease experience and its impact on women	Impact of family	Support from family, Motherhood, lack of support from family, concern for family, reaction of family, role of family in decision making	*My entire family was shocked when I was diagnosed with breast cancer. We were all extremely worried and in complete disbelief because we never considered that this would happen to our family. We had difficulty getting the health care we needed from some doctors, but the family made sure I received the treatments necessary to beat cancer. My treatments were never-ending and caused a great deal of pain and suffering for the entire family. Although we all got through, I still feel down at times. (Patient,Canada)(133)* *So when you see other people got married after your marriage ... and they have two kids ... three kids, then you feel really bad [sniff]. (Patient , Canada)(134)* *My son came crying. I was doing dishes. He hugged me and said, "Mummy, you have such a big problem, and you didn't even tell us?" It is not a big thing, I told him, and it is just a disease. (Patient, Canada)(134)* *The women constructed heroic stories of family members quitting their jobs to accompany them to appointments and treatments, taking over their household duties, and providing physical care. (Researcher,Canada)(133)*

			You know in our culture after the wedding we do need a child soon. (Patient,Canada)(134) *I have my whole family here, but they don’t talk to me because of my love marriage. It’s been almost 5–6 years now but we don’t have a child yet because of my treatment. But my husband is really supportive, but I sometimes I feel bad, and I cry when I am sitting alone, because I didn’t get a baby yet, right? (Patient, Canada)(134)* *Renu (52 years old, in Canada 27 years) described how her 15-year-old daughter did not talk or eat after finding out about her breast cancer diagnosis. (Patient,(Canada)(133)* *The women explained that family members took their illnesses ‘‘hard.’’ They cried and worried, and sometimes did not go to school or work because of their concern. One woman, Ranjit, also indicated that her husband checked her pulse at night to see if she was still alive (Researcher,Canada)(133)* *Using a common Punjabi metaphor, another woman described how her breast cancer had aged her husband, turning his hair grey. (Researcher,Canada)(133)*

			For one survivor, the bald head and the use of a scarf were particularly difficult for her young child: "The shock was with my younger one because she couldn't see me that way and when I used to expose my head in front of her, I always had a dupatta (scarf) on my head while I was at home." (Patient,India)(132) *My daughter when I was having my chemo would sit with me and after she used to give me medication [every] four, four hours at night. She would sleep with me. Until the medications were finished she would stay with me, then she would go home after 3 days. After that my daughter-in-law's mother used to come to me, she stayed with me the first week when I was very sick. I have a lot of family support. (Patient,Canada)(133)* *Would their daughters be eligible for marriage to good suitors? Breast cancer in the mother might mean that a daughter could have breast cancer as well, making matrimony with the daughter a higher risk for the future husband's family(Researcher, Canada)(134)* *When I was diagnosed with breast cancer I was frightened, but my family helped me realize that breast cancer was just like any other disease that could be treated. Now that my treatments are over and I am as healthy as I can be, I try not to think about breast cancer. It was just another health problem among other health problems that I deal with. (Patient,Canada)(133)*

			Some women explained that the cancer diagnosis had to be kept secret from most of the family and community so as to keep the daughters from being marred as unmarriageable—a situation that became burdensome and non-supportive for these particular families as a whole. (Researcher, Canada)(134) *She rationalized that breast cancer was ‘‘an ugly disease’’ and hinted that her family standing in the community could be negatively influenced if her diagnosis was made public. (Researcher,Canada)(133)* *In one instance, a woman recalled how her family refused to let her ‘‘think about things’’ related to breast cancer or ‘‘feel sorry’’ for herself, and pushed her to stay active. (Researcher,Canada)(133)* *They framed family members’ involvement in discussions and decision-making about their treatments as common place, and emphasized the importance of the presence of family members as well as their practical, emotional, and physical support throughout their experiences. (Researcher,Canada)(133)*

			Most of the participants described receiving loving care and extensive practical assistance from family. Participants described relatives moving into the home and caring for the participant and her children, accompanying her around the clock at the hospital, being sympathetic and positive. Husbands too, overall, were described as being emotionally supportive and helpful for household but not childcare tasks. Female relatives, particularly daughters and sisters-in-law, were described as providing assistance and practical support. Sons were not mentioned as providing support. (Researcher, Canada)(131) *You’re not always able to speak to family. No matter how close you are to the family, you’re not always able to speak to them.... The intimacy ... you know ... the very private parts such as those between you and your husband. (Patient,Canada)(134)* *My in-laws were surprised that I was telling everybody about my disease I told them it was not for my advertisement, but for the sake of collecting information, by talking with people (Patient Canada)(131)* *In one situation, family members also pushed the woman to keep hidden any signs of her cancer.(Researcher, Canada)(133)*

			Following the loss of her hair because of chemotherapy, Narinder (53 years old, in Canada 11 years), who lived with her husband and four grown children, recalled hiding herself and her children to avoid having to answer the door when visitors stopped by.(Researcher,Canada)(133) *Participants described hearing graphically vivid stories of pain and suffering from relatives, about others who had died (Researcher, Canada)(131)* *I only told my daughters. I hadn't told anyone, because, as it is, you are depressed that you have this disease. Second, when they say, "Oh! She has this disease, and she is a mother with daughters, what will happen now?... Then your mind gets more depressed. Most of my relatives still don't know that I had breast cancer.(Patient,Canada)(134)* *In all age groups, most women realized that they had the support of their spouses while going through cancer diagnosis and treatment—especially when some participants did not feel like having sex, but wanted intimacy in other ways.(Researcher, Canada)(134)* *Most participants were uncomfortable in sharing details regarding the physiological aspect of sexual functioning or sexual intimacy that are practiced in nonsexual behaviours. The*

			nature of responses was either “no problem,” “there is no sexual intimacy left” or that “there was initial difficulty after the treatment but it’s all fine now.” (Researcher,India)(132) *With relation to motherhood, children of most survivors ranged in age from adolescent to adulthood years when they were diagnosed with the illness and it, therefore, did not affect them. However, it had been a matter of concern for those who were diagnosed with it at an early age in terms of breastfeeding, inability to conceive when they wanted more children, or losing all chances of fertility due to the treatment. (Researcher, India)(132)* *That difference may be a result of priorities being placed on concerns about reproduction and pregnancy. Women felt that their body image, their sexuality, and their reasons for breast reconstruction were all tied into the identity of a woman who has to make decisions for breast reconstruction after reconsidering her personal need for feeling whole (Researcher, Canada)(134)* *I used to say that whatever is going to happen will happen anyway. I didn’t tell my children because I did not want to put that worry on their mind. They were very small; they would feel bad if something happened to their mother. (Patient, Canada)(134)*

			However, several women had flirted with the idea of divorce because of the lack of support displayed by their husbands. One woman realized that negative conditions were already present in the relationship, but the significance of those conditions was heightened by the lack of support she felt after her cancer diagnosis and during treatment. At the time of the interview, she was considering a separation (Researcher, Canada)(134) *As in the previous case, discussion with family members and elders within the community often exacerbated women's distress because of the pervasiveness of this belief. (Researcher, Canada)(131)* *This tendency was attributed to older and less educated members and many women described avoiding family members or others who would speak in this insensitive way (Researcher, Canada)(131)* *For example, 2 of the women less than 30 years of age felt cheated when they were diagnosed and treated for cancer at an early age. They were concerned about the impact that their situation would have on their marriage (Researcher, Canada)(134)*

			Participants from all groups spoke about how childbearing and the addition of children to the family is a highly valued and emphasized role of women in sa (South Asian) culture and society compared with Western society—creating added pressures that make it harder to bearing the cancer diagnosis and treatment. (Researcher, Canada)(134) *Most of the women who had been told directly by their doctors expressed disapproval at having been told without being prepared, or without having a family member present: ''As I was all alone, there should be a better way of telling rather than abrupt declaration if the doctor explains in a better way and you are also accompanied by a family member, you get prepared and have some support as well."(Patient, Canada)(131)* *Because nobody knows the other person when they are telling their story, which is okay. Because some women who feel shy and may like this kind of group.... Because everybody is talking. They feel okay and will share.... You feel relaxed. (Patient Age 44) Canada) (134)* *Like my dad prior to my surgery, he just would not eat, he was very worried about me and then when I finally had my surgery and everything went well, then he started to come around.(Patient,Canada)(133)*

			Repeated encouragement by family members to ‘‘think positively’’ during the course of treatment was prominent in the women’s stories. (Researcher,Canada)(133) *Nevertheless, they sometimes still felt alone because they felt that family members could not share their suffering. (Researcher, Canada)(134)* *Some participants described the experience of social isolation and dependence on family members (Researcher, Canada)(134)* *As women struggled to try to make sense of their experiences, they recalled not fully understanding what they were told about their cancer treatments, even when translators were available, and that physicians often gave full explanations to their family members rather than directly to them. (Researcher,Canada)(133)* *One woman, who described herself as ‘‘uneducated,’’ indicated that she was not told that her entire breast would be removed: ‘‘They may have told my daughter something in English but to me they just said there would be an operation.’’ (Patient ,Canada)(133)* *Although adamant that she could forego cancer treatments, she listened to the advice of*

			family members and consented to conventional treatments offered by Western doctors. (Researcher Canada(133)) *They framed family members' involvement in discussions and decision-making about their treatments as common place, and emphasized the importance of the presence of family members as well as their practical, emotional, and physical support throughout their experiences. (Researcher,Canada)(133)* *Women's unwavering trust in their families was reflected in their ready acceptance of family members' advice and decisions about their breast cancer treatment. (Researcher, Canada)(133)* *These women were not told of their cancer diagnosis directly by their doctor, but instead, were told by family members who judged when the participant was ready to hear the news. (Researcher, Canada)(131)* *Some of the participants described having little or no involvement in treatment decisions and they expressed resentment from exclusion. They described their husbands or sons making treatment decisions for them, without involving the participant. On the occasions when this happened, resentment was expressed about the lack of inclusion and consent.*

			(Researcher, Canada)(131) *Some family members they have neglected us… Before they will come very often but now it was reduced…They will not support me more. But, I have lot of support for my friends. (Carer, India)(135)* *Having that problem was a time filled with fear and suffering for my family, and we worried about what would happen, and thought I might not survive...and it is very hard to talk about. My family attempted to reassure me but we were all suffering so much because my family had to care for me when we were so naive about this disease. And we all feel worn down by everything now and we are trying to get back to normal...I am continually worrying that it will reoccur, and I am suspicious that it has spread. I just want to forget about everything.(Patient, Canada)(133)* *however, she felt that, for most younger sa women, a diagnosis of breast cancer was a much bigger burden because it was coupled with cultural and societal expectations of women bearing children within the first years of marriage (Researcher, Canada)(134)* *However, not all participants had supportive families,*

			and a lack of family support was described in the context of unbending role expectations. Several women described the experience of being required to continue with household and childcare responsibilities immediately post-treatment: ‘‘The members of family don’t realize the weakness in the body after the cancer operation they think all the household work is my responsibility. (Patient, Canada)(131) *The unforeseen nature of the diagnosis was reinforced by suggestions from family and friends that the women were too young to get this disease and that they had always been healthy. (Researcher, Canada)(133)*
	Impacts of community	Negative effect of community, Support from community, disease perception by community, support for employer, support from friends, support	*Several survivors had had the experience of others wanting to see the scar. Few of them were not comfortable with it while few others were comfortable showing it to close relatives. As one survivor who also works as a cancer volunteer expressed, it was dependent on the context: “Some people have wanted to see it especially those who are very curious, I did not feel good at all about their curiosity as this is not a matter to be joked about, it is an illness.”(Patient, India)(132)* *Focus group participants described having conversations, particularly with elders, where they would be asked, ‘‘Why did you get this disease; what have you done to cause this illness?’’ The participants interpreted these questions as meaning ‘‘they think I have done something wrong’’. For many of the women, the communication of this belief through*

		from other patients	*discussion caused them distress, as one woman stated: ‘‘This way of thinking is what bothered me the most by the way they think is as if I must have sinned’’ (Researcher, Canada) (131)* *These women were not happy with the negative response they received from the “well-wishing” visitors because “they did not give person hounsla [hope] “they just come and disturbed you,” and “the relatives say, ‘Ha! How did it happen?’(Patient,Canada)(134)* *These contextual social and cultural factors tended to leave most sa breast cancer survivors in the 45–54 and 55–64 age groups feeling isolated and depressed— emotions that led to hopes of being able to share their suffering with members of the cancer community, preferably others from their own ethnic community. (Researcher, Canada)(134)* *Some women occasionally felt that support from family and community was negative, because people visited only to appear to be doing the right thing socially. (Researcher, Canada)(134)* *Some women also felt that having a support system within the south asian group would be beneficial. Most women found that they could talk with family or community members who*

			were already cancer survivors because they received hope from each other. (Researcher, Canada)(134) *For most women, this meant that they could share their personal cancer experiences within their own cultural and social context, in their mother tongue, making the exchange more meaningful and supportive. (Researcher, Canada)(134)* *Most women felt that sharing with others who had gone through similar experiences was more meaningful, thereby providing social support that would enhance quality of life for sa women who felt shy and who had language barriers. (Researcher, Canada)(134)* *One survivor who was of Islamic faith would wear the religious headgear or the Hijab to handle the situation. One survivor expressed the taboo associated with hair loss: "And all those things unnecessarily traditionally or just it becomes a taboo or stigma also. Actually in Islam you don't have but since we are in India, so those things matter a lot." (Patient,India)(132)* *Renu compared her physicians to God: ''People say there is nothing higher than God...but I feel that those doctors that took care of me were like God.'' (Patient,Canada)(133)*

			Strong belief in a loving God took the form of acceptance of their cancer and a sense of trust that things would eventually work out for the best. (Researcher, Canada)(131) *''I feel that it is only because of my Paht [prayers] that I had cancer in a small part of the body. It could have been worse if I had not done the Paht. God has been kind to me in this way''.(Patient Canada)(131)* *For most sa women, extended family and community were generally an important part of the social support system, especially when family or community members provided transportation for those who lacked the ability to drive to the agency for their numerous treatment-related appointments or acted as interpreters when participants were faced with language barriers.(Researcher, Canada)(134)* *Because nobody knows the other person when they are telling their story, which is okay. Because some women who feel shy and may like this kind of group.... Because everybody is talking. They feel okay and will share.... You feel relaxed. (Patient,Canada)(134)* *But when a patient has said, "Please show it to me. Whatever happened to you, is it same*

			like mine?" Then we show it to them… We show it to them because their curiosity is different, they think, "Mine and hers are same…" (Patient ,India)(132) *They expressed gratitude to the researchers for the opportunity to share feelings, hear others' stories and learn from the other women in the group. There was agreement that some things cannot be shared with family or friends, and that talking with peers was strengthening and supportive (Researcher, Canada)(131)* *These sa women saw those actions as being very supportive, and yet there was a complexity concerning who in the family or community should be privy to the woman's breast cancer diagnosis because of the stigma associated with the disease within the community (Researcher, Canada)(134)* *They shared responses such as "She is going to die now," "This is a horrible disease," and "Everyone gets scared just by the name." (Patient,Canada)(134)* *Would their daughters be eligible for marriage to good suitors? Breast cancer in the mother might mean that a daughter could have breast cancer as well, making matrimony with the daughter a higher risk for the future husband's family (Researcher, Canada)(134)*

			Some women explained that the cancer diagnosis had to be kept secret from most of the family and community so as to keep the daughters from being marred as unmarriageable—a situation that became burdensome and non-supportive for these particular families as a whole. (Researcher, Canada)(134) *She rationalized that breast cancer was ‘‘an ugly disease’’ and hinted that her family standing in the community could be negatively influenced if her diagnosis was made public. (Patient, Canada)(133)* *The richness of these women’s experiential stories of breast cancer, captured in their own language—Punjabi, Hindi, and Urdu, with or without English—defines the “cultural identity” that affects a sa bcs’s grasp of the meaning of illness across varying age groups, migration statuses, acculturation, education, socioeconomic statuses, and other cultural factors (Researcher, Canada) (134)* *Many women disliked being called a “survivor”; rather, they wanted to be called “thrivers.” Participants accepted the diagnosis and treatment and realized that this journey was a personal one, having nothing to do with surviving anything. For most women, the notion of*

			"survivor" was a more Western concept connected with behaviours of "battling the cancer" or "overcoming the cancer (Researcher, Canada) (134) *In our community people say that your family got in a curse, that is why disease will be getting in your family itself.(Patient, India)(135)*
	Impacts of religion	bargaining with God, faith fatalism, fate, God's punishment, impact of religion, spirituality	*Spiritual practices such as praying, reciting holy hymns and visiting the Gurdwara (place of worship) increased as a consequence of cancer. (Researcher, Canada)(131)* *God gave me such strength.... My family members got scared, like my children ... but I didn't get scared.... Paramatma [God] gave me shakti [strength].... I didn't feel scared at all. (Patient, Canada)(134)* *All participants throughout the focus group discussions spoke about a spiritual worldview and expressed the beliefs that their lives and future were ultimately in God's hands. (Researcher, Canada)(131)* *As one woman said: ''Nobody could change the time and cause of my death, it is God's will. So I avoided the chemo treatment'' (Patient ,Canada)(131)* *The pain became very unbearable for me, and I kept praying to God. I kept asking God to*

			save me from this pain, I kept saying that I did not want to die in the hospital. I began to barter with God. I said save me from this pain and I promise to go to the Gurdwara [temple] every day. I began to do paath [prayer] ... .When you believe in God, and really have faith in him then half of your problems [ills] go away. If you believe in God then you can be cured from your pain. ... There is no problem that God cannot cure. (Patient,Canada)(133) *But generally what I have heard is that one would get this if they have done something wrong. They say, "You have done something wrong. You are facing punishment for your wrong doings. God is punishing you." All those things I have heard from my own husband. I have experienced this. The reason why I am telling this is, we are all educated and as per God's will we are quite well off. But even at this level there are people who think like this (Caregiver,India)(135)* *Participants used "karma" in the context of the suffering that humans have to endure as part of "their past lives" and "punishment for their sins." (Researcher, Canada)(134)* *Some women were vivid in their descriptions and acceptance of their destiny in this life; however, they also understood that they could change or "turn" their karma by good deeds*

			that could lessen their current suffering and alter the outcome of the cancer diagnosis. (Researcher, Canada)(134) *Whatever was in my karma, [Punjabi] "Je dukh de ke maharaj sukh deve, tan vi jo hovega, hovega, main raula paa ke ki karna? [If after suffering God gives us happiness, then whatever happens, what would I get by shouting it out to everyone?]" (Patient, Canada)(134)* *I am Hindu by religion. Sometimes I fight with my God and ask ... what did I do wrong? I didn't harm anybody in my life. You know people say that karma is why you have this cancer. Then why do I have it, I would ask? (Patient, Canada)(134)* *As devout Sikh women, they accepted breast cancer as part of their karma (reflection of one's deeds in present or past lives) and drew strength from their religious beliefs that their kismet (fate) was in God's hands. (Researcher,Canada)(133)* *She began her story by attributing her breast cancer to her kismet (fate) to reinforce her belief that the outcome was in God's hands. Following her breast cancer diagnosis, she recalled reassuring her husband, ''I told him not to worry so much... Whatever is going to*

			happen, is going to happen. It's in God's hands.'' (Patient,Canada)(133) *When I got cancer, it was like I was being punished because I did not wear my scarf [head covering] as a Muslim woman. Then I started wearing it, and for that I am grateful. I have always wanted to, but it wasn't the right time. (Patient, Canada)(134)* *When I was diagnosed with breast cancer I knew it was part of my kismet and that whatever was going to happen was in God's hands. I meditated, prayed, and saw my desi doctors but my family insisted I also see a Western doctor and have conventional treatments. These treatments were difficult for the family but I learned to slow down and strengthen my faith to get through these hard times. Looking back on my breast cancer I believe it was an important lesson from God (Patient,Canada)(133)* *I think that God wanted to teach me something, like he punished me so that I would learn something, maybe I had done something wrong. Maybe I was to learn to meditate more strongly, maybe God wanted me to strengthen my faith in him... God can find a way to control you, like in my case, when I got cancer then I was forced to slow down. You see everything happens for a reason.(Patient,Canada)(133)*

			A few of the women outright rejected the belief as being ‘‘non-sense’’, while others indicated that they struggled and questioned themselves, as this woman did: ‘‘I used to say in the earlier stages. I have done no bad act. I have not harmed anybody. I have always tried to be good to everyone. Why am I having cancer?’’ (Patient ,Canada)(131) *Only one woman appeared to have internalized the belief and interpreted it personally: ‘‘I must have sinned against his will. (Patient ,Canada)(131)* *Whoever believes in Waheguru [God] knows that he is wholly, solely the creator and destroyer. There is nothing in the hands of human beings. The body belongs to him; surrender it to him. (Patient, Canada)(134)* *It is therefore important to understand that the sa bcs’s lens maybe coloured by an Eastern spiritual influence in which the “self’ may be different from the Western concept of “self.” This major theme of “quiet acceptance” encompassed subthemes of faith and inner strength; fate and karma; family and community; hounsla (hope and courage); and social or peer support. (Researcher, Canada)(134)* *Strong belief in a loving God took the form of acceptance of their cancer and a sense of*

			trust that things would eventually work out for the best. (Researcher, Canada)(131) *‘‘Saying ‘Satnam Waheguru’ [there is only one God and he is the truth], you have a sort of picture frame in your mind to get relief, along with the treatment which you are already taking. It gives you a lot of relaxation’’ (Patient Canada)(131)* *Several women described making positive healthy lifestyle changes, such as exercising and improving their diet, viewing their illness as being a message from God that they needed to pay greater attention to their health. (Researcher, Canada)(131)* *For most ? women, extended family and community were generally an important part of the social support system, especially when family or community members provided transportation for those who lacked the ability to drive to the agency for their numerous treatment-related appointments or acted as interpreters when participants were faced with language barriers. (Researcher, Canada)(134)*
Women’s individual responses to disease	Psychological response	Body image, Isolation inability to talk about disease,	*And in fact I said that rather than having surgery time and time again I’d rather have it whole, all of it removed. But then they only removed just the lump. So you know, instead of having to suffer many times going through surgery time and time again, like my neighbour, I would have preferred to have it [breast] taken off. (Patient, Canada)(133)*

		Stigma, Sexuality, relationship with partner, difficulty in talking about sex, being a woman, hair loss, fear, appearance, anxiety, worry, courage, fear of death, hope, ignorance, isolation, loss of self-esteem, low mood, depression, positive	*People are worried that this patient who is on treatment, she will spread the cancer to the children in the house and to the neighbours. So we have seen sadly many times that these patients are unnecessarily isolated because of the wrong notion that these people have done something so wrong to get this disease or they may spread it to people in the house. So there is a lot of stigma associated with cancer. Cancer is a disease in our country which will always be associated with stigma even though it is no fault of the patient." (HealthCare provider, India)(135)* *"…If it was pain I could say I could still bear it… But that again you know many times I used to reflect "okay hair loss fine one day it will just come back maybe we just use a couple of wigs." (Patient,India)(132)* *Depression, I used to get it a lot in my mind, in my heart. I used to feel like crying. My mind used to get upset. I am getting better now, but it still bothers me. (Patient, Canada)(134)* *You know, I feel crying every day. I am so stressed out I don't feel like talking to anyone. Nobody's home.... I just stay inside the house I am so depressed. (Patient, Canada)(134)* *"The other thing is that everyone has a feeling that a person having cancer will die soon*

		thinking, practical difficulties, privacy, shock, disbelief, worries about future, uncertainty, effect of treatment, effect on finances, effect on physical activities, physical side effects of treatment, sequelae post-surgery	*and will not survive for long." (Community leader, India)(135)* *was distraught because she knew that she could not conceive children while on hormonal therapy, causing her grief as she struggled with adherence or nonadherence to hormonal therapy. (Researcher, Canada)(134)* *While the belief that cancer inevitably leads to death is not culturally specific, nearly all of the women, upon hearing the diagnosis, felt fear that death was imminent (Researcher, Canada)(131)* *Even educated people, degree holders, teachers, they come in at a later stage because they tend to sit on their tumour for a longer duration for unknown fear. And I think it is the fear of the diagnosis of cancer and the treatment they want to avoid." (HealthCare provider, India)(135)* *Sometimes I am fine and other times, I am very down... Otherwise, I am feeling normal now. My hair has come back. [R: looks nice] Yeah, whenever I go outside or to parties, everybody comments that I am a big survivor. (Patient,Canada)(133)*

			Because relatives think that the disease will spread to them, while eating, talking, they have that kind of fear; even I am unaware whether this will spread like that.(Patient,India)(135) *Positive attitude.... Think positively all the time. Don’t think, “I am going to die.” Keep thinking positive all the time during the treatment. It’s like the mental support from the people around you.... If they are of positive mind, then you become a bit stronger. Some people are not very positive; they get you down, you know. (Patient, Canada)(134)* *Kuldeep (48 years old, in Canada for less than 1 year) explained her initial reaction when she was told she had breast cancer: ‘‘I sort of froze, I was paralyzed as if some sort of mountain had just been dropped on me.’’ Another woman described her breast cancer diagnosis as a ‘‘death sentence.’ (Patient,Canada)(133)* *“They look at me in disgusting way…. People are talking behind me ‘she has cancer who will marry her daughter?’ They don’t talk about me [to my face], but I heard them talk about other people very badly. So, I think even they talk about me badly…They say that ‘she has got cancer, who will marry her daughter?’” (Patient, India)(135)*

			You take our home care team, there are lots of times when family members will tell, 'Please don't park the auto right in front.' They are worried. Now what are they worried about? One is, will somebody else get it? But more importantly, there is a girl to be married in the family…It is not restricted to only the lower socio-economic strata. The guy could be a PhD from Harvard but he might have that fear." (Healthcare provider, India)(135) *Older women (>65 years of age) experienced only slight bouts of depression when they were originally diagnosed; they were more accepting of their situation. (Researcher, Canada)(134)* *"mentally and emotionally, because you are just not the same person afterwards" (participant age 50). (Patient, Canada)(134)* *These sa bcss shared stories of sadness and generally not wanting to be involved in family and community activities. (Researcher, Canada)(134)* *Younger sa women (<44 years of age) experienced depression related to reproductive issues associated with the cancer diagnosis, because the diagnosis changed the normal cycle of life. By contrast, women in the 45–54 and 55–64 age groups were very vocal about the depression they had experienced since diagnosis. (Researcher, Canada)(134)*

			These contextual social and cultural factors tended to leave most sa bcss in the 45–54 and 55–64 age groups feeling isolated and depressed— emotions that led to hopes of being able to share their suffering with members of the cancer community, preferably others from their own ethnic community. (Researcher, Canada)(134) *I only told my daughters. I hadn't told anyone, because, as it is, you are depressed that you have this disease. Second, when they say, "Oh! She has this disease, and she is a mother with daughters, what will happen now?... Then your mind gets more depressed. Most of my relatives still don't know that I had breast cancer. (Patient, Canada)(134)* *My entire family was shocked when I was diagnosed with breast cancer. We were all extremely worried and in complete disbelief because we never considered that this would happen to our family. We had difficulty getting the health care we needed from some doctors, but the family made sure I received the treatments necessary to beat cancer. My treatments were never-ending and caused a great deal of pain and suffering for the entire family. Although we all got through, I still feel down at times. (Patient,Canada)(133)* *The women often left sentences unfinished and interrupted their own telling of their story*

			with experiences of worry, fear, pain, and anxiety. (Researcher Canada)(133) *The women conveyed a sense of being worn down by the physical and emotional suffering caused by breast cancer and struggled to move on with their lives. Preet (50 years old, in Canada 27 years) explained, ‘‘For a year, you know, I could not sleep very well...my aunt had breast [cancer] and then it spread...what if it happened to me.’’ (Patient,Canada)(133)* *Many of the women wept while describing how their lives had changed since their cancer. A substantial minority of the women sounded currently depressed: as one woman said: ‘‘The whole life is changed there is no happiness in life.’’ Another woman expressed: ‘‘I have lost all interest in life. Whatever work I have to do, I push myself through that initiative is missing.’’ (Patient ,Canada)(131)* *“…For the world, I feel quite okay. Personally I stopped looking at myself in the mirror… I’ve had the long full-length mirror I used to have in my room. I’ve removed that now…” (Patient,(India)(132)* *“Even for swimming it’s not possible since it floated out once and I was able to put it back before anyone noticed… When you are holding on top and travelling in a bus, one day the*

			prosthesis came down, but I was able to put it back in its place without anyone seeing…" (Patient,India)(132) *For example, 2 of the women less than 30 years of age felt cheated when they were diagnosed and treated for cancer at an early age. They were concerned about the impact that their situation would have on their marriage(Researcher, Canada)(134)* *I did all the treatment.... They did the operation; they did the surgery.... What is there to be scared of? You can't do anything about it; just accept it. (Patient, Canada)(134)* *"What happens to us females is that it is so difficult when we don't have one breast. That thing can never be explained to anyone…" ."(Patient,India)(132)* *Few survivors also expressed attractiveness as important at a younger age. However, few survivors themes suggested a sense of being "cheated by life" as due to cancer, they no longer received "attention" or "make people notice" them after it. The rarer theme was few survivors continued to feel attractive: (Researcher, India)(132)* *You feel unattractive, and you feel the guilt because you do not have any interest in having sex. I was scared 'coz, and I was [emphasis] scared that he is going to go away, right?*

			(Patient , Canada) (134) *That difference may be a result of priorities being placed on concerns about reproduction and pregnancy. Women felt that their body image, their sexuality, and their reasons for breast reconstruction were all tied into the identity of a woman who has to make decisions for breast reconstruction after reconsidering her personal need for feeling whole.(Researcher, Canada)(134)* *When we were young particularly the breast part… Maybe our community and as well as society at that time was such that you will conceal breast… That's why always one dupatta (scarf) will be there… So losing a breast was not really big thing for me…" …".”(Patient,India)(132)* *For one survivor, the bald head and the use of a scarf were particularly difficult for her young child: "The shock was with my younger one because she couldn't see me that way and when I used to expose my head in front of her, I always had a dupatta (scarf) on my head while I was at home." …".”(Patient,India)(132)* *With a saree blouse, issues were regarding it's fit as it caused "pain" in the surgery site*

			when worn for few hours and the neckline as there was a fear of the scar being exposed: "when I go to my tailor… I have to show him my scar… Because now when I see this scar on someone else then I know that person has had breast cancer or at least cancer of some sort to have this port cut. Because it's very obvious because it's got two lines. You can't miss it… So he has to make sure that the neckline comes this way right or a V …"."(Patient,India)(132) *The survivor who developed leukoderma, her concerns was more related to it: "I used to wear a lot of sleeveless and very low-necked thing. Now I'm… because of this… I don't wear short sleeves so easily if I'm going out." …"."(Patient,India)(132)* *I wear East Indian suits. You want to look nice, but in my mind I know there isn't a breast here. Other people can't see that. I want to be normal, like a lady.(Patient, Canada)(134)* *I am coping with it, but I don't even feel like dating, because I feel like I am missing a part of my body. I am kind of conscious about my body. It's my body image. You know, sometimes when I am dressing, I don't even look at that part. I avoid looking at it in the mirror. (Patient, Canada)(134)* *One participant reported feeling "self-conscious" and "disfigurish" even after more than*

			two decades of the illness. A variant theme was related to the leukoderma that she developed as a reaction to chemotherapy: “My body is like an atlas (laughs).” .”(Patient India)(132) *I feel it’s a cobbler’s job. I feel it should have been like embroidery.” However, most of them also become habituated to the scar though they initially experienced distress when looking at it. One survivor’s response to her child asking about the scar would be: “I tell her she ate it up as a kid….”(Patient, India)(132)* *For those with lumpectomy, they expressed concern about breasts being “lopsided” and it was accentuated as the survivor aged: “My left side looks young, and my right side due to age, length has become long.” .”(Patient,India)(132)* *One survivor also expressed reduced interest in dressing style: “Now I feel I will never look good. Never look attractive to people, to men in general… So that parts gone away so now it’s just dressing for activity which you do… (laughs) but the other thing will also be that I am not as attractive as I used to be because I can’t dress as attractively as I used to.” .”(Patient,India)(132)*

			In contrast, several survivors also reported taking more care than before about their appearance: "When I go out, I take extra care. But… I have make-up on I try to wear nice dress. I have started buying more clothes than I did earlier… So I have something new and just to feel good. ."(Patient,India)(132) *a) going for swims, massages, changing clothes others presence, frisked by security personnel, (b) breast accidently collided with someone else in buses or crowded areas: "When I would travel by train or bus and if someone collided, they would stare for a bit because it would feel different because I would wear a prosthesis and you could make out… I always used to cover the area with my bag." ."(Patient,(India)(132)* *The need for privacy and having to be secretive about the diagnosis and related treatments added a sense of isolation and burden for sa women as they went for months of chemotherapy or radiation, or both (Researcher, Canada)(134)* *It was especially true for women who felt more burdened and depressed when the community stigmatized cancer as a "horrible disease that meant a death penalty." (Researcher, Canada,)(134)*

			The women’s use of the word ‘‘cancer’’ was often avoided, and even after seeking clarification, the interviewers often had difficulty fitting together the pieces of women’s stories. (Researcher, Canada)(133) *For example, the women described their efforts to protect their families from worrying and suffering, and the stigma associated with cancer. (Researcher, Canada)(133)* *Having that problem was a time filled with fear and suffering for my family, and we worried about what would happen, and thought I might not survive...and it is very hard to talk about. My family attempted to reassure me but we were all suffering so much because my family had to care for me when we were so naïve about this disease. And we all feel worn down by everything now and we are trying to get back to normal...I am continually worrying that it will reoccur, and I am suspicious that it has spread. I just want to forget about everything. (Patient, Canada)(133)* *One survivor also expressed the cultural expectation that breasts are to be hidden or covered which thereby reduced impact of the loss: .”(Researcher, India)(132)* *One survivor sensing her husband’s difficulty consulted her physician before resuming sexual activity: “After being cautious for good number of days, I felt he was finding it*

			difficult as males get aroused easily as well as it diminishes fast. Then, I consulted my doctor, he said, 'It is completely normal. Your sexual life is as normal as how it was before the operation. And your worry regarding hurting your breast, it doesn't get hurt.' After that, we had sexual activity, though it was very less." …"."(Patient,India)(132) *Few survivors voiced their concern about a lack of desire to engage in sexual activity and an inability to get aroused which was associated with vaginal dryness and pain. Moreover, one survivor with lumpectomy also expressed a change in her partner's overt sexual behaviour in the form of preference for the normal breast. …"."(Researcher,(India)(132)* *Another participant had extreme views that sexual life could be equated to "animal life" and it serves the function of procreation purposes. …"(Researcher,(India)(132)* *An interesting psychosocial belief which manifested in the present study "sex life is animal life," and family tradition of spouses sleeping separately (apart from age being a factor) again alludes to the tendency to repress sexuality by equating it to the function of procreation. (Researcher,India)(132)* *Loss of libido concerned women who felt that they should have some desire to have sex*

			with their spouses, but this loss of interest *"after the chemo and stuff" led them to feel guilty as wives within their relationships. However, most felt relieved when spouses were supportive. .(Researcher, Canada)(134)* *I don't know.... I just lost interest after the chemo and stuff. (Age 48) You feel unattractive, and you feel the guilt because you do not have any interest in having sex. I was scared 'coz, and I was [emphasis] scared that he is going to go away, right? (Age 50) .(Patient, Canada)(134)* *It was really tough in the beginning. My husband was really good ... very supportive. He wasn't, you know, pushy or any of that stuff; he was very patient with me when it came to, you know, intimacy. (Patient, Canada)(134)* *Another concern expressed by one survivor was the slightest comment by one's spouse about the shape could be distressing. (Researcher,(India)(132)* *My husband was scared to touch me even. Not because of anything else, he thought maybe you know I'm not ready or… He didn't want to force anything on me. I was just left to myself. It had an adverse effect too. Because I was not frank, he was not frank. So there's*

			lot of tension there in the beginning, but now I feel it's all well past gone."(Patient,(India)(132) *However, one survivor said they continue to be intimate through affection: "Somehow my husband also more into… Exercises this and that more into spirituality… We have lot of sharing and bonding but not that physical urge to do sex, maybe we hold hand and things like that but no like intercourse as such…" (Patient, India)(132)* *It's hard to talk to my husband because we don't talk about these things. (Age 54) .(Patient, Canada)(134)* *When we were young particularly the breast part… Maybe our community and as well as society at that time was such that you will conceal breast… That's why always one dupatta (scarf) will be there… So losing a breast was not really big thing for me…."(Patient,India)(132)* *In terms of attractiveness, one of the most common beliefs was that "attractiveness is internal" and it was defined as one's behaviour and not appearance. (Researcher,India)(132)*

			If it was pain I could say I could still bear it… But that again you know many times I used to reflect “okay hair loss fine one day it will just come back maybe we just use a couple of wigs (Patient,India)(132) *Others either shaved their heads before the chemotherapy sessions began and had wigs made out of it or as one participant said: “I bought a couple of wigs off the net and I would go around in my blonde avatar. Actually got a blonde (laughs) just to kind of cut off your nose to spite your face kind of thing…”(Patient,India)(132)* *Adjustments for those undergoing mastectomies involved using substitutes such as prosthesis, padded bras, and pads. The use of prosthesis on an everyday basis was convenient, but its weight was a concern and others would use pads made out of cloth. (Researcher, India)(132)* *They shared responses such as “She is going to die now,” “This is a horrible disease,” and “Everyone gets scared just by the name.” (researcher, Canada)(134)* *When I was diagnosed with breast cancer I was frightened, but my family helped me realize*

			that breast cancer was just like any other disease that could be treated. Now that my treatments are over and I am as healthy as I can be, I try not to think about breast cancer. It was just another health problem among other health problems that I deal with. (Patient, Canada)(133) *I always worry about metastasis going to other parts of the body. I do worry, especially when I hear people dying from breast cancer. That hits me; I get really sad. (Patient Canada))(134)* *Uncertainty and fear of recurrence was also a universal theme .(Researcher, Canada)(134)* *lack of clarity about normal healing, lack of information about lifestyle choices, confusion about side effects, and ambiguity about follow-up care recommendations and resources. Although some sa bcss from all age groups shared their concerns about uncertainty and fear of recurrence, younger women (<44 years of age) were more emotional in their responses because of worry that the cancer might recur and because of the unknown future. Women in the middle age groups (45–54 and 55–64) were more concerned about what would happen to their children if the disease came back. The oldest participants (>65) were mostly not concerned about recurrence or uncertainty. .(Researcher, Canada)(134)*

			Participants from all four age groups complained of nerve damage and pain to various degrees, which got in the way of daily tasks and day-to-day living. Women were concerned by the effects on simple household tasks such as sweeping the floor or lifting heavy dishes. (Researcher, Canada)(134) *Some women experienced fatigue together with a loss of energy and of the ability to mobilize themselves as easily as they could before, especially when their employment entailed heavy lifting or using their arms on a continuous basis in industry related work such as sewing, operating machinery, or farming. (Researcher, Canada)(134)* *These sa women were concerned that the physical impacts of cancer treatments would limit the type of work they would be able to return to or do in the future. (Researcher, Canada)(134)* *I was feeling very fatigued, weak after the chemo and radiation. I didn't have that much energy, but as time goes by, I am getting the strength back. (Patient , Canada)(134)* *I had no idea how tired I was going to be. I still feel fatigued ... as if there is no strength in*

			my body. My lymph node was taken out, that is why I have still a problem with my arm. I don’t lift heavy things. I have lost strength and cannot hold with this hand. I still have some problem. My muscle is still is weak. (Patient , Canada)(134) *A variant theme was the presence of sensations in the area where the mastectomy had occurred: “You may not touch your breast like that every day but now you’re conscious. Now you get a scratchy or if you cut off a leg, don’t they say they get sensation at the end of your toe even if your leg is cut off from here?” (Patient, India)(132)* *The theme of physical impact was described as making the most impression because of the debilitating nature of the side effects of cancer treatments, coupled with reproductive, hormonal, and aging processes, and loss of the ability to continue employment for most sa women less than 64 years of age(Researcher, Canada)(134)* *Women in all groups spoke of “having lower energy than I should have.” Others identified fatigue as a loss of physical strength that drained the body of the physical capacity they had before cancer treatment. (Researcher, Canada)(134)* *After 4 years, I still have some numbness. I feel itchy, and I scratch. And I don’t have any*

			feeling here anymore. This was after radiation. (Age 28) In my fingertips, my palms, my feet. When you wake up in the morning, it's like you are walking on broken glass. (Patient, Canada)(134) *Cognitive changes such as decreased memory, decreased ability to concentrate, impaired word retrieval, and difficulty organizing thoughts were identified. (Researcher, Canada)(134)* *In addition, they provided numerous details of the bodily changes that resulted from their cancer treatments including hair loss, weight gain, skin changes, gastrointestinal upset, and fatigue. (Researcher,Canada)(133)* *Ranjit (34 years old, in Canada 7 years) recalled her first chemotherapy session: ''My tongue was hard as iron. My eyes were pale yellow. My face became swollen. I had six more treatments to go.''(Patient,Canada)(133)* *She changed the dressing and left and when I took a look at the breast there was so much blood and pus. It must have been more than two pounds, more than a kilo and I went to the kitchen and stood up and the kitchen floor was full of blood and pus and my clothes*

			were soaked. ''(Patient,Canada)(133) *Kuldeep, who was interviewed 4 years after her diagnosis, stated:* *I mean I was able to beat it this time around but I don't think that I could survive another attack of cancer. The chemotherapy was the most difficult, I don't know if I could go through that again. I mean even my nails went black. ''(Patient,Canada)(133)* *Along with being worried and fearful about recurrence, the women drew attention to their financial difficulties because they were unable to work due to residual physical pain and weakness. (Researcher, Canada)(133)* *The women conveyed a sense of being worn down by the physical and emotional suffering caused by breast cancer and struggled to move on with their lives. Preet (50 years old, in Canada 27 years) explained, ''For a year, you know, I could not sleep very well...my aunt had breast [cancer] and then it spread...what if it happened to me.(Patient,Canada)(133)*
	Information seeking	Actively seeking information, written communication,	*The participants, overall, did not describe being distressed about this practice. Instead, they expressed the belief that the news of diagnosis should be carefully disclosed and the women should be ''prepared'' and have a family member present. (Researcher, Canada)(131)*

		decision making, lack of communication, language barrier	*Many participants were actively involved in decisions throughout their cancer experience. They sought information, expert and second opinions, and adopted traditional dietary practices to aid in treatment-related side effects. One woman said: ‘‘I read a lot about cancer from the books and the Internet. I was well informed after reading and gathering information.’’ Another commented: ‘‘I was constantly questioning the doctor. He was trying his best to satisfy me.’’ (Patient, Canada)(131)* *More women made statements indicating that they were willing to declare their diagnosis and they valued talking about their cancer with others, even while acknowledging the cultural norm that cancer should be a private matter:(Researcher, Canada)(131)* *My in-laws were surprised that I was telling everybody about my disease I told them it was not for my advertisement, but for the sake of collecting information, by talking with people.’ (Patient, Canada)(131)* *It will be much better if some Asian member, who can speak a patient’s language, should come to talk and explain to her. Talking makes a lot of difference’’. They discussed the importance of having information printed in Punjabi and having it available widely.*

			(Patient, Canada)(131) *Participants preferred a written, language-specific (especially for those who spoke only their own language) care plan in a booklet format. (Researcher, Canada)(134)* *These sa bcss felt that, coupled with the treatment summary, not only should they receive a list of resources, including those for reconstruction, reproduction, sexuality, nutrition, exercise, and prevention, but that the resources should be explained at discharge.(Researcher, Canada)(134)* *The participants expressed a high valuing of information and expert support, particularly at the time of initial diagnosis, but a lack of access to information and support was described. Few participants had been informed by doctors of supportive care resources, and few felt that they had received information or advice about potential emotional consequences of news of diagnosis. (Researcher, Canada)(131)* *Regretful, but uncomplaining, Harpal, (60 years old, in Canada 29 years) who received strong support from her husband and adult children, recalled: And in fact I said that rather than having surgery time and time again I'd rather have it whole, all of it removed. But*

			then they only removed just the lump. So you know, instead of having to suffer many times going through surgery time and time again, like my neighbour, I would have preferred to have it [breast] taken off. (Patient,Canada)(133) *As women struggled to try to make sense of their experiences, they recalled not fully understanding what they were told about their cancer treatments, even when translators were available, and that physicians often gave full explanations to their family members rather than directly to them. (Researcher,Canada)(133)* *One woman, who described herself as ''uneducated,'' indicated that she was not told that her entire breast would be removed: ''They may have told my daughter something in English but to me they just said there would be an operation.'' (Patient, Canada)(133)* *Some of the participants described having little or no involvement in treatment decisions and they expressed resentment from exclusion. They described their husbands or sons making treatment decisions for them, without involving the participant. On the occasions when this happened, resentment was expressed about the lack of inclusion and consent. (Researcher, Canada)(131)* *However, a larger portion of women indicated that treatment options were extensively*

			discussed within the family and that they were involved in the final decision. (Researcher, Canada)(131) *The women said that information about these possible toxicities should be explained or described in the context of the resulting constraints and potential chronicity, especially in light of productivity at work and daily living.(Researcher, Canada)(134)* *For those reasons, participants felt that health care providers should inform their patients about the side effects of cancer treatments—especially the long-term effects on hormones and reproduction—so that women could make informed decisions.(Researcher, Canada)(134)* *Most of the women who had been told directly by their doctors expressed disapproval at having been told without being prepared, or without having a family member present: ‘‘As I was all alone, there should be a better way of telling rather than abrupt declaration if the doctor explains in a better way and you are also accompanied by a family member, you get prepared and have some support as well.’’ (Patient Canada)(131)* *however, they also reported struggles with language barriers and a limited ability to*

			navigate the health care system because of recent migration to Canada.(Researcher, Canada)(134) *Most women felt that sharing with others who had gone through similar experiences was more meaningful, thereby providing social support that would enhance quality of life for sa women who felt shy and who had language barriers. .(Researcher, Canada)(134)* *For most women, this meant that they could share their personal cancer experiences within their own cultural and social context, in their mother tongue, making the exchange more meaningful and supportive.(Researcher, Canada)(134)* *Formal or informal peer support from people who speak the same language was especially valued, because participants could not always confide in or burden family members. Other participants felt that formal counselling in their own language would also be helpful because they could describe their feelings much better in their own language .(Researcher, Canada)(134)* *It will be much better if some Asian member, who can speak a patient's language, should come to talk and explain to her. Talking makes a lot of difference''. They discussed the*

			importance of having information printed in Punjabi and having it available widely. (Researcher, Canada)(131)
	Coping and the barriers involved	Hope, Acceptance, stoicism, change in life style, creating awareness, perception of disease, practical adaptations, support from other patients, faith in medical personnel	*Some women described that hounsla was hope to "maintain your strength to go through the cancer diagnosis and treatment." (Researcher, Canada)(134)* *Women said that being counselled about the long-term side effects of surgery and cancer treatments should be explained in terms of the practical implications for function and quality of life. (Researcher, Canada)(134)* *As one 60-year-old woman (in Canada for 29 years, 3 years since diagnosis) summed up her current health status, ''I have the sugar problem, I have the heart problem, I have the cancer problem and which one should I think about?' So [laughs] I just don't worry too much.'' The women ended their stories by describing their breast cancer as a ''choti mushkal'' (small problem) that was dealt with like any other health problem and how they now continue on with their ''normal'' lives. (Patient,Canada)(133)* *That's just life! It was just one more thing in life to go through and learn from. I don't consider myself a survivor but a "thriver" from this. (Age 60). (Patient, Canada)(134)*

			I did all the treatment.... They did the operation; they did the surgery.... What is there to be scared of? You can't do anything about it; just accept it. (Sikh, age 69) (Patient, Canada)(134) *I finished my radiation in May. I just felt I had to do something for other patients. I was thinking that somebody else has donated their time and knowledge, and we got our treatments, so I had to do something for others. (Sikh, age 41) (Patient, Canada)(134)* *As a theme, "quiet acceptance" reflects the sa bcs's sense of who "she" is because of her religious beliefs and cultural upbringing and how she uses those experiences, rather than the values central to being a sa woman, at the survivor stage of coping. (Researcher, Canada)(134)* *Many participants were actively involved in decisions throughout their cancer experience. They sought information, expert and second opinions, and adopted traditional dietary practices to aid in treatment-related side effects. One woman said: ''I read a lot about cancer from the books and the Internet. I was well informed after reading and gathering information.'' Another commented: ''I was constantly questioning the doctor. He was trying his best to satisfy me. (Patient, Canada)(131)*

			The survivor who developed leukoderma, her concerns was more related to it: "I used to wear a lot of sleeveless and very low-necked thing. Now I'm… because of this… I don't wear short sleeves so easily if I'm going out." (Patient,India)(132) *One survivor also expressed reduced interest in dressing style: "Now I feel I will never look good. Never look attractive to people, to men in general… So that parts gone away so now it's just dressing for activity which you do… (laughs) but the other thing will also be that I am not as attractive as I used to be because I can't dress as attractively as I used to." (Patient,India) (132)* *In contrast, several survivors also reported taking more care than before about their appearance: "When I go out, I take extra care. But… I have make-up on I try to wear nice dress. I have started buying more clothes than I did earlier… So I have something new and just to feel good. (Patient,India)(132)* *Some women indicated that they "didn't stop exercising, but went to the gym during chemo. After the chemo, I would eat my chapatti and go for a walk. This helped me from getting tired" (Patient, Canada)(134)*

			If people who have cancer are in each other's company, they come to know and understand each other, because they get hounsla [hope or encouragement] from each other. I will feel better if I talk with similar people who give me hounsla. (Patient,Canada)(134) *Everyone used to give me hounsla [encouragement or hope].... That's ok ... you are alright .. you'll be fine. Do your Paath [prayers].... I did a lot of Paath and went to the Sikh temple.... Everyone used to give me hounsla. (Patient, Canada)(134)* *It is therefore important to understand that the sa bcs's lens maybe coloured by an Eastern spiritual influence in which the "self' may be different from the Western concept of "self." This major theme of "quiet acceptance" encompassed subthemes of faith and inner strength; fate and karma; family and community; hounsla (hope and courage); and social or peer support. (Researcher, Canada)(134)* *Positive attitude.... Think positively all the time. Don't think, "I am going to die." Keep thinking positive all the time during the treatment. It's like the mental support from the people around you.... If they are of positive mind, then you become a bit stronger. Some people are not very positive; they get you down, you know. (Patient, Canada)(134)*

			Those who do not have cancer do not understand you or know what you are going through. But those who have gone through cancer, they understand you by giving you hounsla [hope or encouragement] instead of talking down to you. (Patient ,Canada)(134) *however, they also reported struggles with language barriers and a limited ability to navigate the health care system because of recent migration to Canada (Researcher, Canada)(134)* *The women's experiences were also influenced by prior health care experiences in their own country, meaning that the emotional and psychosocial impacts labelled as "universal" are coloured by the uniqueness of being a sa woman with personal contextual factors of social and cultural values and beliefs. (Researcher, Canada)(134)* *I think the only person I really listened to were people who had cancer ... and had gone through it already. (Patient,Canada)(134)* *Formal or informal peer support from people who speak the same language was especially valued, because participants could not always confide in or burden family members. Other*

			participants felt that formal counselling in their own language would also be helpful because they could describe their feelings much better in their own language (Researcher, Canada)(134) *When you listen to others that are also suffering from same disease, you get some sort of consolation with the exchange of ideas; you also feel relieved and know new things. We can share each other's feelings, whatever good or bad. (Patient Canada)(131)* *Other women described being obligated to provide childcare as a condition of immigrant status; many stated that they would have difficulty attending education or support sessions because of childcare duties and an inability to travel without family assistance. One woman explained: ''She was expecting a baby and wanted me to do everything. In fact, it was one of the reasons she sponsored us.'' (Patient Canada)(131)* *This theme highlighted how bcss tried generally to learn and to adapt to the practical tasks of activities of daily living, and changed their original ways of doing things as they dealt with physical deficits associated with the cancer diagnosis and its treatment. (Researcher, Canada)(134)*

			Some women described that hounsla was hope to "maintain your strength to go through the cancer diagnosis and treatment." (Researcher, Canada)(134) *Being active helped to "motivate myself and go for it, because nobody else can help me in this case" (Patient, Canada) (134)* *Although Manjit used a combination of strategies to deal with her cancer, including following a recommended diet, taking vitamins, using desi (traditional) medicines, being optimistic, surrounding herself with positive people, and drawing encouragement from others who survived cancer, it was her increasing reliance upon religious practices that dominated her story. (Researcher, Canada)(133)* *They felt that they did not receive adequate patient support and counselling from the bcca or their family physician, especially in their own language, which prolonged the depression .(Researcher, Canada)(134)* *Some women in these age groups felt that counselling about the impact of diagnosis and treatment should have been provided from the beginning so that they could prepare for the side effects of depression and distress.(Researcher, Canada)(134)*

			Along with being worried and fearful about recurrence, the women drew attention to their financial difficulties because they were unable to work due to residual physical pain and weakness. (Researcher, Canada)(133) *It is understood, however, that this concern is not unique to sa bcss, but applies to the migrant population who may be reduced to working under strenuous conditions when their family income depends on both spouses being gainfully employed. Two-spouse incomes are more central in an immigrant population in which vocational options may sometimes tend to be more physical in nature, with longer hours of employment (Researcher, Canada)(134)*

8.3 Appendix 3 Participant Information sheet and Consent form Interview study

INFORMATION SHEET

Title of Project Qualitative study to assess the suffering and distress in breast cancer patients undergoing **r**adiotherapy and surgery.

Coordinating centre Department of Pain and Palliative Medicine, Amrita Institute of Medical Sciences and Research centre, Elamakkara P O, Kochi, Kerala, India

Patient Details

Name

Hospital MRD

Invitation:

We are conducting a study to understand the experience of breast cancer patients undergoing radiotherapy and surgery. You are invited to be part of the above titled research study to explore the experience of distress/suffering women with breast cancer with special focus on patients undergoing radiotherapy and surgery. Please go through the details of project below

What is being studied?

Breast cancer is the commonest form of cancer among women of all racial and ethnic groups and is the most common cancer among women all over India. The women diagnosed with breast cancer often seem to have psychological symptoms due to the considerable distress associated with cancer diagnosis, fear of relapse or death, body image issues, treatment related side effects and many others.

In the proposed research study, we plan to systemically explore the experience of women with breast cancer undergoing treatment with special focus on psychological symptoms.

What are the methods employed in the study?

We will be conducting non- structured interviews with the patients during any of the days they attend for treatment. For the sake of data accuracy the interview will be recorded using digital voice recorder.

What are the Benefits?

- Talking and discussing their thoughts might be therapeutic to some patients.
- The results of study when published will increase awareness of health care professionals caring for such patients in the future

Is participation compulsory?

Your participation in this study is voluntary. It is up to you to decide whether to participate in this study. If you change your mind, you are free to withdraw from the study at any time and without giving a reason. Your decision to participate or not will not affect the standard of care you receive. You can withdraw from the study at any time and that refusal to participate will not involve any penalty or loss of benefits to which You are already eligible for.

How will the information collected in the study be used? (Confidentiality)

All the information collected as well recorded will be kept confidential. Your information will be archived in a coded form. This will not include name, address or any other private information. Your permission to the study doctor and staff to use this information as described for the study does not automatically end at a particular time.

Name and Contact Details of the Investigator:

Dr Sunitha Daniel

Tel: 0484- 2801234, Extn –3012/3017

Declaration of Consent

I confirm that I have read the written information for study, "-----Qualitative observational study to assess the level of **s**uffering and **d**istress in **b**reast cancer patients undergoing **r**adiotherapy and surgery.-----------------------", and confirm that I have had the opportunity to ask questions about this study and I am satisfied with the answers and explanations that have been provided.. I understand my participation is voluntary and that I am free to withdraw at any time, without giving reason I agree to take part in this study.

Signature of Patient ______________________ ___________________

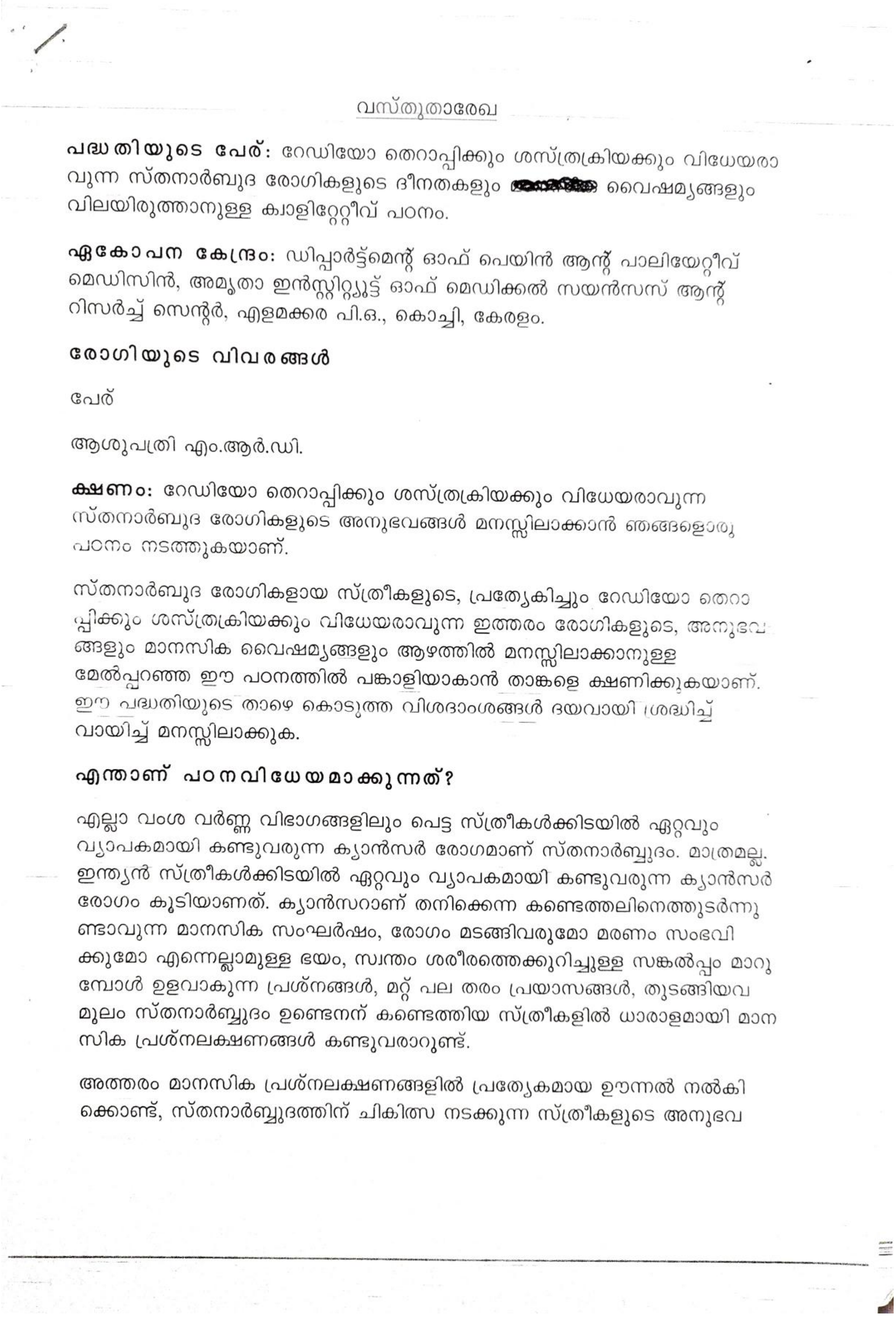
Date: dd/ mmm/ yyyy

Name of patient

Name & Signature of Investigator ______________________ ___________________

Date: dd/ mmm/ yyyy

8.4 Appendix 4 Consent form Malayalam: Interview study



വസ്തുതാരേഖ

പദ്ധതിയുടെ പേര്: റേഡിയോ തെറാപ്പിക്കും ശസ്ത്രക്രിയക്കും വിധേയരാവുന്ന സ്തനാർബുദ രോഗികളുടെ ദീനതകളും [redacted] വൈഷമ്യങ്ങളും വിലയിരുത്താനുള്ള ക്വാളിറ്റേറ്റീവ് പഠനം.

ഏകോപന കേന്ദ്രം: ഡിപ്പാർട്ട്മെന്റ് ഓഫ് പെയിൻ ആന്റ് പാലിയേറ്റീവ് മെഡിസിൻ, അമൃതാ ഇൻസ്റ്റിറ്റ്യൂട്ട് ഓഫ് മെഡിക്കൽ സയൻസസ് ആന്റ് റിസർച്ച് സെന്റർ, എളമക്കര പി.ഒ., കൊച്ചി, കേരളം.

രോഗിയുടെ വിവരങ്ങൾ

പേര്

ആശുപത്രി എം.ആർ.ഡി.

ക്ഷണം: റേഡിയോ തെറാപ്പിക്കും ശസ്ത്രക്രിയക്കും വിധേയരാവുന്ന സ്തനാർബുദ രോഗികളുടെ അനുഭവങ്ങൾ മനസ്സിലാക്കാൻ ഞങ്ങളൊരു പഠനം നടത്തുകയാണ്.

സ്തനാർബുദ രോഗികളായ സ്ത്രീകളുടെ, പ്രത്യേകിച്ചും റേഡിയോ തെറാപ്പിക്കും ശസ്ത്രക്രിയക്കും വിധേയരാവുന്ന ഇത്തരം രോഗികളുടെ, അനുഭവങ്ങളും മാനസിക വൈഷമ്യങ്ങളും ആഴത്തിൽ മനസ്സിലാക്കാനുള്ള മേൽപ്പറഞ്ഞ ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ താങ്കളെ ക്ഷണിക്കുകയാണ്. ഈ പദ്ധതിയുടെ താഴെ കൊടുത്ത വിശദാംശങ്ങൾ ദയവായി ശ്രദ്ധിച്ച് വായിച്ച് മനസ്സിലാക്കുക.

എന്താണ് പഠനവിധേയമാക്കുന്നത്?

എല്ലാ വംശ വർണ്ണ വിഭാഗങ്ങളിലും പെട്ട സ്ത്രീകൾക്കിടയിൽ ഏറ്റവും വ്യാപകമായി കണ്ടുവരുന്ന ക്യാൻസർ രോഗമാണ് സ്തനാർബ്ബുദം. മാത്രമല്ല. ഇന്ത്യൻ സ്ത്രീകൾക്കിടയിൽ ഏറ്റവും വ്യാപകമായി കണ്ടുവരുന്ന ക്യാൻസർ രോഗം കൂടിയാണത്. ക്യാൻസറാണ് തനിക്കെന്ന കണ്ടെത്തലിനെത്തുടർന്നുണ്ടാവുന്ന മാനസിക സംഘർഷം, രോഗം മടങ്ങിവരുമോ മരണം സംഭവിക്കുമോ എന്നെല്ലാമുള്ള ഭയം, സ്വന്തം ശരീരത്തെക്കുറിച്ചുള്ള സങ്കൽപ്പം മാറുമ്പോൾ ഉളവാകുന്ന പ്രശ്നങ്ങൾ, മറ്റ് പല തരം പ്രയാസങ്ങൾ, തുടങ്ങിയവ മൂലം സ്തനാർബ്ബുദം ഉണ്ടെനന് കണ്ടെത്തിയ സ്ത്രീകളിൽ ധാരാളമായി മാനസിക പ്രശ്നലക്ഷണങ്ങൾ കണ്ടുവരാറുണ്ട്.

അത്തരം മാനസിക പ്രശ്നലക്ഷണങ്ങളിൽ പ്രത്യേകമായ ഊന്നൽ നൽകിക്കൊണ്ട്, സ്തനാർബ്ബുദത്തിന് ചികിത്സ നടക്കുന്ന സ്ത്രീകളുടെ അനുഭവ

സ്റ്റഡി ഡോക്ടർക്കും സ്റ്റാഫിനും നിങ്ങൾ നൽക്കുന്ന സമ്മതം ഏതെങ്കിലും ഒരു പ്രത്യേക സമയത്ത് തന്നത്താൻ അസാധുവാകുന്ന ഒന്നല്ല.

പഠനകർത്താവിന്റെ പേരും ബന്ധപ്പെടാനുള്ള വിശദാംശങ്ങളും

ഡോ. സുനിത ഡാനിയൽ

ഫോൺ: 0484 2801234; എക്സ്റ്റൻഷൻ– 3012/3017

സമ്മതപത്രം

“......റേഡിയോ തെറാപ്പിക്കും ശസ്ത്രക്രിയക്കും വിധേയരാവുന്ന സ്തനാർബുദ രോഗികളുടെ ദീനതകളും [redacted] വൈഷമ്യങ്ങളും വിലയിരുത്താനുള്ള ക്വാളിറ്റേറ്റീവ് പഠനം......” എന്ന പഠനത്തിനെക്കുറിച്ചുള്ള എഴുതി തയ്യാറാക്കിയ വിശദാംശങ്ങൾ ഞാൻ വായിച്ചു എന്ന് ഇതിനാൽ സാക്ഷ്യപ്പെടുത്തുന്നു. എനിക്ക് ഈ പഠനത്തെക്കുറിച്ചുള്ള ചോദ്യങ്ങൾ ചോദിക്കാൻ അവസരം ലഭിച്ചുവെന്നും, അവക്കെല്ലാം ലഭിച്ച ഉത്തരങ്ങളിലും വിശദീകരണങ്ങളിലും ഞാൻ തൃപ്തയാണ് എന്നും ഇതോടൊപ്പം സാക്ഷ്യപ്പെടുത്തുന്നു. എന്റെ ഈ പഠനത്തിലെ പങ്കാളിത്തം സ്വമേധയാ ആണെന്നും, കാരണം പറയാതെ ഈ പഠനത്തിൽ നിന്ന് ഏത് സമയത്തും പിൻമാറാൻ എനിക്ക് സ്വാതന്ത്ര്യം ഉണ്ടെന്നും ഞാൻ മനസ്സിലാക്കുന്നു. ഈ പഠനത്തിൽ പങ്കാളിയാകാൻ എനിക്ക് സമ്മതമാണ്.

രോഗിയുടെ ഒപ്പ്: ---------------------

തിയ്യതി: (ദിവസം/മാസം/വർഷം) -------------

രോഗിയുടെ പേര്: -----------------------

പഠനകർത്താവിന്റെ പേരും ഒപ്പും: ---------------

ങ്ങൾ ഘട്ടംഘട്ടമായി പരിശോധിക്കാനാണ് നിർദ്ദിഷ്ട പഠനത്തിൽ ഞങ്ങൾ ഉദ്ദേശിക്കുന്നത്.

എന്തൊക്കെയാണ് പഠനത്തിന് ഉപയോഗിക്കുന്ന ഉപാധികൾ?

രോഗികൾ ചികിത്സക്ക് വിധേയരാവുന്ന ഏതെങ്കിലും ദിവസങ്ങളിൽ, നിയത ഘടനയില്ലാത്ത അഭിമുഖങ്ങളാണ് ഞങ്ങൾ എടുക്കുക.

കൃത്യത ഉറപ്പാക്കാൻ ഈ അഭിമുഖങ്ങൾ ഒരു ഡിജിറ്റൽ വോയ്സ് റെക്കോഡർ ഉപയോഗിച്ച് റെക്കോഡ് ചെയ്യുന്നതായിരിക്കും.

എന്താണ് നേട്ടങ്ങൾ?

ചില രോഗികൾക്ക് സംസാരിക്കുന്നതും, അവരുടെ പ്രശ്നങ്ങൾ ചർച്ച ചെയ്യുന്നതും, ഒരു തെറാപ്പിയുടെ ഗുണം ചെയ്യും.

ഈ പഠനത്തിന്റെ ഫലങ്ങൾ പുറത്തു വരുമ്പോൾ, ഭാവിയിൽ ഇത്തരം രോഗികളെ ചികിത്സിക്കുന്ന ആരോഗ്യരംഗത്തെ വിദഗ്ധരുടെ ഈ വിഷയത്തിലുള്ള അറിവ് വർദ്ധിക്കും.

ഈ പഠനത്തിൽ നിർബ്ബന്ധമായും പങ്കെടുക്കേണ്ടതുണ്ടോ?

ഈ പഠനത്തിലെ നിങ്ങളുടെ പങ്കാളിത്തം സ്വമേധയാ മാത്രമാണ്. ഇതിൽ പങ്കെടുക്കണോ, വേണ്ടയോ എന്ന് നിങ്ങൾക്ക് തീരുമാനിക്കാം. നിങ്ങളുടെ മനസ്സ് മാറുകയാണെങ്കിൽ, ഈ പഠനത്തിന്റെ ഏത് ഘട്ടത്തിലും, ഒരു കാരണവും ബോധിപ്പിക്കാതെ, പിൻമാറാനുള്ള സ്വാതന്ത്ര്യം നിങ്ങൾക്കുണ്ട്. നിങ്ങൾ ഈ പഠനത്തിൽ പങ്കെടുക്കുന്നുണ്ടോ, ഇല്ലയോ എന്ന ഒരു വിധത്തിലും നിങ്ങൾക്ക് ലഭിക്കുന്ന ആരോഗ്യസേവനങ്ങളുടെ ഗുണനിലവാരത്തെ ബാധിക്കില്ല. നിങ്ങൾക്ക് ഈ പഠനത്തിൽ നിന്ന് ഏത് സമയത്തും പിൻമാറാവുന്നതാണ്. നിങ്ങൾക്ക് അർഹതയുള്ള ഏതെങ്കിലും ആനുകൂല്യങ്ങൾ അതുമൂലം നഷ്യമാവുകയോ, എന്തെങ്കിലും പിഴ അതിന്റെ പേരിൽ നിങ്ങൾക്കുമേൽ ചുമത്തുകയോ ഇല്ല.

ഈ പഠനത്തിലൂടെ ശേഖരിക്കുന്ന വിവരങ്ങൾ എങ്ങനെയാണ് ഉപയോഗിക്കപ്പെടുക? (സ്വകാര്യത സൂക്ഷിക്കൽ)

ശേഖരിക്കുന്നതും, റെക്കോഡ് ചെയ്യുന്നതുമായ എല്ലാ വിവരങ്ങളും രഹസ്യമായി സൂക്ഷിക്കുന്നതാണ്. നിങ്ങളെക്കുറിച്ചുള്ള വിവരങ്ങൾ കോഡുകളുടെ രൂപത്തിലാണ് സൂക്ഷിക്കപ്പെടുക. പേരോ, മേൽവിലാസമോ, എന്തെങ്കിലും വ്യക്തിപരമായ വിവരങ്ങളോ അതിലുണ്ടാവില്ല. ഇപ്പോൾ വിവരിച്ചതുപോലുള്ള ഈ പഠനത്തിലൂടെ ശേഖരിക്ക്പെടുന്ന വിവരങ്ങൾ ഉപയോഗിക്കാൻ

പങ്കെടുക്കുന്നവർ പറയുന്ന ചില വാചകങ്ങൾ
സ്വകാര്യത നിലനിർത്തി തന്നെ പഠനം
പ്രസിദ്ധീകരിക്കുമ്പോൾ ഉപയോഗിക്കുന്നതാണ്

8.5 Appendix 5 Topic guide: Interview Study

Prompts for focussed interview

- Could you tell me more about yourself and the reasons for coming to the hospital?
- Could you tell me more about your experience after being diagnosed with cancer?
- Could you tell more about how you feel after you came to know the diagnosis?
- Could you tell more about treatment that you are receiving /received?
    - Tell me about your understanding of the treatment.
    - Practical difficulties
    - Side effects-radiotherapy
    - Surgery: how did you feel after having your breast removed? How has this affected your relationship with your partner/spouse?
- Could you tell how do you feel about the treatment?
- Could you tell how you view your life after the diagnosis?

Could you tell more about the hopes in your life and whether it has changed since

- diagnosis?
- Could you tell more about your daily activities?
- During your treatment period, were you mentally disturbed in any way?
- Are you able to talk about it with anyone?
- Could you tell more about how you have been coping with the current situation?
- What resources have you drawn to cope with your suffering?
- How did you cope with difficult times in your life before you had cancer?
- Has having cancer changed how you cope with things in your life?
- Has having cancer changed your role in family and expectations by other family members?
- Does faith or spirituality play a part in your life? In what way?
- Can you tell me more about that?

How do you feel about talking about this and the interview?

8.6 Appendix 6 Table showing the themes, subthemes, codes and quotes of Interview study

Themes	Subthemes	Codes	**Quotes**
Far-reaching psychological distress	Anxiety	Anxiety, fear, uncertainty, worries about future Anxiety in relation to: Effect on function, Inability to do physical activity, Change in routine habits and Impact on sexual function, Surprise, unexpected	*'In my family in all these years there is a history of heart attack, my father's father had it. I was expecting that since I am a bit overweight (laughs) I would be getting that and I never thought that I would get cancer' (Participant 17;aged (40-50))* *'I don't talk about my distress to others; I feel that I have to suffer my problems. Also nobody asks specifically--- and I always say there is no problem, everything is ok I don't have any problem, I am taking treatment---. But others are scared; they are scared that it has happened to me' (Participant 11;aged 40-50)* *'I never thought it is going to be this, I was convinced that I will not get this disease, somebody mentioned the word carcinoma and I didn't know that it meant this, I always thought the word was cancer, also there was a mention of malignancy in mammogram, I didn't know that was cancer either. So when doctor told me the result, I said I didn't understand. Then he explained that it is the first stage of cancer: then I was really shocked' (Participant 7; aged 40-50)*

			‘My main thoughts were, my children are still young, I have a husband, I am the one who looks after everything in house…(Participant 14;aged 50-60) *‘But when chemotherapy started I had lots of issues, I was alone in house with nobody to help me as I am used to doing things on my own, my mind was always tensed thinking ‘how did this happen to me, ‘oh, it has happened to me’ and I keep thinking about other people dying. I am normally an anxious person and I worry about small things and I had problems with depression in past… (Participant 13; aged (60-70))* *‘I keep worrying about whether the disease will come again. I listen to doctor talking on radio and they say it could come again; some doctors say after some time it could come again. Here also when I see other patients, they say they had it before, and it has come back second time. But my test are negative in armpit so I am a bit relieved’. (Participant 11; aged (40-50))* *Initially I was sad, (tearful) (pause) then everybody talked to me and reassured me. I*

			know about the disease as I work in medical field, but when I thought about the future (pause) (voice breaking) I was sadder. My children were not settled, my son was studying a course in Engineering, thinking all that (voice breaking), and younger son is studying in school. Husband has retired from work. Thinking of all that made me sad. Then I started giving reassurance to my mind, by praying to God.' (Participant 15; age 50-60) *I have this fear inside my mind about if the disease will recur. But doctor said it will not recur. Because it has been removed thoroughly. Also, five radiations were given inside the body. Along with that surgery here it is after that I am undergoing radiation outside my body. So, the doctor said () my doctor and Dr. Vijayakumar have assuredly told me that it will not recur' (Participant 6; age 50-60)* *'I haven't had any contact since the diagnosis, mainly because I am too tired and fatigued to do it and my husband is accepting that. He doesn't have any problem with that'. (Participant 16; age (40-50))*

			'I have some problems with my bladder and have difficulties sitting down, so I can't clean myself properly, husband is still keen on having sex, so it is a problem, also if we don't have physical contact he might develop some prostate problems, so I am worried about that (Participant 12; aged (60-70)) *'I didn't feel any different but thinking about the future I have anxiety. (pause) But I have great support from family, younger brother; he works locally so he used to come with me all the time, my older brother is abroad. My mother is around, they all help me'. (Participant 15; age 50-60)* *'So I was anxious and especially when chemo started and I had problems I was worried whether I would be able to complete it till the end, there was so much difficulty, it took nearly 10 days for me to get up and sit on the bed. It could be different for different people depending on their health if my body's resistance is low so probably it is that. Also I couldn't eat any food and so my body becomes very weak. Mainly it was vomiting and tiredness. Then towards the third week after first cycle I started losing my hair.' (Participant 16; age (40-50)*

			I went into the room I was very scared, worried about the stab from radiation. Once I had the first dose, I was fine. Also I had to hold my breath, which I was not very confident in doing initially, then I got used to it. (Participant 7; aged 40-50) *I used to face all my problems bravely in the past, now I don't have much courage. I have noticed that I lost all my confidence even some time before I was diagnosed, I was scared, I keep having thoughts in my mind, when I think about the news of road traffic accidents, I keep thinking about that, then I worry about that. Even in television when I see in movies people fight among themselves, I get upset. I am very sensitive about these things. I used to be very bold and face everything, now I don't have any courage. Now I just exist with the support of my husband' (Participant 12; aged (60-70)* *Now since the diagnosis we haven't had much contact, it has not affected our relationship, husband is not much bothered, we are more like friends and that is not the most important thing for both of us. Our kids have grown up and are in our house, husband goes to work at night sometimes, so it has not been possible but both of us are not affected by that. My husband has not told anything to me and he usually says*

			everything so I will know if there is any problem. (Participant 14 age (50-60) *‘I haven’t had any contact since the diagnosis, mainly because I am too tired and fatigued to do it and my husband is accepting that. He doesn’t have any problem with that’. (Participant 16; age (40-50)* *My interest for sex is coming down, it has been so for the past few years, I don’t feel mentally ready for that and I am also diabetic and I am old now, it is not due to disease, and my husband is also not very keen now (Participant 13; aged (60-70)* *No we haven’t any sexual intercourse since disease, before the diagnosis it was not very frequent but I haven’t had any since the diagnosis. But it has not affected our relationship and husband also does not have any problem due to that’ (Participant 9; age 50-60)* *We haven’t had any sexual contact since diagnosis; I am planning to ask doctor whether it is ok to do it now. Once I got the diagnosis and during treatment, I was very*

			tired and also, I was worried that having sexual intercourse can lead to infection. So, I want to check with doctor about it' (Participant 11; age 40-50)
	Depression	Sleep issues, Loss, grief Lack of interest Loss of hope	*'So, when I saw Dr X for the first time, I did not say anything, I was crying throughout the consultation. My husband did all the talking; I was sitting and crying there all the time' (Participant 7; aged 40-50)* *'Of course, when I was diagnosed with this disease- because all say this is a terrible disease- I started thinking that I am doomed for a life time that my near and dear ones will undergo great mental suffering, because it has always been me who stood as a pillar that supported our family. That caused me great pain. Even now I am in that pain' (Participant 2; aged 60-70)* *Still, I don't know whether it is due to my age, but I don't have the desire to live longer also. But thinking about my children and husband, if something happens to me, they will not be able to bear it. I have enough of my life, I am fed up of life' (Participant 12; aged (60-70)*

			‘So, during chemotherapy, when I am alone in house, I become upset thinking about lot of things and had problems with all the medications. I lost my appetite, I am not able to go out of the house, I started losing my hair. I became more and lower in mood’ (Participant 13; aged (60-70) *I am sad and disappointed that this has happened to me, I worked as a nurse in North India, I was very supportive to all patients. I was held in high esteem by my peers where I was working. I have looked after similar patients also some staff also had this disease who used to work with me, but the treatment at those hospitals were not good enough and also family support is not good enough there, so we decided to come here. It is 6 months since diagnosis and I have been like this since then, I do cry in between’ (Participant 15; age 50-60)* *On the whole I feel disappointed with life, my daughter and husband are very supportive and guide me a lot. My friends, relatives and well-wishers all guide me and talk about positive thinking, but still, I am disappointed. Also, I am scared now, thinking about future, what if something negative happen? I always think like that’*

			(Participant 12; aged (60-70) *Initially I was sad, (tearful) (pause) then everybody talked to me and reassured me. I know about the disease as I work in medical field, but when I thought about the future (pause) (voice breaking) I was sadder. My children were not settled, my son was studying a course in Engineering, thinking all that (voice breaking), and younger son is studying in school. Husband has retired from work. Thinking of all that made me sad. Then I started giving reassurance to my mind, by praying to God' (Participant 15; age 50-60)*
	Other psychological response	Guilt, Blame, Shock, Anger, Inability to talk about problems Distress due to physical side effects of treatment, Alopecia, scarring, skin changes, Lymphedema,	*'If I had come earlier the chemo would have been avoided, it had become 2 cm about 1.5 to 2cm, if I had come earlier maybe if it was less than 1cm... (Participant 17; aged (40-50))* *But I am upset that I am not able to help her back or support her. If my daughter becomes pregnant again, I will have to look after her and her kids, I am not able to do that now. She had a late marriage, she was about 28 when she got married, now it is*

		Treatment experience, body image	*about 3 years. I used to tell her as soon as she got a job to get married, but she didn't want it. If it had happened earlier then I could have managed everything before I retired from work. (Participant 12 age 60-70)* *'I was also very angry initially, when I reached home after chemotherapy due the discomfort in my body, I used to get very angry and I used to speak angrily with all my family. I used to answer back to my family members, so my husband was angry with me.' (Participant 9; aged 50-60)* *Since the surgery, I have lost interest in the general housework that I used to do before; even when I am doing it I am very slow. I still manage to do a bit of cooking but don't do anything else; I have lost interest in anything. I used to be very active before, used to lead a busy life. (Participant 12 age 60-70)* *No nothing has changed. (Low voice) Only now the doctor here was telling that if I had come to this hospital 2 years back when I first detected swelling, I could have been treated by oral medicines (Participant 5; age 70-80)*

			‘After coming back to our home town both of us are alone. Where I used to work, we used to live in official accommodation and there used to be lots of neighbours near our house, now I am alone and isolated in my house, so that has also affected my mood. There it used to be an active life brighter and felt more active, here I feel very isolated. (Participant 12 age 60-70) *‘Like I am able to talk to you also openly, but normally I don't talk to anybody or I don't open up easily. I don't talk to others because they don't retain what we tell them, they interpret in their own way. They also exaggerate and speak to others like that. (Participant 14; aged (50-60))* *Even that after watching for some time, I become fed up of that. Then I help my husband to cook the breakfast. I don't have any interest in anything. I find it difficult to spend time. I go and lie down for a long time, husband says don't lie down all the time. He is also upset thinking about me, that I am not active anymore; I used to be very*

			active before. If I develop any complications due to being inactive, then my husband has to deal with that'. . (Participant 12 age 60-70) *'I am glad that I talked to you as I realise that I am able to talk about my disease and answer the questions in detail. I didn't realise that I would be able to talk like this. I am glad I did it' (Participant 16; aged (40-50))* *'I can't do anything on my own independently, I can't even travel on my own, because of this pain in knee, I don't travel in bus, we keep a driver for our car and travel everywhere. I have always been like that; I need my husband's support for doing everything. I used to work, my salary would come to my account, but all the financial management has been my husband. I didn't have to know about anything. I only used to do all the cooking and house work. (Participant 12 age 60-70)*
	Distress due to physical side effects of treatment	Hair loss, mastectomy, Lymphoedema, Physical pain nausea vomiting appetite taste	*'I lost a lot of hair, I had long and thick hair, so I was very sad when I lost my hair, my hair was not even grey, it was still black in spite of my age. Now it is coming back and I am getting more grey hair now. All people used to comment on my long black hair but now everything is gone. My daughter had got a wig for me, I used it a couple of times when I went to temple, but when I used it I felt strange, so mentally I was not*

		Alopecia surgical scar skin changes, Fatigue, body image	*comfortable in using that.' (Participant 12; aged (60-70)* *'That disease might not be a good cancer and is likely to be risky, but I only have to be ashamed of hair loss, but in front of people they think that hair loss is an important indicator of disease severity (laughs). (Participant 17; aged 40-50)* *No nothing, but I lost my hair during chemotherapy at that time I was really upset, ie to face people. I lost all my hair, it was full bald, so I was putting scarf, But I managed and I was not upset after that' (Participant 7;age 40-50)* *I had lumpectomy and then reconstruction with flap, the doctor said that either we can do the mastectomy or doing lumpectomy alone should be fine. But when we do lumpectomy alone there would be a gap and so should do flap. I agreed to flap, as doctor explained that when mastectomy is done and later I might become upset or irritated on seeing my body, he said it might or might not happen. When we look at our body in future, I should not regret the decision. (Participant 16; aged 40-50)*

			‘If it is in temple then definitely there will be questions about why I have covered my head. Even people who know us would say “Oh you have lost all your hair”? Then we will have to explain everything. So, I don’t go to temple but pray in the house, prayer is the one that leads me forward.’ (Participant 16; aged 40-50) *‘I had brought a wig, but you see I have a grandchild and I was worried what will the kids think If they see me wearing that and I wore it once but I felt uncomfortable wearing that in front of kids even though they didn’t say anything. So, I have not worn it since.’ (Participant 18; aged (50-60))* *‘I didn’t have much problem but loss of hair is the most troublesome (laughs) I thought I wouldn’t lose much hair in the first chemotherapy but when I lost it I had a difficult feeling then I got adjusted, now that it has started coming back I am feeling better but initially when I had lost all the hair I was upset, even people will be staring (laughs)’ (Participant 17; aged 40-50)* *‘During the first 2-3days when I had chemo, I was feeling very unwell and nauseous all*

			the time. I was tired all the time. Then it will settle after 3-4 days and I will be back to my routine with housework. I lost all my hair, now I am keeping a wig. I was upset when I lost my hair. Doctor said it is ok, even if I lose my hair, it will come back, it is important to treat the disease' (Participant 20; age 50-60) *'I was not worried about surgery but more about chemotherapy due to the hair loss. I was thinking about that all the time. I never thought about the surgery and I was not scared about anything related to surgery. But my main worry was I will lose my hair due to chemotherapy' (Participant 7; age 40-50)* *'I do feel a bit upset especially now I have depended on others for help, as I used to everything on my own before. Also losing my hair has made me sad, I find it difficult to face others, especially when people come to my house and notice that I don't have hair.' (Participant 20; age 50-60)* *'Another reason is my hair; I don't want to go to temple tying the scarf on my head. Probably that is the reason and I am upset about it. It is more in the past few days, but*

			I still can’t do it. Then I think “let radiation be over and I will start doing it gradually” (Participant 7; age 40-50) *I had total mastectomy and I am a bit upset about that, especially when sitting down there is some disfigurement, so I have to be very careful about appearance while sitting down’ (Participant 12; aged (60-70)* *Initially when I heard about it, I did not like it, initially they said they won’t do surgery but will give radiotherapy. Then everybody said it is better to remove it. Then they said about breast reconstruction, but then I felt I am 60 years old now, so what is the point now? So, I agreed for mastectomy. Then there was my neighbour, he works in the bank as manger and his wife had mastectomy, and she was younger than me. So, I felt they all had it done and lead a normal life so why can’t I do it. (Participant 13; age 60-70)* *Also, I can't use my left hand properly as before, not able to take weight, have to be very careful about not having cuts or breaks in skin. Also, when I lift the hand, it is uncomfortable, and I can't do anything with that. I am so upset that it has happened, I*

			have been working till the age of 60, I have just retired from my work and settled in my home town and when this happened suddenly, I was really upset' (Participant 12; aged (60-70) *Now when I have a wash and I become upset when I see it, I am a human it is only natural. So that is the only problem. When I go out and sometimes at home, I wear pads to support breast, I have purchased few. I feel hot sometimes then I remove it and if someone comes to house just were a towel over dress to cover it. Also, I am 60 years now so why should I bother about it. When I go outside, I disguise it properly so that nobody would know about it. In house people might come and visit unexpectedly so I just do something quickly to cover it up. But even if somebody knows about it, I don't care as I am old now. (Participant 13; age 60-70)* *'I discussed it with doctor (not Dr Y) and he was saying "Oh you will lose all of it" jokingly. He didn't give importance to it (nervous laugh) I used to care for my hair a lot---- and I already had short hair –then--- I got used to it. Now I am upset that it is not growing back and every day I keep checking to see whether it is growing back. (Participant 18; aged 50-60)*

			I felt upset at the thought of going in front of other people, because I usually go out all the time especially, to temples to read religious books in groups like Ramayan, Bhagavad Gita, etc So in front of others I felt uncomfortable and the thought about mingling with other people with single breast especially since I am hefty, I felt it would cause some difficulty for me. (Participant 9; age 50-60) *'No, I was not upset about that, I am not young, I am now old, I also know that there are new methods to cover that. But I don't need any of that, I am now old and I was not upset by that' (Participant 10; aged 60-70)* *'I was a bit upset thinking about that but then realised if I have a disease then there is no other way and no point in keeping it. (Participant 15; aged 50-60)* *'I had total mastectomy and I am a bit upset about that, especially when sitting down there is some disfigurement, so I have to be very careful about appearance while sitting down.' (Participant 12; aged 60-70)*

Getting on with life	Making sense of the disease	Disease perception, understanding, knowledge by patient, why me	*'My understanding is that surgery has completely cured it and chemotherapy also helped in the removal, if anything is left behind then radiation is to destroy the cells by burning them.' (Participant 12; aged (60-70)* *I always keep thinking what the reason is. One should know what the exact reason is. Doctor told me, some cells in my body have become defective and they multiply. This can happen in any part of the body. that was all he told me. But I do not know why this is happening' (Participant 2 age 60-70)* *Once my family knew about the diagnosis, they have all contacted me and said I should go and get treatment immediately; also, they are upset that I got the disease and nobody in our family has it before, so why did I get it.? All my sisters support me, then my children and then husband' (Participant 8; age 50-60)* *Then I consulted Dr X and then I felt better and I am now about 90 % better. But still do occasionally think, 'this has happened to me', 'I am the only one who got it'. Such*

			thoughts were coming to my mind' (Participant 13; age 60-70) *'I also had such thoughts. I thought, why God let me had this disease when my husband himself was ailing. Then I thought this might be God testing me, so that I could know Him better. I find relief in that thought (Participant 1 age;70-80)* *I know about the treatment; I believe it is to prevent recurrence. Radiotherapy is done to burn any residual tissue left behind. I did not have any problem during radiotherapy. I did not have any concerns or worries about radiotherapy' (Participant 10; age 60-70)* *Doctor has not told me much details, I just know that radiotherapy is to destroy the cancer cells completely, is that right? I have not been told anything more than that. I did not have any fears about it. Right now, I have developed some skin changes as well as burning sensation during radiotherapy' (Participant 18; age 50-60)* *'I know that surgery was done because I had the swelling and it needs to be removed, I don't know why chemotherapy was done. I have heard people say that chemotherapy*

			is done so that the tumour shrinks I don't know anything more than that, I also know about radiotherapy that it is used to burn the tissues but I don't know anything more than that. (Participant 9; age 50-60)
	Actively seeking information	Seeking knowledge Utilisation of resources	*'I read about things, I try to be bold and brave in the situation rather than thinking I have a terrible disease. I gather information as much as possible, now there are lot of printed material available which are good sources of information. I am not scared about reading and getting more knowledge, especially there are lot of misconceptions among people.' (Participant 14; aged 50-60)* *'Prayer, studying, reading more about it, else I was in a shocked stage, but knowing that it is different from other cancers, I hope it is true, if it is detected in primary stage there is 98% chance of cure, the doctor also reassures me that good cure rate with surgery at early stage and results look positive.' (Participant 17; aged 40-50)* *'I also keep reading books about the disease and radiation, so I didn't have any fears about that and I gained more understanding. Everybody thinks that it is like passing*

			electric current to body, will be painful like injection and people keep telling that to me' (Participant 14; age 50-60) *Also, I read a lot, watch educational programs in television, so I don't get bored or I don't have unnecessary thoughts and I also sleep well at night as I am active in the day. (Participant 14; age 50-60)*
	Role of medical professional	Role of medical professionals	*'Also, the consulting doctors are a relief; Dr X and Dr Y are very good at explaining things and we can ask them anything. Some doctors we can't ask anything.' (Participant 14; aged (50-60)* *Even the doctor was very supportive, said that there is nothing to fear and there is treatment for anything now. So, I had the support of doctor and family, so it hasn't affected me mentally till now. (Participant 14; age 50-60)* *But now after coming here and seeing other patients, meeting health professionals and seeing all treatment, my thoughts are better. Now I have confidence that I can face whatever that comes to me. (Participant 14; age 50-60)*

			'So, the doctor reassured me a lot, was very consoling, he was like a brother to me. I had worries about this hospital; we didn't know much about it as we have never visited here before. It was the first time we had come to this hospital. But after seeing the doctor we were very satisfied with all the care and decided not to go anywhere else. (Participant 13; age 60-70) *His counselling is the reason I am so strong mentally. Initially I was scared, my daughter is working in Bangalore, I have only my husband with me, so I had a bad feeling, but the Doctor and his words------(crying)---then I had no problem, had full confidence. I will recover from this (Participant 4; age 50-60)*
	Practical aspects	Access to care, transport Economic, Financial lack of resources	*'Because I was thinking that we would have to spend lot of money, then my son said, mother you should not think like that, money is not an issue, the important thing is to get recovered from the disease.' (Participant 6; aged 50-60)* *'Initially doctor said I need 16 doses of chemotherapy and then because I had problems*

			in travelling and my son couldn't take time off work and come all the time, so we discussed it with doctor and changed it to eight.' (Participant 10; aged 60-70) *'During chemotherapy I was accompanied by my father, sister and husband and during radiotherapy my father is coming with me. On the first day my husband and sister came and now father is coming. I had 18 days of treatment and father comes with me daily. The daily travel is a bit of hassle but otherwise ok'.* *(Participant 11; age 40-50)* *So, we went back to RCC just to do radiotherapy. But they were not happy to treat us, they said they are busy there and they gave a late date, so we called here again, they said we should not delay it. So, we came back here, we go back to our place every weekend and then come here for treatment in other days. So, I am doing radiotherapy here. (Participant 11; age 40-50)*
	New way to live normal	Rationalisation Information	*'No, it is more hobbies like looking after my plants and vegetables, cooking my favorite recipes, doing things around the house that I like, watch my favorite*

		Intellectualization Pragmatism, stoicism, acceptance Positive thinking Maintaining normal Practical, active, adaptation, personal life style change Keeping busy	*programs on TV. I try and do things I enjoy so that I don't become upset thinking about my disease.' (Participant 13; aged (60-70)* *I read about things, I try to be bold and brave in the situation rather than thinking I have a terrible disease. I gather information as much as possible now there are lot of printed material available, which are good sources of information. I am not scared about reading and getting more knowledge, especially there are lot of misconceptions among people. (Participant 14; age 50-60)* *'There are a lot of people near our house who has had surgery long time ago about 10 to 23 years and they are all fine and alive now. So, seeing them is a great relief and they have come and talked to me and gave me support. There were times when I was really upset especially during chemotherapy when I felt that I was not able to do much but now gradually I feel better'* *(Participant 10; age 60-70)* *Then I felt reassured and braver as the doctor said that our mental strength is very*

			important to ensure a cure for the disease. It is not just treatment but our faith in treatment is also important. Later I was not scared, then when I went in for surgery, I was scared but doctor was very caring and did a good job and asked me not to worry and reassured me. (Participant 10; age 60-70) *I had some strength, everybody has problems, but I just face them bravely and move on in life, I have strength in my mind. Also, my husband is very supportive. If I have any problem he consoles me, so I didn't have any problem'* *Participant 10; age 60-70)* *'Just like I told you, I was very bold, so I didn't feel upset or think why this has happened to me..... Now I have got the disease, I need to get on with treatment and get on with my life. I did not feel like 'Oh, this has happened to my life", nothing like that. (Participant 4; age 50-60)* *I get up as usual in the morning and do my daily work in the house; I avoid lifting heavy weights but do all other work. After the radiation treatment, I feel my body heat is*

			more especially in my head, I feel it is hotter, so I don't do much work in kitchen. My mother is at home so I just help her in the kitchen. Whatever I am able to do, I do it at home. (Participant 7; age 40-50) *I make breakfast then work in garden, look after my plants. Then I do the cooking for lunch time, I do everything on my own, very rarely we buy food from outside, even during treatment time, I used to do it on my own. I don't like asking anybody else for help; my daughter helps me when she can. But I don't like anybody else doing the cooking, I have to do it as I like, I have specific likes and I want to do it like that. Even doctor has advised me that If can do light work then I should do it but if I am tired I should lie down and take rest. So, whenever I am hungry or feel like special food, I cook and eat. I don't rely on anybody else* *(Participant 13; age 60-70)* *Also, I read a lot, watch educational programs in television, so I don't get bored or I don't have unnecessary thoughts and I also sleep well at night as I am active in the day. (Participant 14;age 50-60)*

			No, my hopes have increased, I would like to do more things now, especially in house, look after my plants. Plants are the most important thing for me; I want to buy new plants and other new things. I have hopes in my life. What is the point in living without any hopes or feeling numb in mind? I think my hopes have increased from before. My desire for material things has gone up. I never used to like going out or going travelling before. But now I want to go travelling, I want to go to my daughter's house and stay there occasionally. I feel that I should spend more time with family daughter and grandchildren look after them, look after my plants. My plants are my life. So my hopes have increased, I don't feel low at all.(Participant 13;age 60-70)
	New future	Responsibility for people Action: warn others Raising awareness Positive thinking: Resilience Caring for self, hobbies	*'I pray that nobody else would get this disease, whatever we say that we are not upset; this disease is a great sorrow for everyone. So whenever anybody or my colleagues call me to talk about this and I ask them and I advise them that even when they see any small swelling, I ask them to check it out so that nobody develops into this disease.' (Participant 16; aged (40-50)* *Yes, I am able to talk about it and if I talk about it, I feel that if they want to give any advice they can and we can accept any good advice in that. Also, other people can be*

		Emotional resilience Facing up to the future Downwards comparison	*warned about my condition and take necessary precautions, they can check for symptoms and take the necessary action if needed. I talk only to people like that, those I am comfortable with. (Participant 16; aged (40-50)* *Then I also have heard about people who are much older, who had the disease and not taken medical treatment leading to ulceration and if they had sought medical help earlier the treatment could have been done without much complication. So, I feel that I need to do something to increase awareness level among people, I feel strongly about it, I am not sure whether I will be able to do that. I also want to learn more about it' (Participant 17; age 40-50)* *I think it is a good idea, if other people are able to know about us and understand our problems, I know a person who comes here and I talk to her and I encourage her to think more positively. So, I believe that others who hear this will benefit from it. I believe those who had the disease are able to talk more about it'. (Participant 18;age 50-60)*

			No, it is more hobbies like looking after my plants and vegetables, cooking my favourite recipes, doing things around the house that I like, watch my favourite programmes on TV. I try and do things I enjoy so that I don't become upset thinking about my disease. (Participant 13; age 60-70) *I had some strength, everybody has problems, but I just face them bravely and move on in life, I have strength in my mind. Also, my husband is very supportive. If I have any problem he consoles me, so I didn't have any problem* *(Participant 10; age 60-70)* *No, I have never felt like that, I don't think what I have gone through is suffering, compared to what some people have to go through in their lives. I observe other people, and then I read about things, I like observing people and learning from their problems. There are programmes in television that shows about other people's life and their problems. I see them regularly. Some people find it distressing to watch, but I like it. When I see that, I think "God, they have so much problems and my problems are nothing compared to theirs" and I pray that God would look after them and make them well. I also watch religious channel of our community and I enjoy watching them.*

			(Participant 13; age 60-70)
Support system	Family and friends	Role of family in decision making Relationship with husband Family changes, role in family Feeling of burden to family Role of friends	*'Family was very supportive; my sister-in-law has come from Abu Dhabi to look after me, so that she can accompany me while I go for radiotherapy. Sometimes my husband comes with me and some days she accompanies me, someday she stays at home to get my kids ready for college every day. Before that my husband's sister who is in Bahrain, came over during chemotherapy and stayed for the entire time. They all have been very supportive.' (Participant 20; aged 50-60)* *'My husband is finding it very difficult to cope, especially taking time away from work and we try and manage between ourselves especially my son and brothers; but they also have family and so can't spend lot of time with me. Also, my son has exams now, so it is difficult to take time off. But when I think about my husband, I am a bit upset.' (Participant 14; aged 50-60)* *'I didn't know about this decision. Once I was in the theatre, they discussed with my husband about it and he said to go ahead with reconstruction. But now I feel they*

			shouldn't have done the reconstruction as it is causing me more discomfort ...' (Participant 3; aged 60-70) *That troubled me because it is not proper that a man stays at home without doing any job. My daughter in law is employed. She goes to her office in the morning and comes back in the evening. All that gives me some mental trouble. I hope he would get a job here. It has been six months since he came back. And in the meantime, I had this disease. Sometimes also tend to think that God has made him stay back in order to help me in this situation. Don't you think so? I also think that way sometimes. He is also greatly disturbed because I have this disease. He is taking care of me in all ways possible. My daughter in law leaves for office after cooking food. It is he who takes me here regularly and does all other needful things for me. I wish he gets a job before I have to leave this world'(Participant 2;age 60-70)* *'I did not have support from husband. Maybe because I was always active, he was not thinking that I was having this illness or I need some care because of that, he was not very aware. (Participant 17; age40-50)* *I am doing all the work so he was thinking I don't have any problem (laughs), He is*

			always like that not very caring, but I have to care for him a lot even if I have a lot of illness---‘(Participant 17; age40-50) *They asked me first and I said I would consult with my husband and decide. Then they asked the question after I was in the theatre, so they asked my husband and he answered in favour of reconstruction (Participant 3; age 60-70)* *I had thought I wouldn’t go for any treatment; I am only doing this because my children asked me to go for treatment, I felt I didn’t want any treatment. I felt that it is a small lesion and will not spread so there is no need for treatment’(Participant 8; age 50-60)* *‘My son came with me to get diagnosis. Initially for one month he was going into depression, he is very attached to me, we have been alone in the house for a long time. So, he became very upset, initially after first month he stopped talking to anyone, then gradually he got better. He is still not concentrating in his studies as before’ (Participant 7; age 40-50)*

	Faith	Prayer Faith, spirituality, faith fatalism Bargaining with God	*'God has planned something for me and it will happen like that. God doesn't do anything without a plan, also if something happens to me then God will provide for my children. I have faith in God. I go to temples, take part in religious ceremonies, so I believe that God wouldn't let anything bad happen to me.' (Participant 14; aged 50-60)* *'I am able to face others and speak with confidence to others and to you because of my faith. I believe that the disease will be completely cured by treatment. I used to visit temples but I don't do it anymore, mainly due to my hair. Muslims can wear purdah overhead but both Christians and Hindus people will notice if we cover our head.' (Participant 16; aged 40-50)* *'I used to go to temple all the time even before I had this illness and I used to pray all the time. But now since the diagnosis my faith seems to have decreased. I light the lamp and pray but I don't spend a long-time chanting prayer as I used to do. I used to*

			spend lots of time in prayer before the illness. For the past few days, I have been thinking about that actually but I don't know the reason for my change in behaviour.' (Participant 3; aged 60-70) *'Then since the gynaecologist checked me, I didn't think this was going to happen, else I would have been more cautious, I was also observing a penance as I was going to visit a sacred temple. So, I did not do breast self-examination during that time, but my doctor had checked me and said everything was clear.' (Participant 12; aged (60-70))*
	Community	Perception by community Lack of empathy from professional Social stigma Social isolation Invasion of privacy Preference of female doctor	*'Not really harassing, but they will ask me, "Oh, you have cancer? What happened? Are you undergoing chemotherapy?" Even if somebody is not undergoing chemotherapy treatment, they will say, she is. So, we get mentally disturbed.' (Participant 1; aged 70-80)*

8.7 Appendix 7 Participant Information sheet Focus group study: staff

Participant leaflet

(Focus groups - staff)

PARTICIPANT INFORMATION LEAFLET: STAFF (FOCUS GROUP)

Title of study: Qualitative observational study to assess the level of **s**uffering and **d**istress in **b**reast cancer patients undergoing **r**adiotherapy and surgery (SDBR).**Error! Not a valid bookmark self-reference.**

We are inviting you to help us in our research study. If you would like some more information, please feel free to contact us. Thank you for taking the time to read this.

Why is the study being done?

Women undergoing treatment for breast cancer can experience a variety of distress in relation to the consequences of treatment, the disease. There is very little information about how this affects Indian women. This study is conducting focus groups with health care professionals regarding their thoughts about how this might affect women under their care.

Why have I been asked to take part?

You have been chosen because you are a health care professional that looks after patients with breast cancer.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect your employment in any way.

What will happen if I decided to take part in the study

One of the research team, Sunitha Daniel would contact you to notify you of the time and place of the focus group. The focus group would consist of you and a group of health care professionals and two researchers. The researchers will facilitate group discussion about the issues faced by women with breast cancer. The focus group would take about one hour. The interview would be audio recorded to make sure discussion is noted accurately.

What are the possible advantages or disadvantages of taking part in the study?

You may find it helpful to reflect on the care of these patients but there is no specific advantage to you to taking part in this study. We are doing it to see if we can help the care of patients with breast cancer in the future. We will give you an anonymous summary of the discussion.

What if there is a problem?

If you have a concern about any aspect of this study, you may to speak to the researchers who will do their best to answer your questions. We do not provide indemnity for the focus group discussion and members participate at their own risk.

Will my taking part in the study be kept confidential?

Everything you tell us will be strictly confidential. Any information held on computer will be password protected and all audio-recordings and written notes will be stored securely in locked filing cabinets in the Research Department. The information will only be available to the research team and transcripts will be anonymised. The files will be destroyed five years after the study is complete. Anonymised information will be archived and may be used in future research.

We may use quotes from your group discussion, but we will ensure that any identifying information will be removed.

What will happen to the results of the research study?

This research is part of an MD thesis, registered at the Hull York Medical School in England. We also intend to write up our work in reports and papers for medical journals and conferences. We would like to assure you that nothing published will be traceable back to you.

Who is organising and funding the research?

The salary of the main researcher is paid by Amrita Institute Of Medical Sciences and Research Centre, Kochi, India.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Hull York Medical School Research Ethics Committee.

This study is being carried out by researchers from Hull York Medical School and by Amrita Institute Of Medical Sciences and Research Centre, Kochi. The research team are:

- Sunitha Daniel: Fellow in Pain and Palliative Medicine at by Amrita Institute Of Medical Sciences and Research Centre, Kochi; Tel 0484; email sunithadaniel@nhs.net and registered at the Hull York Medical School for the degree of MD.
- Dr. Chitra Venkateswaran: **Consultant in Psycho Oncology and Palliative Care,** Amrita Institute of Medical Sciences and Research Centre, Kochi
- Dr Charu Singh, Additional Professor, Amrita Institute of Medical Sciences and Research Centre, Kochi
- Dr Miriam Johnson: Professor of Palliative Medicine at the Hull York Medical School; email Miriam.johnson@hyms.ac.uk

You will be able to find out more about the study by contacting Dr Sunitha Daniel.

If you do decide to take part in the study you will be given a signed copy of your consent form.

Thank you very much for considering taking part in our research.

8.8 Appendix 8 Participant Information sheet Focus group study: members of public

Participant leaflet

(Focus groups –members of public)

PARTICIPANT INFORMATION LEAFLET: MEMBERS OF PUBLIC (FOCUS GROUP)

Title of study: Qualitative observational study to assess the level of **s**uffering and **d**istress in **b**reast cancer patients undergoing **r**adiotherapy and surgery (SDBR).**Error! Not a valid bookmark self-reference.**

We are inviting you to help us in our research study. If you would like some more information, please feel free to contact us. Thank you for taking the time to read this.

Why is the study being done?

Women undergoing treatment for breast cancer can experience a variety of distresses in relation to the disease and its treatment. There is very little information about how this affects Indian women. This study is conducting focus groups with members of the community to explore the views of general public on the impact of breast cancer and its treatment on all aspects of a women's life.

Why have I been asked to take part?

Since breast cancer is a common cancer in Indian subcontinent, you have been asked to share your understanding of breast cancer and how it affects women in your community, as a member of the general public.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen if I decided to take part in the study?

One of the research team, Sunitha Daniel would contact you to notify you of the time and place of the focus group. The focus group would consist of you and a group of other people from the community. The researchers will facilitate group discussion about the issues faced by women with breast cancer. The focus group would take about one hour. The interview would be audio recorded to make sure discussion is noted accurately.

What are the possible advantages or disadvantages of taking part in the study?

We are doing this study to see if we can help the care of patients with breast cancer in the future. This will help us understand how experience of breast cancer is perceived by members in the community. We will give you an anonymous summary of the study findings once these have been analysed.

What if there is a problem?

If you have a concern about any aspect of this study, you may to speak to the researchers who will do their best to answer your questions.

We do not provide indemnity for the focus group discussion and members participate at their own risk.

It is possible that some issues discussed may be distressing for you, particularly if you have some personal or family experience of breast cancer. If this occurs, you will have time to decide whether to continue in the discussion and you will be supported by the group facilitators who are experienced doctors.

Will my taking part in the study be kept confidential?

Everything you tell us will be strictly confidential. Any information held on computer will be password protected and all audio-recordings and written notes will be stored securely in locked filing cabinets in the Research Department. The information will only be available to the research team and transcripts will be anonymised. The files will be destroyed five years after the study is complete.

We may use quotes from your group discussion, but we will ensure that any identifying information will be removed.

Anonymised information will be archived and may be used in future research.

What will happen to the results of the research study?

This research is part of an MD thesis, registered at the Hull York Medical School in England. We also intend to write up our work in reports and papers for medical journals and conferences. We would like to assure you that nothing published will be traceable back to you.

Who is organising and funding the research?

The salary of the main researcher is paid by Amrita Institute of Medical Sciences and Research Centre, Kochi, India.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Hull York Medical School Research Ethics Committee.

Further information and contact details

This study is being carried out by researchers from Hull York Medical School and by Amrita Institute of Medical Sciences and Research Centre, Kochi. The research team are:

- Sunitha Daniel: Fellow in Pain and Palliative Medicine at by Amrita Institute Of Medical Sciences and Research Centre, Kochi; Tel 0484; email sunithadaniel@nhs.net and registered at the Hull York Medical School for the degree of MD.

- Dr. Chitra Venkateswaran: **Consultant in Psycho Oncology and Palliative Care,** Amrita Institute Of Medical Sciences and Research Centre, Kochi

- Dr Charu Singh, Additional Professor, Amrita Institute of Medical Sciences and Research Centre, Kochi

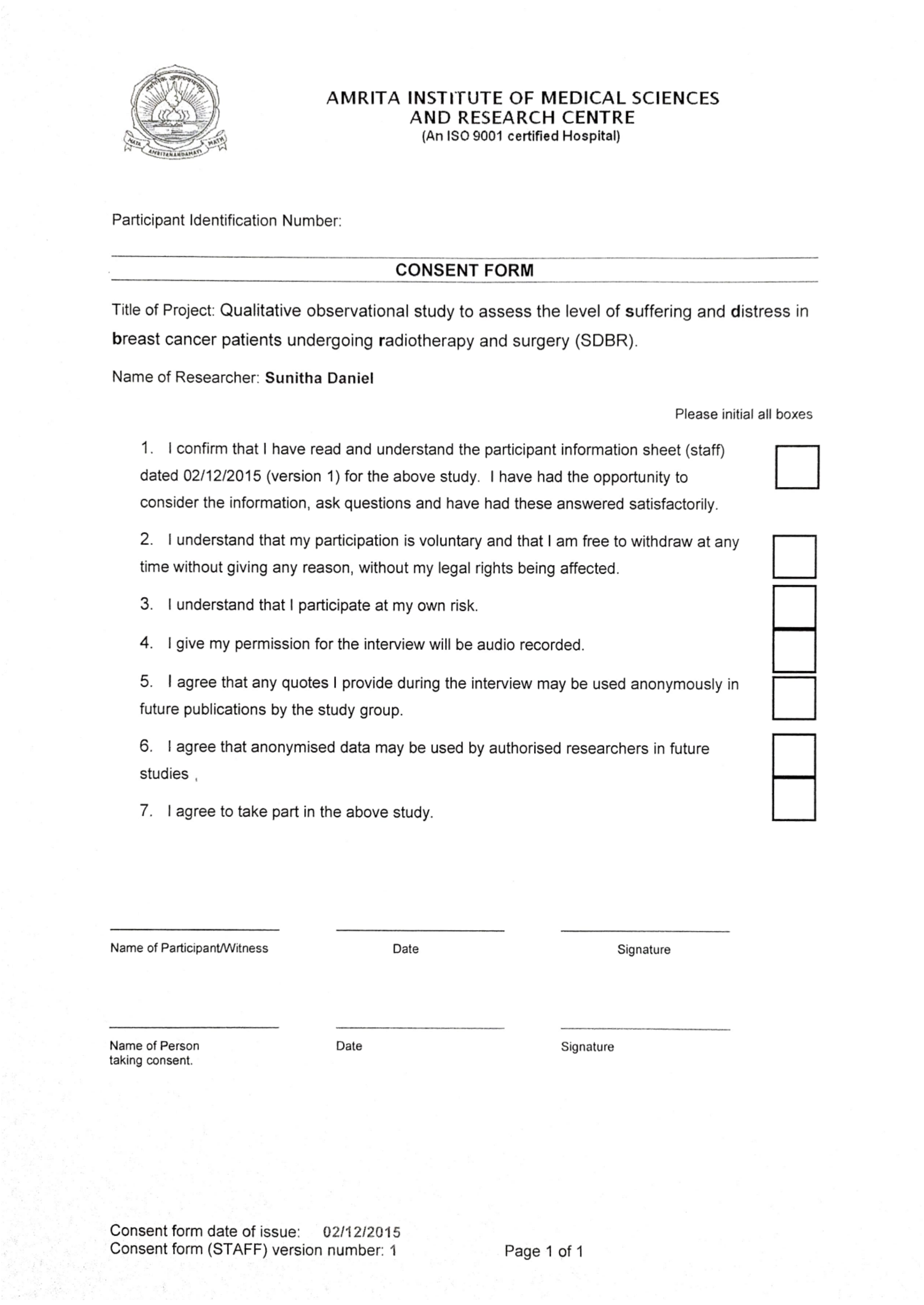
- Dr Miriam Johnson: Professor of Palliative Medicine at the Hull York Medical School; email Miriam.johnson@hyms.ac.uk

You will be able to find out more about the study by contacting Dr Sunitha Daniel.

If you do decide to take part in the study you will be given a signed copy of your consent form.

Thank you very much for considering taking part in our research.

8.9 Appendix 9 Consent form English Focus group study: staff



AMRITA INSTITUTE OF MEDICAL SCIENCES
AND RESEARCH CENTRE
(An ISO 9001 certified Hospital)

Participant Identification Number:

CONSENT FORM

Title of Project: Qualitative observational study to assess the level of **s**uffering and **d**istress in **b**reast cancer patients undergoing **r**adiotherapy and surgery (SDBR).

Name of Researcher: **Sunitha Daniel**

Please initial all boxes

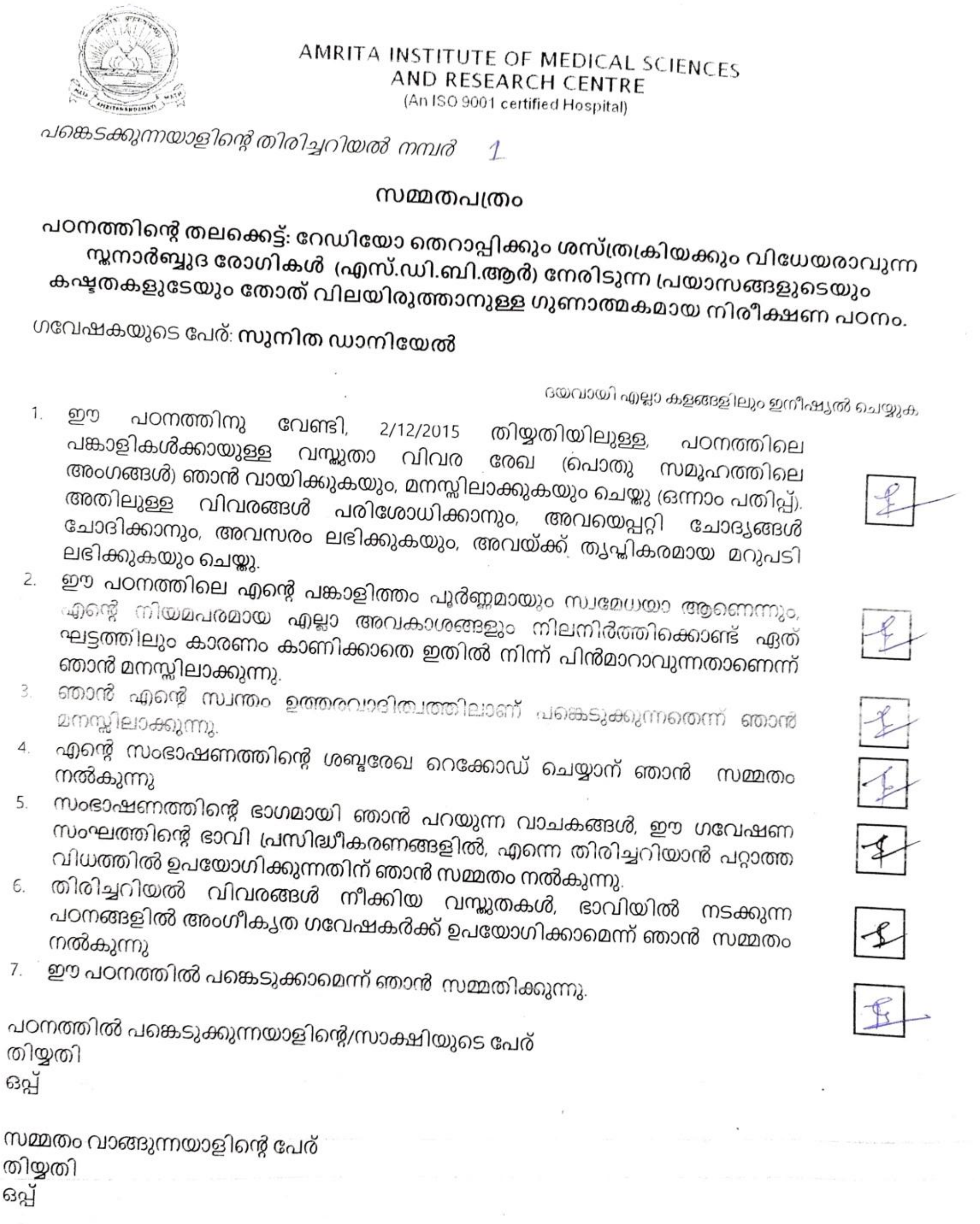
1. I confirm that I have read and understand the participant information sheet (staff) dated 02/12/2015 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐
3. I understand that I participate at my own risk. ☐
4. I give my permission for the interview will be audio recorded. ☐
5. I agree that any quotes I provide during the interview may be used anonymously in future publications by the study group. ☐
6. I agree that anonymised data may be used by authorised researchers in future studies , ☐
7. I agree to take part in the above study. ☐

Name of Participant/Witness	Date	Signature
Name of Person taking consent.	Date	Signature

Consent form date of issue: 02/12/2015
Consent form (STAFF) version number: 1

Page 1 of 1

8.10 Appendix 10 Consent form Malayalam Focus group study: members of public



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AND RESEARCH CENTRE
(An ISO 9001 certified Hospital)

പങ്കെടക്കുന്നയാളിന്റെ തിരിച്ചറിയൽ നമ്പർ 1

സമ്മതപത്രം

പഠനത്തിന്റെ തലക്കെട്ട്: റേഡിയോ തെറാപ്പിക്കും ശസ്ത്രക്രിയക്കും വിധേയരാവുന്ന സ്തനാർബ്ബുദ രോഗികൾ (എസ്.ഡി.ബി.ആർ) നേരിടുന്ന പ്രയാസങ്ങളുടെയും കഷ്ടതകളുടേയും തോത് വിലയിരുത്താനുള്ള ഗുണാത്മകമായ നിരീക്ഷണ പഠനം.

ഗവേഷകയുടെ പേര്: **സുനിത ഡാനിയേൽ**

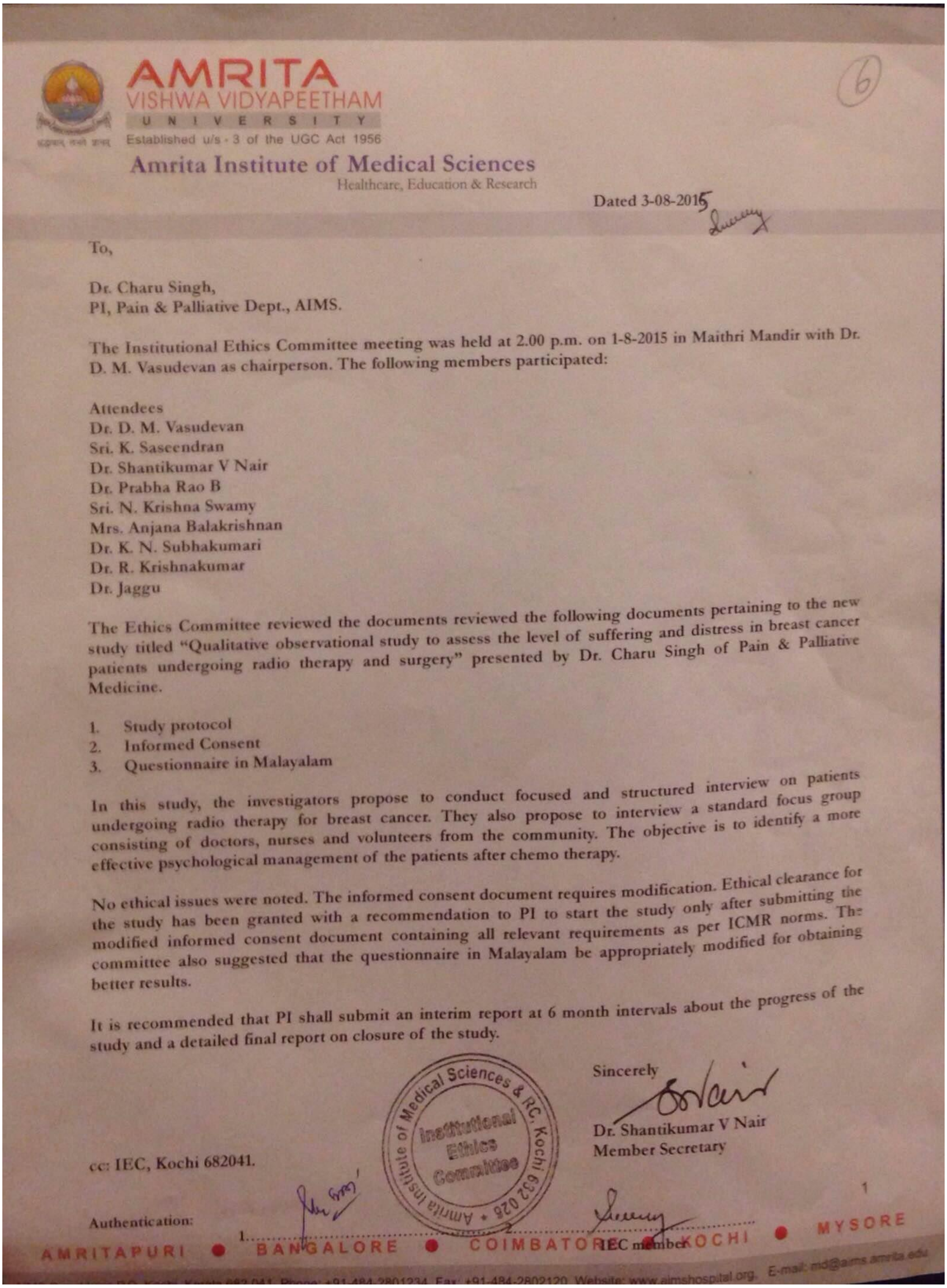
ദയവായി എല്ലാ കളങ്ങളിലും ഇനീഷ്യൽ ചെയ്യുക

1. ഈ പഠനത്തിനു വേണ്ടി, 2/12/2015 തിയ്യതിയിലുള്ള, പഠനത്തിലെ പങ്കാളികൾക്കായുള്ള വസ്തുതാ വിവര രേഖ (പൊതു സമൂഹത്തിലെ അംഗങ്ങൾ) ഞാൻ വായിക്കുകയും, മനസ്സിലാക്കുകയും ചെയ്തു (ഒന്നാം പതിപ്പ്). അതിലുള്ള വിവരങ്ങൾ പരിശോധിക്കാനും, അവയെപ്പറ്റി ചോദ്യങ്ങൾ ചോദിക്കാനും, അവസരം ലഭിക്കുകയും, അവയ്ക്ക് തൃപ്തികരമായ മറുപടി ലഭിക്കുകയും ചെയ്തു.
2. ഈ പഠനത്തിലെ എന്റെ പങ്കാളിത്തം പൂർണ്ണമായും സ്വമേധയാ ആണെന്നും, എന്റെ നിയമപരമായ എല്ലാ അവകാശങ്ങളും നിലനിർത്തിക്കൊണ്ട് ഏത് ഘട്ടത്തിലും കാരണം കാണിക്കാതെ ഇതിൽ നിന്ന് പിൻമാറാവുന്നതാണെന്ന് ഞാൻ മനസ്സിലാക്കുന്നു.
3. ഞാൻ എന്റെ സ്വന്തം ഉത്തരവാദിത്വത്തിലാണ് പങ്കെടുക്കുന്നതെന്ന് ഞാൻ മനസ്സിലാക്കുന്നു.
4. എന്റെ സംഭാഷണത്തിന്റെ ശബ്ദരേഖ റെക്കോഡ് ചെയ്യാന് ഞാൻ സമ്മതം നൽകുന്നു
5. സംഭാഷണത്തിന്റെ ഭാഗമായി ഞാൻ പറയുന്ന വാചകങ്ങൾ, ഈ ഗവേഷണ സംഘത്തിന്റെ ഭാവി പ്രസിദ്ധീകരണങ്ങളിൽ, എന്നെ തിരിച്ചറിയാൻ പറ്റാത്ത വിധത്തിൽ ഉപയോഗിക്കുന്നതിന് ഞാൻ സമ്മതം നൽകുന്നു.
6. തിരിച്ചറിയൽ വിവരങ്ങൾ നീക്കിയ വസ്തുതകൾ, ഭാവിയിൽ നടക്കുന്ന പഠനങ്ങളിൽ അംഗീകൃത ഗവേഷകർക്ക് ഉപയോഗിക്കാമെന്ന് ഞാൻ സമ്മതം നൽകുന്നു
7. ഈ പഠനത്തിൽ പങ്കെടുക്കാമെന്ന് ഞാൻ സമ്മതിക്കുന്നു.

പഠനത്തിൽ പങ്കെടുക്കുന്നയാളിന്റെ/സാക്ഷിയുടെ പേര്
തിയ്യതി
ഒപ്പ്

സമ്മതം വാങ്ങുന്നയാളിന്റെ പേര്
തിയ്യതി
ഒപ്പ്

8.11 Appendix 11 Ethics Approval form from Amrita Institute of Medical Sciences



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UNIVERSITY
Established u/s - 3 of the UGC Act 1956
Amrita Institute of Medical Sciences
Healthcare, Education & Research

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Dated 3-08-2015

To,

Dr. Charu Singh,
PI, Pain & Palliative Dept., AIMS.

The Institutional Ethics Committee meeting was held at 2.00 p.m. on 1-8-2015 in Maithri Mandir with Dr. D. M. Vasudevan as chairperson. The following members participated:

Attendees
Dr. D. M. Vasudevan
Sri. K. Saseendran
Dr. Shantikumar V Nair
Dr. Prabha Rao B
Sri. N. Krishna Swamy
Mrs. Anjana Balakrishnan
Dr. K. N. Subhakumari
Dr. R. Krishnakumar
Dr. Jaggu

The Ethics Committee reviewed the documents reviewed the following documents pertaining to the new study titled "Qualitative observational study to assess the level of suffering and distress in breast cancer patients undergoing radio therapy and surgery" presented by Dr. Charu Singh of Pain & Palliative Medicine.

1. Study protocol
2. Informed Consent
3. Questionnaire in Malayalam

In this study, the investigators propose to conduct focused and structured interview on patients undergoing radio therapy for breast cancer. They also propose to interview a standard focus group consisting of doctors, nurses and volunteers from the community. The objective is to identify a more effective psychological management of the patients after chemo therapy.

No ethical issues were noted. The informed consent document requires modification. Ethical clearance for the study has been granted with a recommendation to PI to start the study only after submitting the modified informed consent document containing all relevant requirements as per ICMR norms. The committee also suggested that the questionnaire in Malayalam be appropriately modified for obtaining better results.

It is recommended that PI shall submit an interim report at 6 month intervals about the progress of the study and a detailed final report on closure of the study.

Institutional Ethics Committee

Sincerely

Dr. Shantikumar V Nair
Member Secretary

cc: IEC, Kochi 682041.

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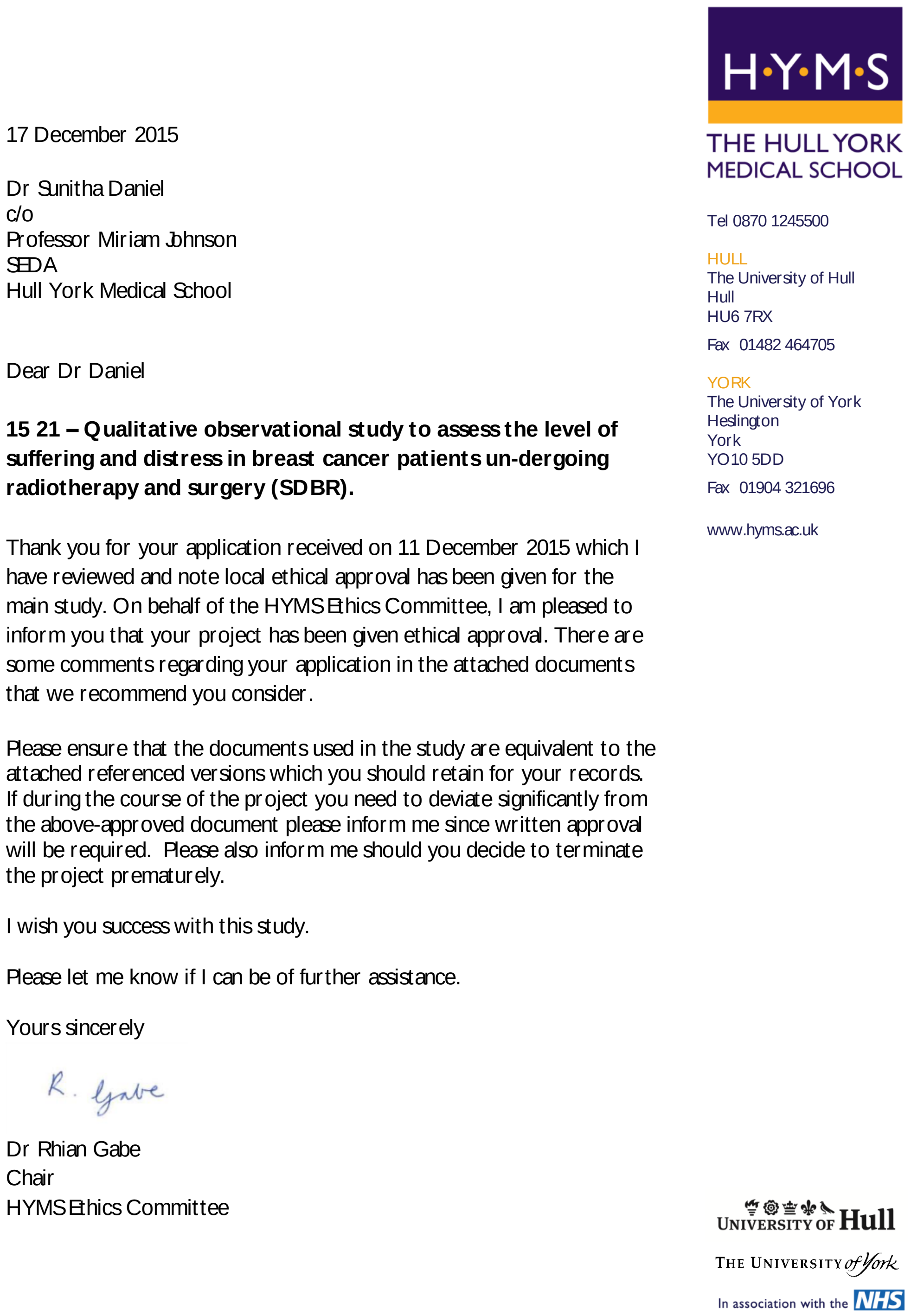
Authentication: 1.………………… 2.…………………
IEC member

8.12 Appendix 12 Ethics approval form from Hull York Medical School



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17 December 2015

Dr Sunitha Daniel
c/o
Professor Miriam Johnson
SEDA
Hull York Medical School

Dear Dr Daniel

15 21 – Qualitative observational study to assess the level of suffering and distress in breast cancer patients un-dergoing radiotherapy and surgery (SDBR).

Thank you for your application received on 11 December 2015 which I have reviewed and note local ethical approval has been given for the main study. On behalf of the HYMS Ethics Committee, I am pleased to inform you that your project has been given ethical approval. There are some comments regarding your application in the attached documents that we recommend you consider.

Please ensure that the documents used in the study are equivalent to the attached referenced versions which you should retain for your records. If during the course of the project you need to deviate significantly from the above-approved document please inform me since written approval will be required. Please also inform me should you decide to terminate the project prematurely.

I wish you success with this study.

Please let me know if I can be of further assistance.

Yours sincerely

R. Gabe

Dr Rhian Gabe
Chair
HYMS Ethics Committee

University of Hull
The University of York
In association with the NHS

8.13 Appendix 13 Themes subthemes and quotes from focus group discussion

Themes	Subthemes	Codes	Quotes
Psychosocial issues related to diagnosis	Recognition of psychological distress	Distress ,Need for psychological support, lack of time for doctors, lack of psychological support, shock, disbelief, body image, hair loss, lack of importance of psychological issues	*When disease is diagnosed, instead of seeking treatment, she will decide to keep the disease a secret, also that is a private part of my body, even my husband will reject me, such a fear. All this is part of a social stigma, what people have imposed on women saying a woman should be like this. The stigma in Indian culture is a major factor in this." (Volunteer2;3 Age 40-50)* *There was a lady who was behaving abnormally at home, jumped into a well. It was a cancer in the curable stage, even then patient became like that, because of incomplete information. Then finally she got admitted and was managed when she became well enough to share her story she said' don't laugh I will tell you the reason, I was told I will lose my hair, when the doctor said like that I thought why should I live with no hair, my husband liked my hair and married me." (she had a lot of hair) (Nurse1 Age 50-60)*

			tend to kind of prioritise and take care of the medical aspects and leave all the rest of it thinking that it will sort out on its own. (Doctor2/Male/40-50) *“they think these issues are a part of life, because most of them, they are alone, their family goes out to work so there is no one to talk to them, family just ensures that they are well at home when they come back but do not ask how they feel when they are alone.” (Doctor 4 /Female 40-50)* *And it is very difficult kind of for patients who are going through so much of chaos in life, with no hair, who can’t eat anything, for them to realise, ok these people are taking care of me, they might be physically doing a lot of things, but how much of emotional support they get, I am really not sure and that is the scenario where we find things difficult. (Doctor2/Male/40-50)* *The question is more of the psychology of that at that point of time.*

			So again you have to find them a convincing enough reason to lose their hair, if you can convince them , why it is needed, if you can give them a better explanation for that. (Doctor2/Male/40-50) *surgeon can only answer in one word, a detailed conversation is not possible there, so when they ask " Will I lose my hair doctor?' They say yes, they can only answer that. But if they add one more sentence like 'don't worry it will come back' it might be more reassuring to patient. (Nurse1 Age 50-60)* *My daughter's friend's mother is always angry, she had lots of problems in family due to her anger and it has affected her kid. Her child used to come well looked after and well-dressed to school but since her mother had diagnosis, she was not paying attention to child and it affected the child's appearance. She is always angry at everyone. Her daughter had told me about that and said mother is always angry and does things like that. (Nurse 3 Age 30-40)* *"Then she had chemotherapy, radiation, lost all her hair and then she*

			became very upset mentally. All these are the things they say, lot of mental stress, losing hair so much, when they have their shower and see the hair falling like water, they can't bear it." (Church1 Age 60-70) *They get shocked in the beginning know about the illness, then cost of the treatment ,that is too much for most to bear, for one who is employed, it affects their job, they will not be able to go for job for those days, the income, the household income, treatment cost affects mostly.(Volunteer group 1;3 Age 60-70)* *Most of us appreciate beauty and want to be beautiful (laughing), so if we lose hair or skin becomes dark, I saw one of my friends recently who had this disease, she was very fair , no since radiation, she became very dark skinned and lost all her hair, seeing all that they become depressed. When such changes happen in their body they feel they are not the same, they are somebody else different. (Church1 Age 60-70)*

			Most of the women feel great mental agony when breast is removed. Before surgery, all are given a psychological counselling now. That does some good. Some patients do plastic surgery after the removal surgery. But only those with money can afford that.(Volunteer group 1;8 age 40-50) *And thirdly, I will lose my identity. My long hair will fall off, my breasts will be removed. My personality will change. Even if plastic surgery is done, it is artificial is the thought inside me.* (*Volunteer group 2; 3 (Age 40-50))* *One of my friends, who had this, and lost her hair after radiation, she used to hide , hide and live her life. She used to get into her car, and into the lift, and treatment was in AH. She was beauty conscious and hence she had lot of such problems. Once she had asked me to sleep over since her husband was away, I went , and she had covered her head with a black cloth, trying not to let us know anything about her*

			and suppress any difficulty she has having unto herself, and then psychological distress increases. Not only that, she didn't want anyone to know, no one in the community. (Volunteer group 1; 4 (Age 40-50) *I think It should be a multidisciplinary team approach, I think, if you want to really support them from the day one, sometimes we are not looking at all the factors of their distress, because sometimes we take certain decisions for them actually , we don't ?support for eg: the body image the patient may want to retain her breast and not to undergo a mastectomy, but then she looks at the other factors like the u know avoiding the radiation therapy, minimising the risk you know risk perceptions also varies, sometimes people think that , removing the breast itself is you know a better way of getting a higher cure rate so enough time and enough confidence and enough talking should be done in the beginning and probably the care givers are you know work as a team and spend more time in the beginning itself which never happens actually because everybody , patient is also in a hurry to get the treatment done and you know we don't*

			really go into the depths of the patients needs and perceptions at that point of time. Probably I think there are some areas in which we can do a better job. (Doctor2/Male/40-50) *That is the most important concern, the figure change. But the nurse who gives chemotherapy is able to educate the patient and they will be able to accept the figure change, then they will be concerned about what to do at home, I am a patient should I take rest all the time? All these fears can be allayed in the first chemotherapy if the nurse is educating the patient. I have a lot of experience in this regard, for those patients whom we don't educate, within first week; they will be coming back with a neutropenic infection which will lead to unwanted expenses. So this can be changed with education. (Nurse1 Age 50-60)*
	Delayed diagnosis	cultural impact/stigma, strain on	*Generally breast cancer is something which, in most, maybe western countries it is screened and detected and screening is high but in India there is no organised screening. (Doctor1 Male/50-60)*

		finances/ awareness of disease, importance of family/ feeling of being burden to family/ worries about family, reluctance to seek medical help, privacy, government funded treatment, variation with socio economic status, preference for female doctor	*What I have noticed is that none of the women actually detect it in the early stage. When I asked about the reason, the first reason was a busy life, second is lack of awareness. (Nurse4 Age 40-50)* *Now these things like mammography, just like when health workers used to collect samples from houses for filariasis etc., in a similar manner, with the support of the social leaders, government should make it compulsory that after 35 years, all women should do mammogram. (Volunteer group 1; 8 Age 40-50)* *The general difficulty, one of the biggest thing is stigma, many people are worried that if the news gets out, it is going to affect my daughter's marriage, my family in general. The marriage is the biggest concern of a lot of people. If there is a history of cancer, it might somehow hinder future alliances in family.* (*Doctor1 Male/50-60)*

			similarly, if even those who do not have the disease are made compulsorily to undergo the detection tests, then it will be more useful in detecting the disease. But there is no basic diagnosis facilities available for a person to find out if he has, any part of his body has been affected by cancer. There is no government level arrangement for that. (Volunteer group 2; 1 (Age 50-60)) *because it is the breast, and because of the difficulty to decide if it is an illness by one self, I have seen a lot of patients who don't feel like seeing the doctor, once you know, then what has to be done, will things need to be done like what we have seen in the community or hospitals, will others get to know, will we have to take a lot of medicines, should it be removed, after removal will this go to secondaries, like this, lot of psychological distress is felt. (Volunteer group 1; 2 (Age 50-60))* *When surgery was suggested she was again reluctant, she was wondering how she will wear her clothes, she used to call me so*

			many times, I haven't looked after patients with breast cancer, I have only learned about it. Initially she had been feeling the swelling for about 4 years prior to all things but was reluctant to talk to husband, she was reluctant to talk to anyone, and she kept silent and finally did surgery only last year. Now it has started in the opposite breast, and we have asked her to come again, and do mammogram again but she has not come yet. (Nurse3 (Age 30-40) *Today's Indian woman is of the habit of living for others. She thinks my life is meant for others. so she will hide the disease thinking other will have to suffer for me.* (*Volunteer2; 3Age 40-50)* *Initially many people hide the disease. Only after it spreads and becomes unmanageable, it is communicated and then the situation will be beyond cure. (Volunteer2; 1 Age 50-60)* *I have been working in oncology for a long time and have seen lot of*

			patients with breast cancer, and on evaluating them I found that most of them are reluctant to talk about it when it first starts as a swelling, they all consult doctors after a long time. So they will only consult in the late stage. (Nurse 2 Age 30-40) *There can be problems finding the required amount for treatment. A woman would be controlling everything in the family, there won't be anyone to take up the responsibility and this can affect them. Not just being a mother there are other responsibilities also which the woman needs to take up. (Church4 age (60-70))* *But people from the lower class have financial difficulties to get the tests done, also they find it difficult to go for a test leaving their day's job behind. Also they have to attend to the needs of their children, husband, so even when they see something, they think this is a minor problem and postpone the tests. Volunteer group 2; 3 (Age 40-50)*

			mostly when it is breast cancer, they feel isolated from family, will the love from the husband lessen, that is seen a lot. So they will keep it for a long time, even if it is a small gland, not much developed, if they go to the doctor, if the breast is removed, will there be a change in the behaviour of others towards me, there is fear which is seen.(Volunteer group 1; 4 (Age 40-50) *there will be children, husband, women need to look after the needs of the husband. Even when women have this disease they have to look after the needs of the husband and children. There is a woman that I know of who has to look after the needs of the husband and children even when she has this disease.(Church 1 (Age 60-70))* *The social stigma behind the patients' diagnosis of cancer is quite big because the family support is not always what we expect. The close family may be supporting but then the distant family, because we have a close knit family like, it is not just a nuclear family, all of the relatives will be there. (Doctor3/Female 50-60)*

			because of that people who live in villages don't know we can identify or do breast self-examination or the treatment and its complications, they don't know anything about that (Nurse 4 Age 40-50) *"one of the biggest problems is stigma; many people are worried that if the news gets out, it is going to affect my daughter's marriage, my family in general. (Doctor 5/Male 50-60)* *When disease is diagnosed, instead of seeking treatment, she will decide to keep the disease a secret, also that is a private part of my body, even my husband will reject me, such a fear. If I am sick, who will shoulder the financial burden of the treatment? (Volunteer group 2; 3 (Age 40-50))* *I haven't looked after patients but I had a relative who had breast cancer about 10 years back. We live in a village and she had lots of financial issues and we did a lot of fund raising for her treatment.*

			Also for the education of her children, there wasn't anybody to look after her; she was a small child, so a lot of people helped with the child's education also. So I think financial issues are a great burden. (Nurse 8 (Age 40-50) *They get shocked in the beginning know about the illness, then cost of the treatment ,that is too much for most to bear, for one who is employed, it affects their job, they will not be able to go for job for those days, the income, the household income, treatment cost affects mostly. (Volunteer group1; 3 (Age 60-70))* *They don't want to give more trouble to family or add to their trouble of care givers that's another thing. They always feel that when they say they have got more pain or they are tired or they have got some other issues, if they tell that their children will be more anxious and children will have more problems, so they don't want to do it. (Doctor3/Female 50-60)*

			I have to say something different, some patients who are educated ladies they do breast self-examination and at very small size of swelling people have identified due to their own personal initiation and then they consult a local doctor and the doctor because it is small size would send her back saying it is nothing and such patients have gone back to those doctors and asked them to do a biopsy at their own risk and compel the doctor to do it which would turn out to be positive. (Nurse1 Age 50-60) *To avoid such treatment from expensive private hospitals, people take some effort and struggle but go to regional cancer centres to get treatment, even if the travel is so difficult, people tend to go like that. Because they know that expense will be too much if they go to nearby places.(Church 5 Age 60-70)* *If we talk about cancer treatment, the drugs and all are very costly. Usually what we see among patients is that above poverty line, once*

			a treatment is over they become below poverty line. Since the situation is like that, I think finance is the most important aspect that we need to take into consideration. So if all these lifesaving drugs we can get some incentive, I know government is doing a lot of things, I don't think it is sufficient,. So I think from the government some sort of financial aid should be given to the patients who are suffering from cancer. (Nurse5 (Age 60-70)) *Some will think that this is so minute thing which I can tolerate whereas family matters are more important like child's education, husband going for work or his meeting at work. Why do I have to trouble them for such a trivial matter? Also some people think I have to expose myself in the hospital or will there be female doctor to consult. That is also an issue. (Nurse1 Age 50-60)* *Generally the Indian women sacrifice a lot for the family and they always keep their priorities the last. I had a lady whose husband had rectal cancer , she actually did not reveal about her breast lump till*

			her husband completed his full treatment , only after that she told me that doctor I want you to look at my breast lump , then I realised that it was a large lump and we have lost almost 4-5 months . So plenty of people are like that ,they sacrifice a lot. (Doctor4/Female 40-50) *her second breast was also diagnosed with the disease. So now though the doctor has told her chemotherapy was enough, she is not doing it. The single reason being, if she loses her hair again, the society will come to know of her disease again, that problem is haunting that family, she is ready to die but not ready to give up her hair…" (Volunteer2; 3 Age 40-50)* *There was an example of a patient who was in the ICU and the bystander, who was a teacher had some doubts that she has breast cancer but in her condition she was not able to talk to anybody or get the required medical attention .Her husband was in the ventilator for about 2 months, from there he recovered and started working and then she told about her condition. By that time it had spread all over. (Nurse1 Age 50-60)*

			Now most of the families are nuclear families now so if the woman becomes sick, the day to day running of the family is really a problem. Also if it is working women financial issues also comes and job related issues so they will postpone the treatment till the job issues are sorted and settled. So such kind of issues is also there. (Doctor 5/Male 50-60) *When she came here for chemotherapy and radiation, all the women patients. They do not have anyone else at home, only the husbands will be accompanying them, so their jobs will be affected, they will have to take care of their wives, so that causes lot of mental suffering for women. Even if they have good financial backup…also there are many people who do not have the means..for food, or money..I have seen many such people here. (Volunteer group 2; 8 (Age 40-50))*
Psychosocial impact of cancer treatment	Experience of treatment	inappropriate medical treatment, issues with quality of	*“The next thing is, of course surgery is usually the first line of treatment once the patient is diagnosed and I don’t think that it is either breast conservation or reconstruction is offered as often as it should be. A lot of people are reluctant to come forward for surgery*

		medical care, lack of empathy from doctors, cultural impact, strain on finances, hair loss, side effects of treatment, sequelae post-surgery, practical difficulties, problem with decision making, lack of uniformity in care, reluctance to accept treatment	*because of the fear of losing the breast. (Doctor1 Male/50-60)* *“our culture is totally different, or like somebody wearing a saree, it is not very obvious, she does not have one breast, I think it does not make much of a difference(Doctor 3/Female 50-60)* *Most of the women feel great mental agony when breast is removed. Before surgery, all are given a psychological counselling now. That does some good. Some patients do plastic surgery after the removal surgery. But only those with money can afford that.” (Volunteer1; 8 Age 40-50)* *I have known many who cannot reconcile with the removal of their breast. That is more prevalent among younger women around 30-35 years of age, than old women. Old women do not have that much difficulty.” (Volunteer1; 8 Age 40-50)* *Post operatively patient develops lymph oedema; again this is due to lack of information. Lymphoedema is very disabling, they are free of*

			disease for 8-10 years and they live with 15kg of one limb .Even with such swollen limb they live well, enjoy life and live happily, that's another thing. (Nurse 1 Age 50-60) *Also if it is working women financial issues also comes and job related issues so they will postpone the treatment till the job issues are sorted and settled".” (Doctor 5/Male 50-60)* *“The society has taught all of us to consider long hair and breasts as the yardsticks of woman hood. So when you don't have any of this, it is a very painful situation.” (Volunteer2; 3 Age 40-50)* *She had a lot of problem during chemotherapy and she went to A hospital for treatment. She had a lot of discolouration in skin, lost weight and was very tired. Her kids were very small and she was not able to look after them. (Nurse5 (Age 60-70))*

			If women have an illness, it is an issue from the start because that woman would have been the main person in the family, then there is a disruption of the rhythm in all aspects, taking care of children , husband, so it is very difficult.(Volunteer group 1; 5 Age 60-70) *So when they become ill, the total structure of the family is affected, they can't do anything, so the kid's studies will be affected, husband's work is affected. Husband is not able to go to work, so the income of the family is affected. So the total structure of the family is getting changed. (Nurse1 Age 50-60)* *In Kerala most women in house have an important role, right from getting up in the morning, cooking, getting kids ready for school, looking after husband, some husbands if they are lazy (laughing in background) right from getting their shirt ironed and ready to wear, feeding them, and getting their bags ready and giving it to them so*

			that they can go for working".(Nurse 10 Age 60-70) *Once I was working in a ward and there was a patient who had breast cancer and had surgery, but her main concern was whether her husband would abandon her. As one of her breast is removed she was concern that her husband would leave her. The patient used to talk to me about it and cry about that. (Nurse7(age 40-50))* *Most of the patients accept the hair fall and don't go for a wig, only around roughly 30% would go for a wig, and sometimes when we talk about hair donation, now that is becoming popular, few of the patients have gone for it, very few, because they get a discount on the donated hair, and they can have the pleasure of having the same hair being made into a wig so that is attracting more number of patients, that is a recent trend now. So by and large they are happy covering with scarf. (Doctor5/Male 50-60)* *first follow up is with surgeon and then they say they have to take chemotherapy, immediately the patient's face changes, because once*

			they hear the word chemo the two things that come to their mind is either they will vomit or they will lose hair. Figure change and fatigue are already in their mind. (Nurse7(age 40-50)) *Now most of the families are nuclear families now so if the woman becomes sick, the day to day running of the family is really a problem. Also if it is working women financial issues also comes and job related issues so they will postpone the treatment till the job issues are sorted and settled. So such kind of issues is also there. (Docto4r/Female 40-50)* *I completely agree with her. I know about a few patients with similar experience. Even if they know that the patient has reached the last stage the doctors still continue treatment, they do not stop it. They know that is the last stage and there isn't any hope, but they still continue treatment. They could actually explain everything to family and console them, they do not do that. In most private hospitals they just give unnecessary treatment, they just say 'shall we give 30 more*

			radiation? And they just start it. So the net result is they get lot of money, if the patients re rich then they know they will get the amount. (*Church1 (Age 60-70))*
	Experience of Medical care		*"the hospital management said he is an elderly doctor, when he becomes busy with lot of patients he is not able to manage things and so gets angry." (Church 8 Age 40-50)* *"To be quiet honest this is all a business to make money. Even when doctors know that the patient is going to die soon they still give radiation, chemotherapy do all treatment and get money."* (*Church 14 Age 60-70)* *"Another experience is even if patients are diagnosed with cancer the doctors don't behave in a compassionate manner with them. I know about an experience, if we ask anything to doctor he immediately loses temper and will not explain things to us. He would say 'The patient is 80 years old, what more do you need, how long should she be alive?'" (Church8 Age 40-50)* *"Compared to doctors from other specialities those working in palliative care shows more love and compassion People working in*

			palliative care are very caring and I have personal experience, they have at least a bit more compassion. We need more people like that." (*Church5 Age 60-70)* *"Here (public hospital) the treatment is very good. We do not have anything to complain. All the doctors and nurses, attenders, chemo ward staff, volunteers, are very good. I had gone to a private hospital before coming here. What I feel is, here we have better treatment than even that. All patients get equally good treatment. That government is doing all these things. Many people do not know. (Volunteer1; 8 Age 40-50)*
	Solutions		*"similarly, government should ensure adequate screening services for asymptomatic people then it will be more useful in detecting the disease." (Volunteer2; 1 Age 50-60)* *"I think what's best you could do is probably just have people to provide inputs, have somebody who is always available on call to support, because all that they , I realize, , most of the time, twenty people who call, about ten or twelve of them just call for reassurance like this is nothing wrong, this is alright," D5: (Doctor/Male 50-60)*

			"How they are going to face the treatment, few days ahead, how you will face, what changes will happen to patient and what should you do?" (Nurse4 Age 40-50) *"I still feel the best way to address it is to get people who have gone through it, show them the photograph, talk to them and make them talk. 'I have also gone through this hair loss and my hair is grown back'. That confidence cannot come from any amount of preaching, it has to be actually talked to with the person who has gone through it." (Doctor 5/Male 50-60)* *'Will I lose my hair doctor?' They say yes, they can only answer that. But if they add one more sentence like 'don't worry it will come back' it might be more reassuring to patient'.* (*Nurse 7 Age 40-50)*
Coping with diagnosis and treatment	Response to illness		*"encourage and support the patient to face the treatment bravely and help them to go through the illness." They should create a supportive environment for the patient; all these are needed for the patient". (Church 1 Age 60-70)* *"Also after staring chemotherapy we will really be fatigued, then we*

			have to take rest and the whole family needs to support them, else they the patient would be low in mood and lose all hope. Also because of the mental strain they will continue to go downhill. If the family are very supportive then the patient would get better quickly". (Church 9 Age70-80) *"they don't want to tell others they are cancer patients. ' how will public see me?' I will lose all my hair'. (Nurse 5 Age 60-70)* *"There was an author and college lecturer who used to go to college and say, I am a cancer patient, keep an eye in newspaper for my obituary. So the students only knew about it when she spoke about that. Else she was not looking like a cancer patient." (Nurse1 Age 50-60)* *"there was a patient who had breast cancer and had surgery, but her main concern was whether her husband would abandon her. As one*

			of her breasts is removed she was concern that her husband would leave her. The patient used to talk to me about it and cry about that". (Nurse 7 Age 40-50) *"they become better, get their hair back, wear breast supports such things are available now, then they become better and cope." (Church 1 Age 60-70)* *"Whereas there is another lady who is nearby , she after radiation, with no issues, went to temple with her husband daily, showing her power, for them , it will not come back again" (Volunteer1; 4 Age 40-50):*
	Sources of support	role of religion,role of volunteers lack of psychological	*"it is good for her children's sake point of view". Or "if she becomes depressed, same thing is going to affect children when they grow up if they ever have to face this again".(Doctor 1 Male/50-60)* *"automatically become more religious, pray to God more" (Nurse 10 Age 60-70)*

		support,social isolation lack of support from husband, partner support from other patients support from community support from medical personnel, motherhood importance of family role of religion impact of distant	*“then socially like neighbours, people whom we interact with are all very compassionate to cancer patients, they provide them with whatever assistance they can. With all that these patients cope. Then they all have acceptance and they accept it as their fate.” (Nurse 3 Age 30-40)* *“Generally the Indian women sacrifice a lot for the family and they always keep their priorities the last. I had a lady whose husband had rectal cancer, she actually did not reveal about her breast lump till her husband completed his full treatment, only after that she told me that doctor I want you to look at my breast lump, then I realised that it was a large lump and we have lost almost 4-5 months .” (Doctor 4 /Female 40-50)* *“Sometimes they are worried if their husbands will leave them and go away they have to spend a lot of money for their treatment, or they are worried about their kids and them wasting a lot of money. “They have just started their life and they are spending a lot of money for my treatment”. “it is better to die’. There are people who say like that. (Nurse 4 Age 40-50)*

		family lack of consistency in family support support from family	*"Probably it is so much easier in western countries to voice out your love or concern which is probably still a taboo in our country. I don't think there are too many husbands who go around saying, "no, don't worry. I love you, I am still here." I don't do it, so I don't know how the patient's might be doing it". (Doctor 2/Male/40-50)* *"People find solace in religion and spirituality. They look for prayer groups and attend that, they are consoled by people praying together. That will give them happiness. They will pray more." (Church 8 Age 40-50)* *"I have a cousin, he wouldn't even go to church but once the wife developed this condition, he started going to church, started praying for her, asked everyone to pray for his wife. Such husbands are also there". (Church 5 Age 60-70)* *"Even if somehow the treatment is done and it is successful, she thinks, this organ is given to me by God, I should not allow the God given body to be cut and parts removed. That is a religious view" (Volunteer2; 3 Age 40-50):*

8.14 Appendix 14 HYMS ethics application form

H·Y·M·S

THE HULL YORK
MEDICAL SCHOOL

HYMS ETHICS COMMITTEE

**APPLICATION FOR APPROVAL OF A PROJECT INVOLVING
HUMAN PARTICIPANTS, HUMAN DATA, OR HUMAN MATERIAL**

This application form is to be used by researchers seeking approval from the **HYMS Ethics Committee**.

Applications to HYMS Ethics Committee, with the specified attachments, should be **submitted electronically to: ethics@hyms.ac.uk**

RESEARCH MUST NOT BEGIN UNTIL ETHICAL APPROVAL HAS BEEN OBTAINED

Please complete every section, using N/A if appropriate.

Incomplete forms will be returned to the applicant.

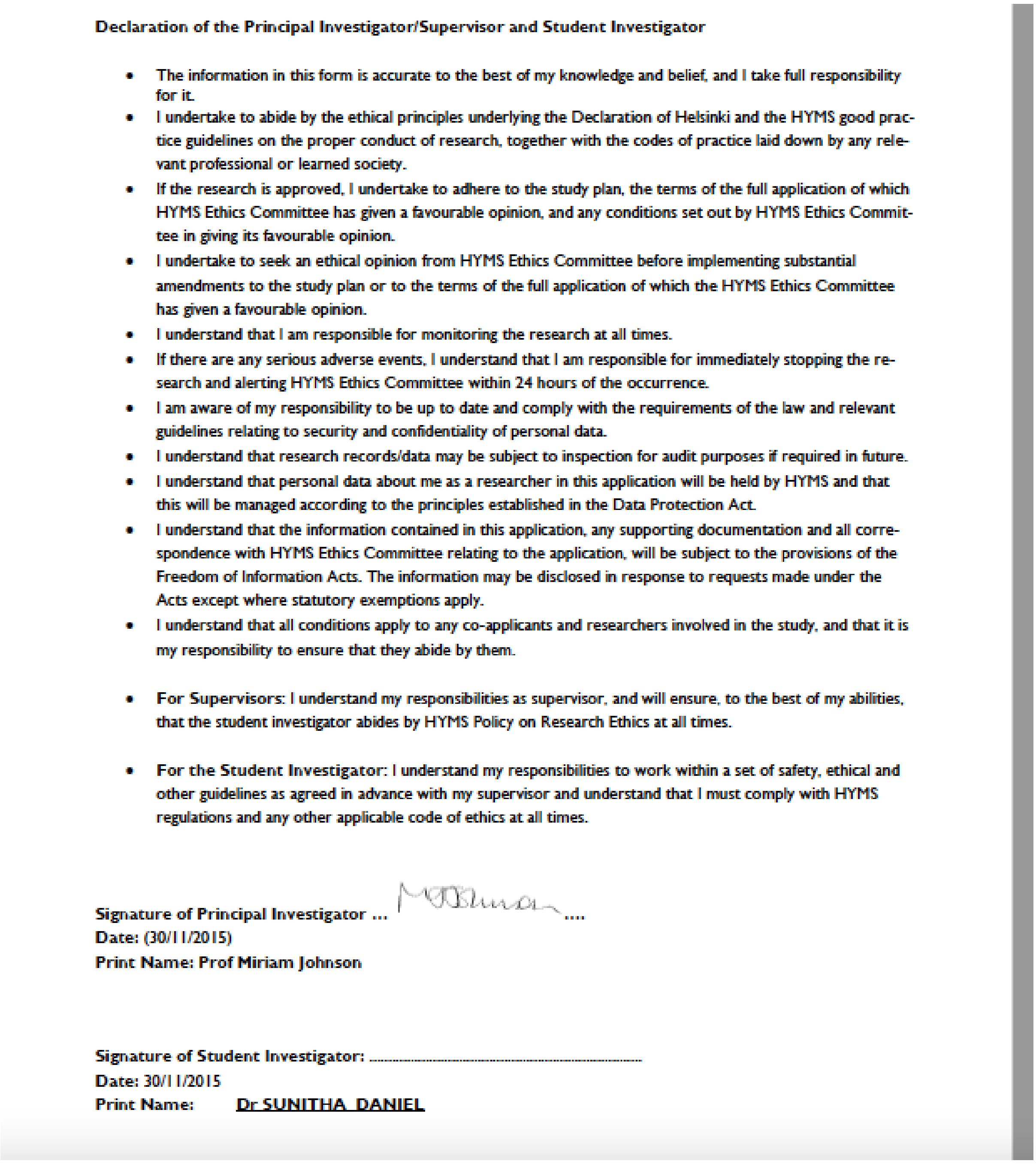
Office Use Only *(for final hard copies)*

Reference Number:
Date final copy received:

Approval decision:

- **Approved – no conditions** ☐
  - **Committee** ☐
  - **Chairs Action** ☐
  - **Expedited** ☐

- **Approved with conditions** ☐
  - **Committee** ☐
  - **Chairs Action** ☐
  - **Expedited** ☐



Declaration of the Principal Investigator/Supervisor and Student Investigator

- The information in this form is accurate to the best of my knowledge and belief, and I take full responsibility for it.
- I undertake to abide by the ethical principles underlying the Declaration of Helsinki and the HYMS good practice guidelines on the proper conduct of research, together with the codes of practice laid down by any relevant professional or learned society.
- If the research is approved, I undertake to adhere to the study plan, the terms of the full application of which HYMS Ethics Committee has given a favourable opinion, and any conditions set out by HYMS Ethics Committee in giving its favourable opinion.
- I undertake to seek an ethical opinion from HYMS Ethics Committee before implementing substantial amendments to the study plan or to the terms of the full application of which the HYMS Ethics Committee has given a favourable opinion.
- I understand that I am responsible for monitoring the research at all times.
- If there are any serious adverse events, I understand that I am responsible for immediately stopping the research and alerting HYMS Ethics Committee within 24 hours of the occurrence.
- I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- I understand that research records/data may be subject to inspection for audit purposes if required in future.
- I understand that personal data about me as a researcher in this application will be held by HYMS and that this will be managed according to the principles established in the Data Protection Act.
- I understand that the information contained in this application, any supporting documentation and all correspondence with HYMS Ethics Committee relating to the application, will be subject to the provisions of the Freedom of Information Acts. The information may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
- I understand that all conditions apply to any co-applicants and researchers involved in the study, and that it is my responsibility to ensure that they abide by them.

- **For Supervisors**: I understand my responsibilities as supervisor, and will ensure, to the best of my abilities, that the student investigator abides by HYMS Policy on Research Ethics at all times.

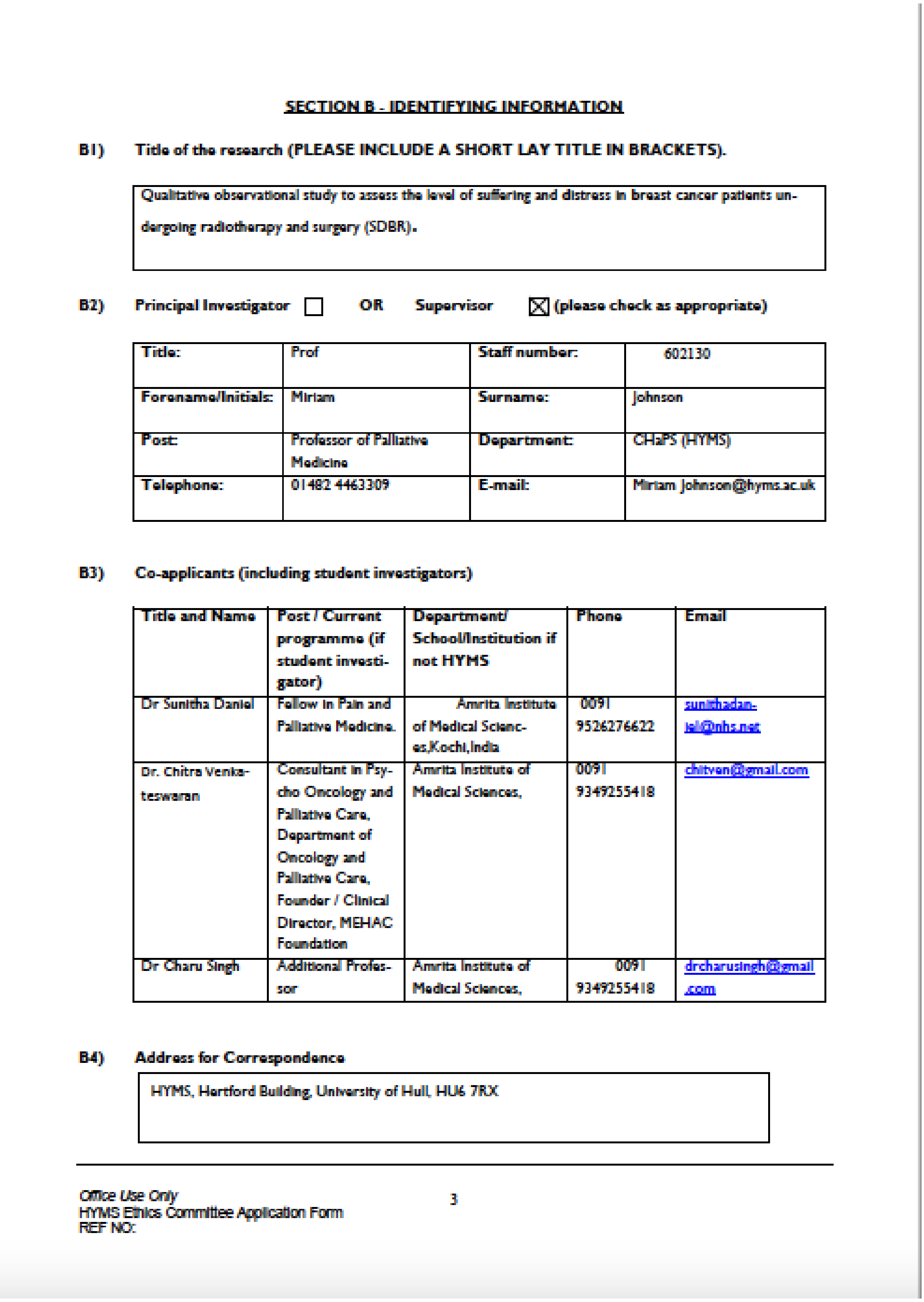
- **For the Student Investigator**: I understand my responsibilities to work within a set of safety, ethical and other guidelines as agreed in advance with my supervisor and understand that I must comply with HYMS regulations and any other applicable code of ethics at all times.

Signature of Principal Investigator … ….
Date: (30/11/2015)
Print Name: Prof Miriam Johnson

Signature of Student Investigator: ……………………………………………
Date: 30/11/2015
Print Name: **Dr SUNITHA DANIEL**

SECTION A - CHECKLIST OF ENCLOSURES

Study Plan / Protocol	√
Recruitment advertisement	
Participant information sheet	√
Participant Consent form	√
Research Participant Advocate Consent form	
Evidence of external approvals	
Questionnaires on sensitive topics	
Interview schedule	√
Debriefing material	
Other (please specify)	
Evidence of peer review (If H I = Yes)	



SECTION B - IDENTIFYING INFORMATION

B1) **Title of the research (PLEASE INCLUDE A SHORT LAY TITLE IN BRACKETS).**

Qualitative observational study to assess the level of suffering and distress in breast cancer patients undergoing radiotherapy and surgery (SDBR).

B2) **Principal Investigator** ☐ **OR** **Supervisor** ☒ **(please check as appropriate)**

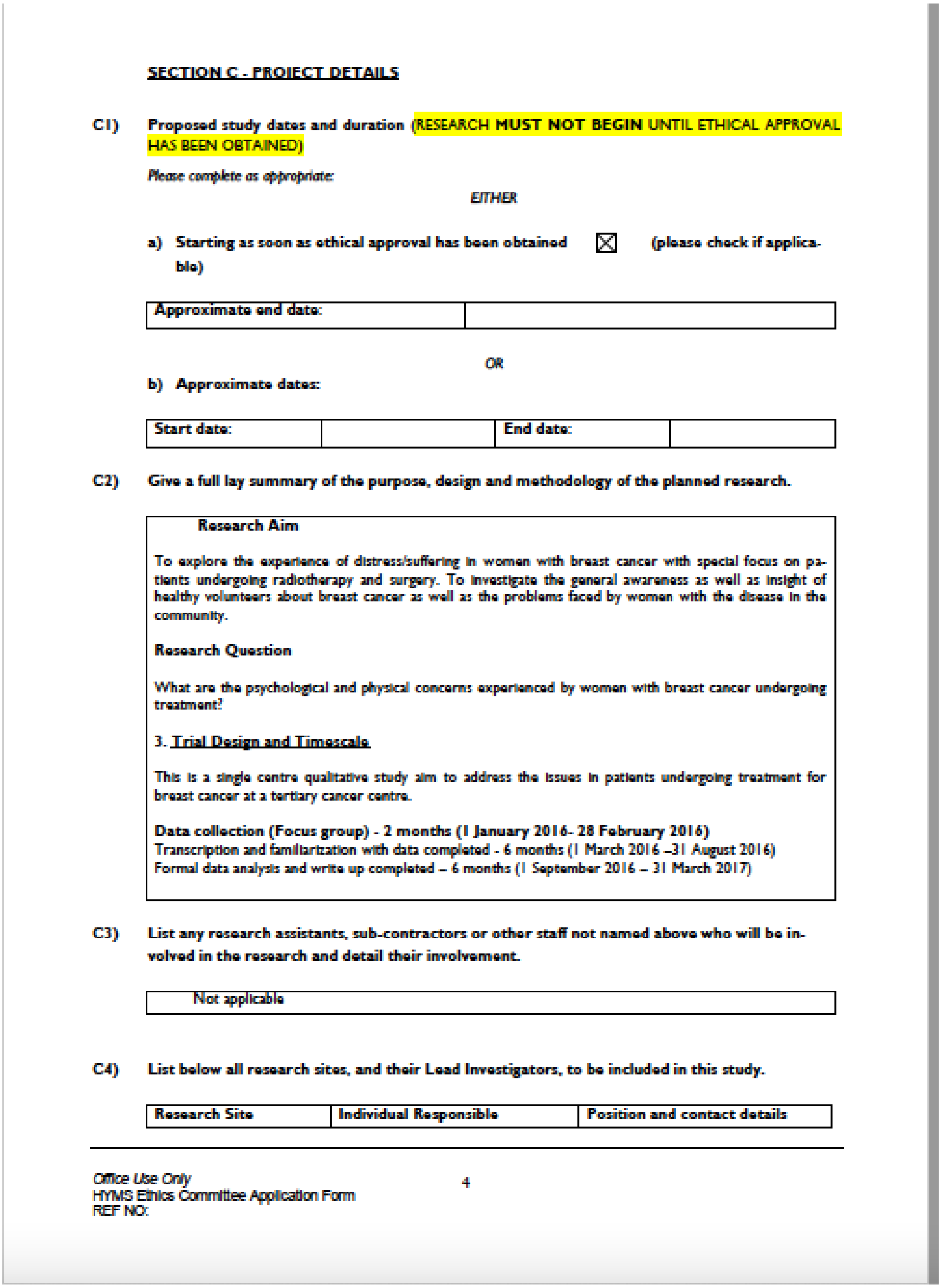
Title:	Prof	**Staff number:**	602130
Forename/Initials:	Miriam	**Surname:**	Johnson
Post:	Professor of Palliative Medicine	**Department:**	CHaPS (HYMS)
Telephone:	01482 4463309	**E-mail:**	Miriam Johnson@hyms.ac.uk

B3) **Co-applicants (including student investigators)**

Title and Name	**Post / Current programme (if student investigator)**	**Department/ School/Institution if not HYMS**	**Phone**	**Email**
Dr Sunitha Daniel	Fellow in Pain and Palliative Medicine.	Amrita Institute of Medical Sciences,Kochi,India	0091 9526276622	sunithadaniel@nhs.net
Dr. Chitra Venkateswaran	Consultant in Psycho Oncology and Palliative Care, Department of Oncology and Palliative Care, Founder / Clinical Director, MEHAC Foundation	Amrita Institute of Medical Sciences,	0091 9349255418	chitven@gmail.com
Dr Charu Singh	Additional Professor	Amrita Institute of Medical Sciences,	0091 9349255418	drcharusingh@gmail.com

B4) **Address for Correspondence**

HYMS, Hertford Building, University of Hull, HU6 7RX



SECTION C - PROJECT DETAILS

C1) **Proposed study dates and duration** (RESEARCH **MUST NOT BEGIN** UNTIL ETHICAL APPROVAL HAS BEEN OBTAINED)

Please complete as appropriate:

EITHER

a) Starting as soon as ethical approval has been obtained ☒ **(please check if applicable)**

Approximate end date:	

OR

b) Approximate dates:

Start date:		**End date:**	

C2) **Give a full lay summary of the purpose, design and methodology of the planned research.**

Research Aim

To explore the experience of distress/suffering in women with breast cancer with special focus on patients undergoing radiotherapy and surgery. To investigate the general awareness as well as insight of healthy volunteers about breast cancer as well as the problems faced by women with the disease in the community.

Research Question

What are the psychological and physical concerns experienced by women with breast cancer undergoing treatment?

3. Trial Design and Timescale

This is a single centre qualitative study aim to address the issues in patients undergoing treatment for breast cancer at a tertiary cancer centre.

Data collection (Focus group) - 2 months (1 January 2016- 28 February 2016)
Transcription and familiarization with data completed - 6 months (1 March 2016 –31 August 2016)
Formal data analysis and write up completed – 6 months (1 September 2016 – 31 March 2017)

C3) **List any research assistants, sub-contractors or other staff not named above who will be involved in the research and detail their involvement.**

Not applicable

C4) **List below all research sites, and their Lead Investigators, to be included in this study.**

Research Site	Individual Responsible	Position and contact details

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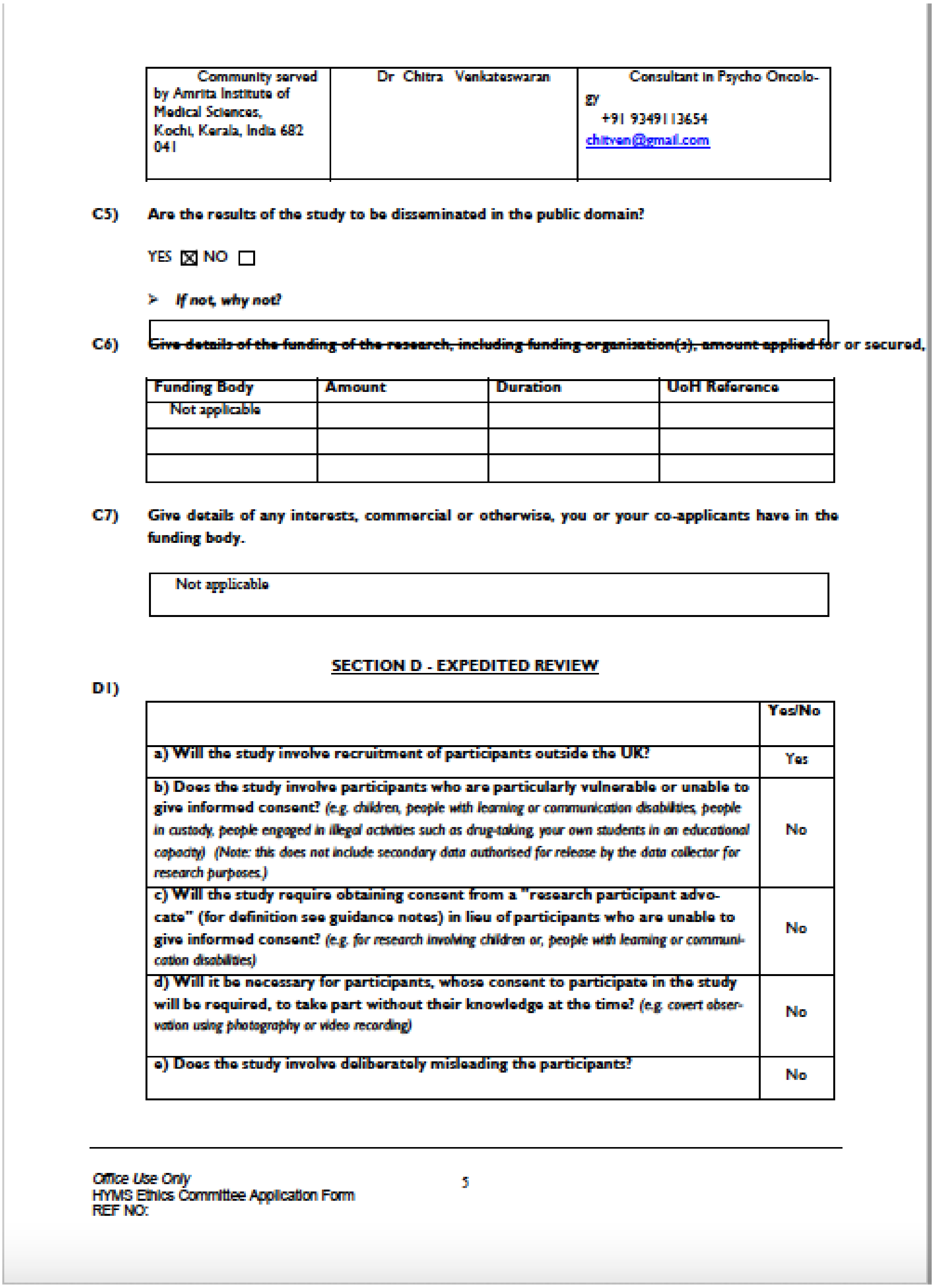


Community served by Amrita Institute of Medical Sciences, Kochi, Kerala, India 682 041	Dr Chitra Venkateswaran	Consultant in Psycho Oncology +91 9349113654 chitven@gmail.com

C5) **Are the results of the study to be disseminated in the public domain?**

YES ☒ NO ☐

➢ ***If not, why not?***

C6) ~~**Give details of the funding of the research, including funding organisation(s), amount applied fo**~~**r or secured,**

Funding Body	**Amount**	**Duration**	**UoH Reference**
Not applicable			

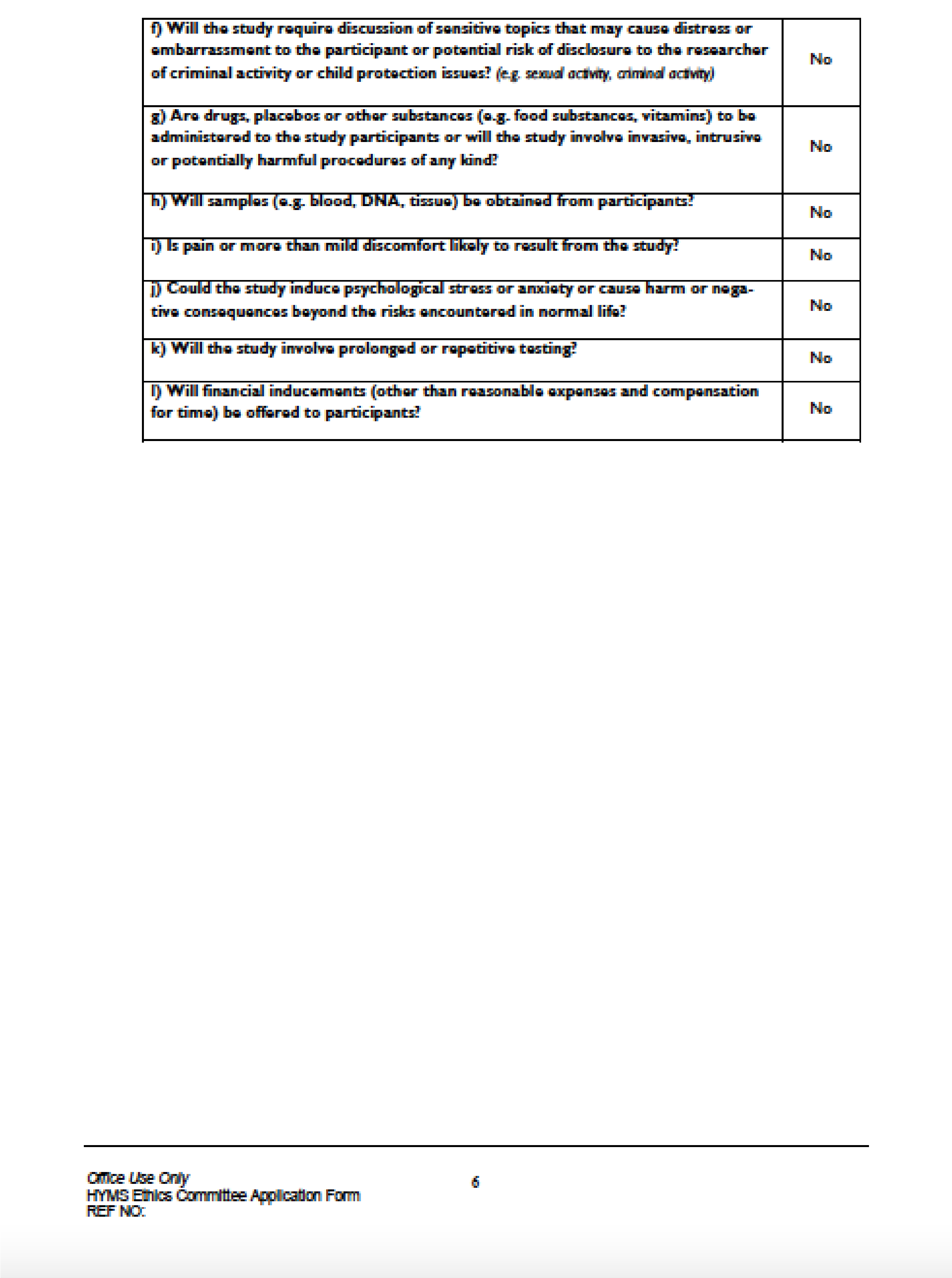
C7) **Give details of any interests, commercial or otherwise, you or your co-applicants have in the funding body.**

Not applicable

SECTION D - EXPEDITED REVIEW

D1)

	Yes/No
a) Will the study involve recruitment of participants outside the UK?	Yes
b) Does the study involve participants who are particularly vulnerable or unable to give informed consent? *(e.g. children, people with learning or communication disabilities, people in custody, people engaged in illegal activities such as drug-taking, your own students in an educational capacity) (Note: this does not include secondary data authorised for release by the data collector for research purposes.)*	No
c) Will the study require obtaining consent from a "research participant advocate" (for definition see guidance notes) in lieu of participants who are unable to give informed consent? *(e.g. for research involving children or, people with learning or communication disabilities)*	No
d) Will it be necessary for participants, whose consent to participate in the study will be required, to take part without their knowledge at the time? *(e.g. covert observation using photography or video recording)*	No
e) Does the study involve deliberately misleading the participants?	No



f) Will the study require discussion of sensitive topics that may cause distress or embarrassment to the participant or potential risk of disclosure to the researcher of criminal activity or child protection issues? *(e.g. sexual activity, criminal activity)*	**No**
g) Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	**No**
h) Will samples (e.g. blood, DNA, tissue) be obtained from participants?	**No**
i) Is pain or more than mild discomfort likely to result from the study?	**No**
j) Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	**No**
k) Will the study involve prolonged or repetitive testing?	**No**
l) Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?	**No**

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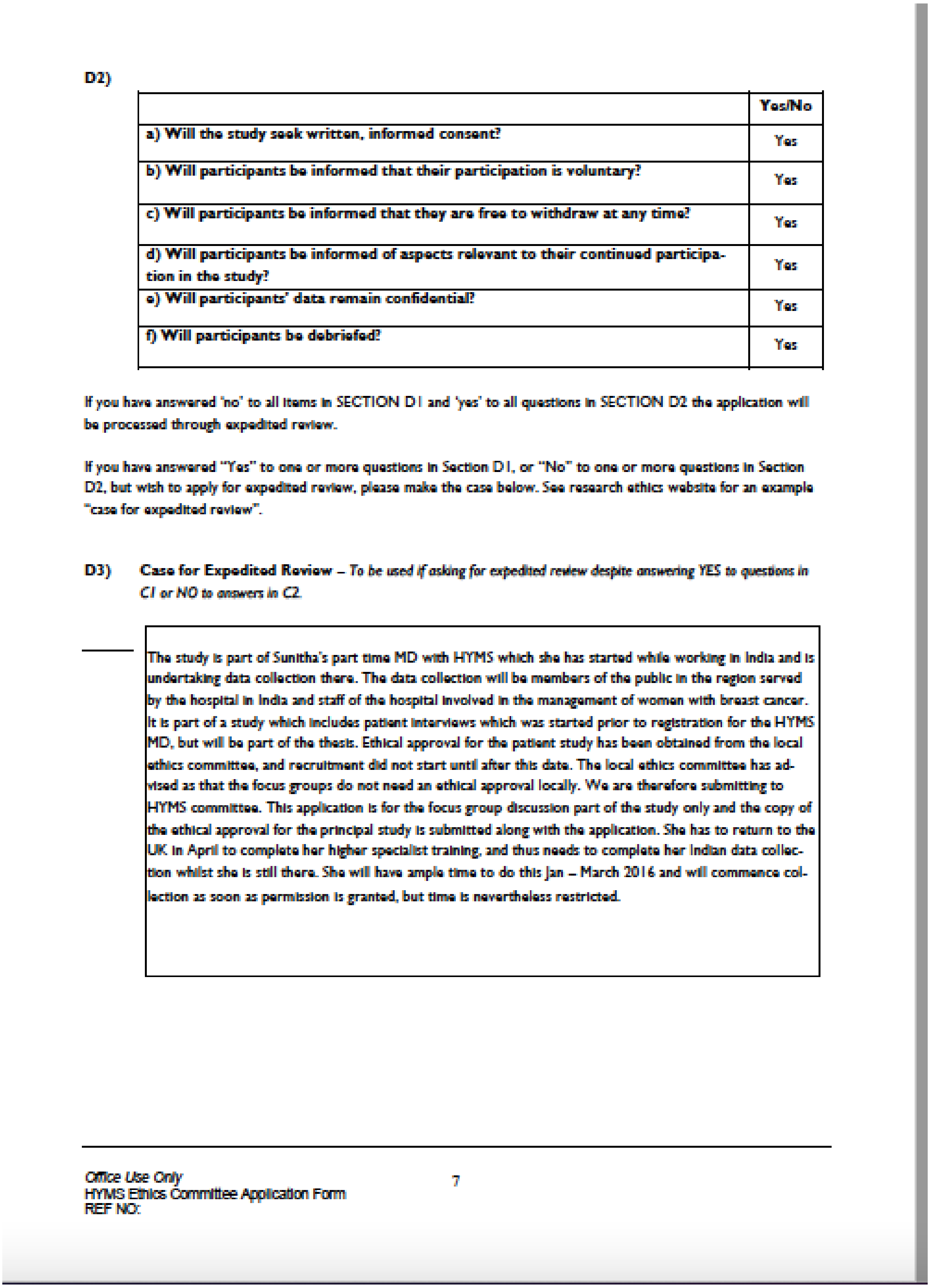

D2)

	Yes/No
a) Will the study seek written, informed consent?	Yes
b) Will participants be informed that their participation is voluntary?	Yes
c) Will participants be informed that they are free to withdraw at any time?	Yes
d) Will participants be informed of aspects relevant to their continued participation in the study?	Yes
e) Will participants' data remain confidential?	Yes
f) Will participants be debriefed?	Yes

If you have answered 'no' to all items in SECTION D1 and 'yes' to all questions in SECTION D2 the application will be processed through expedited review.

If you have answered "Yes" to one or more questions in Section D1, or "No" to one or more questions in Section D2, but wish to apply for expedited review, please make the case below. See research ethics website for an example "case for expedited review".

D3) **Case for Expedited Review** – *To be used if asking for expedited review despite answering YES to questions in C1 or NO to answers in C2.*

The study is part of Sunitha's part time MD with HYMS which she has started while working in India and is undertaking data collection there. The data collection will be members of the public in the region served by the hospital in India and staff of the hospital involved in the management of women with breast cancer. It is part of a study which includes patient interviews which was started prior to registration for the HYMS MD, but will be part of the thesis. Ethical approval for the patient study has been obtained from the local ethics committee, and recruitment did not start until after this date. The local ethics committee has advised as that the focus groups do not need an ethical approval locally. We are therefore submitting to HYMS committee. This application is for the focus group discussion part of the study only and the copy of the ethical approval for the principal study is submitted along with the application. She has to return to the UK in April to complete her higher specialist training, and thus needs to complete her Indian data collection whilst she is still there. She will have ample time to do this Jan – March 2016 and will commence collection as soon as permission is granted, but time is nevertheless restricted.

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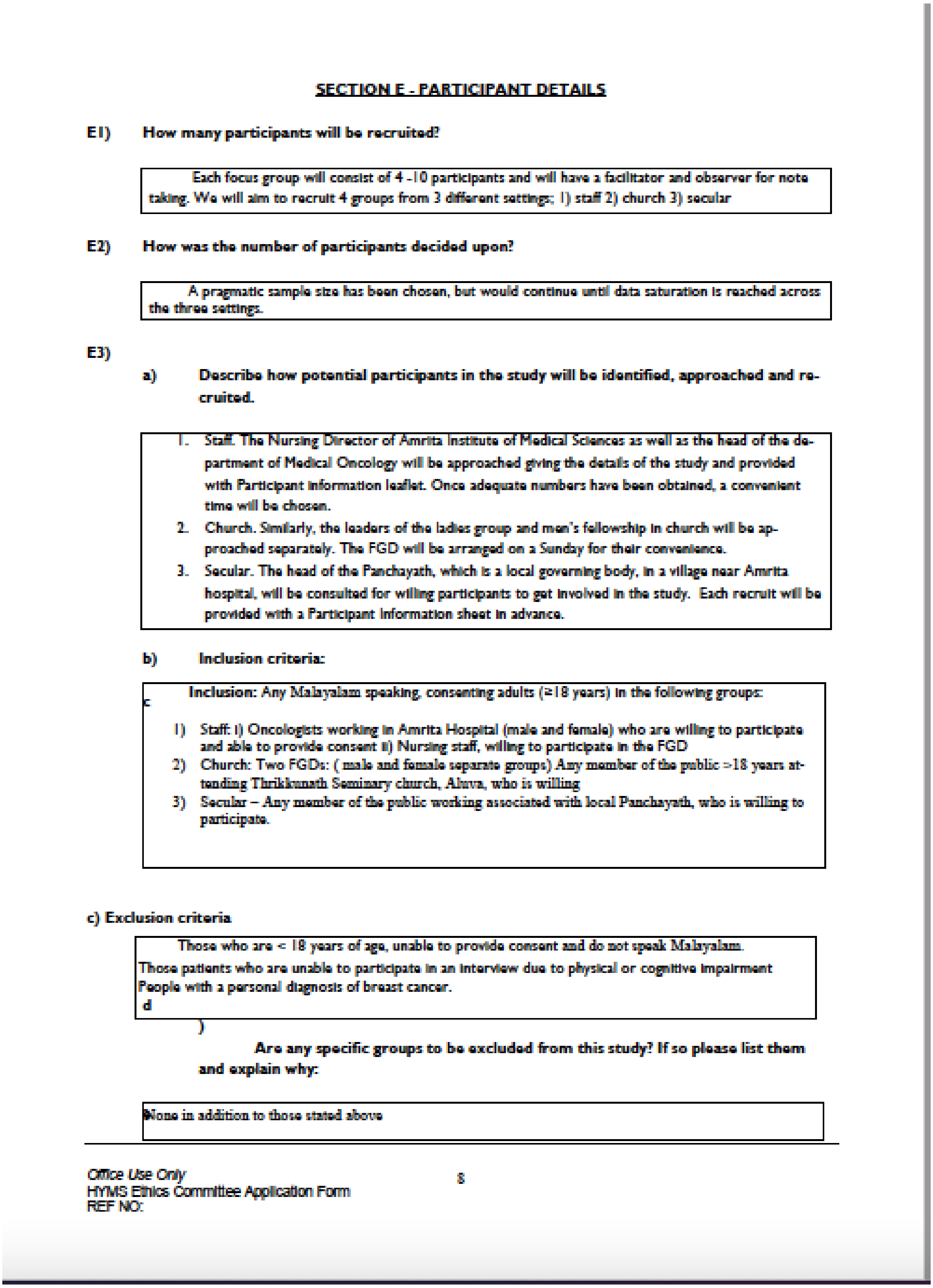


SECTION E - PARTICIPANT DETAILS

E1) How many participants will be recruited?

Each focus group will consist of 4 -10 participants and will have a facilitator and observer for note taking. We will aim to recruit 4 groups from 3 different settings; 1) staff 2) church 3) secular

E2) How was the number of participants decided upon?

A pragmatic sample size has been chosen, but would continue until data saturation is reached across the three settings.

E3)

a) Describe how potential participants in the study will be identified, approached and recruited.

1. Staff. The Nursing Director of Amrita Institute of Medical Sciences as well as the head of the department of Medical Oncology will be approached giving the details of the study and provided with Participant information leaflet. Once adequate numbers have been obtained, a convenient time will be chosen.
2. Church. Similarly, the leaders of the ladies group and men's fellowship in church will be approached separately. The FGD will be arranged on a Sunday for their convenience.
3. Secular. The head of the Panchayath, which is a local governing body, in a village near Amrita hospital, will be consulted for willing participants to get involved in the study. Each recruit will be provided with a Participant Information sheet in advance.

b) Inclusion criteria:

c

Inclusion: Any Malayalam speaking, consenting adults (≥18 years) in the following groups:

1) Staff: i) Oncologists working in Amrita Hospital (male and female) who are willing to participate and able to provide consent ii) Nursing staff, willing to participate in the FGD
2) Church: Two FGDs: (male and female separate groups) Any member of the public >18 years attending Thrikkunath Seminary church, Aluva, who is willing
3) Secular – Any member of the public working associated with local Panchayath, who is willing to participate.

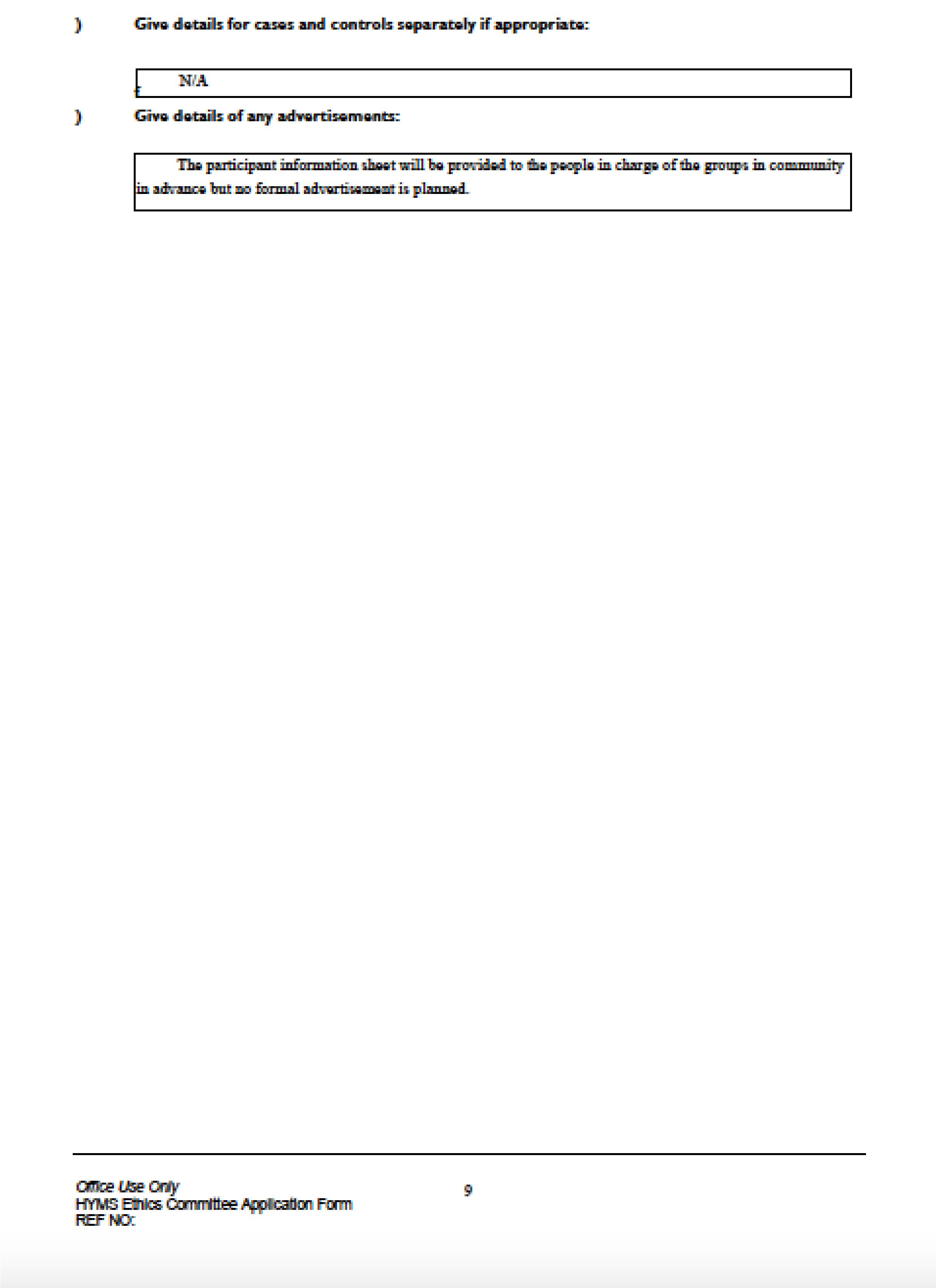
c) Exclusion criteria

Those who are < 18 years of age, unable to provide consent and do not speak Malayalam.
Those patients who are unable to participate in an interview due to physical or cognitive impairment
People with a personal diagnosis of breast cancer.
d

)

Are any specific groups to be excluded from this study? If so please list them and explain why:

None in addition to those stated above

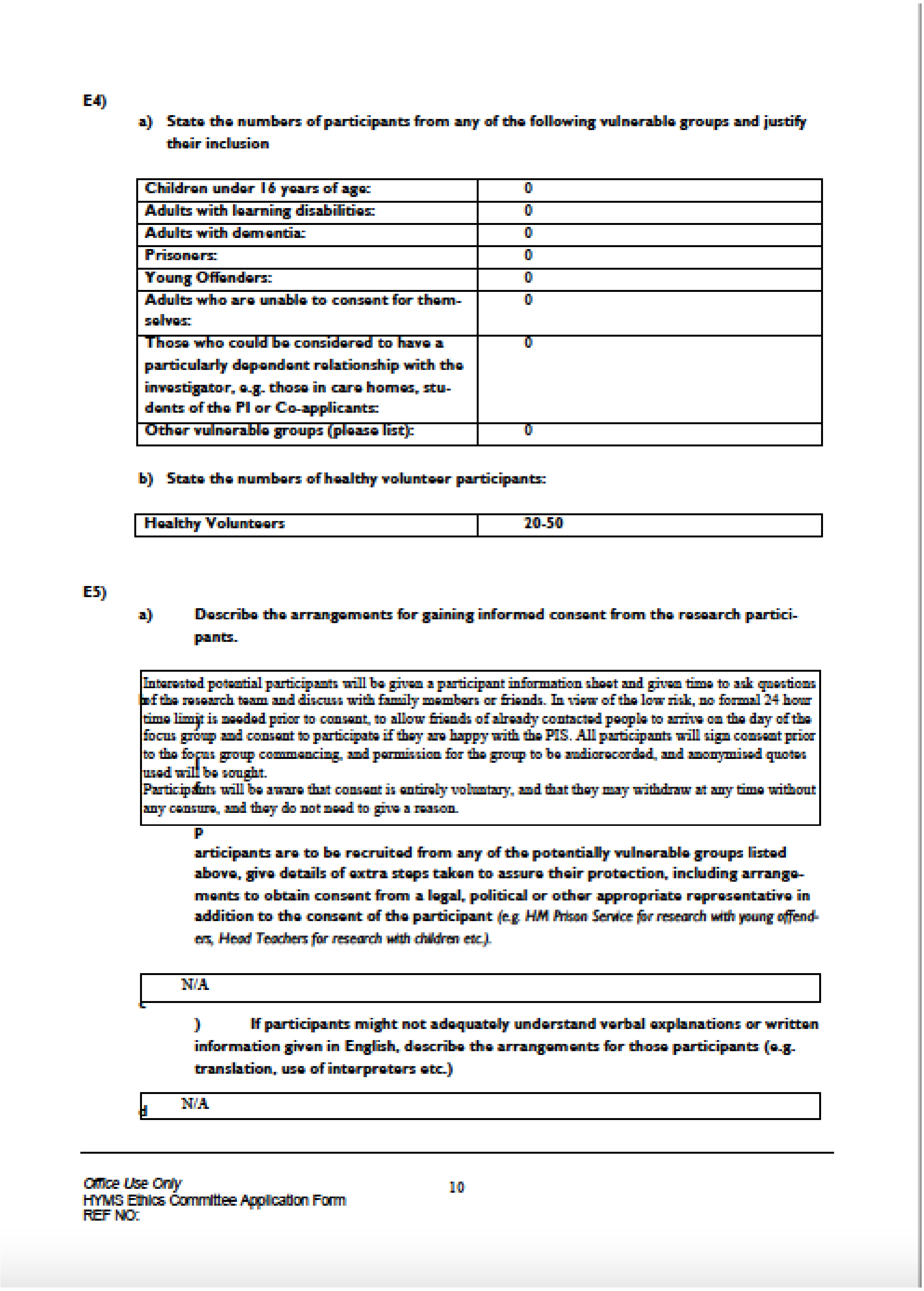


) **Give details for cases and controls separately if appropriate:**

f N/A

) **Give details of any advertisements:**

The participant information sheet will be provided to the people in charge of the groups in community in advance but no formal advertisement is planned.



E4)

a) State the numbers of participants from any of the following vulnerable groups and justify their inclusion

Children under 16 years of age:	0
Adults with learning disabilities:	0
Adults with dementia:	0
Prisoners:	0
Young Offenders:	0
Adults who are unable to consent for themselves:	0
Those who could be considered to have a particularly dependent relationship with the investigator, e.g. those in care homes, students of the PI or Co-applicants:	0
Other vulnerable groups (please list):	0

b) State the numbers of healthy volunteer participants:

Healthy Volunteers	20-50

E5)

a) Describe the arrangements for gaining informed consent from the research participants.

Interested potential participants will be given a participant information sheet and given time to ask questions of the research team and discuss with family members or friends. In view of the low risk, no formal 24 hour time limit is needed prior to consent, to allow friends of already contacted people to arrive on the day of the focus group and consent to participate if they are happy with the PIS. All participants will sign consent prior to the focus group commencing, and permission for the group to be audiorecorded, and anonymised quotes used will be sought.
Participants will be aware that consent is entirely voluntary, and that they may withdraw at any time without any censure, and they do not need to give a reason.

P

articipants are to be recruited from any of the potentially vulnerable groups listed above, give details of extra steps taken to assure their protection, including arrangements to obtain consent from a legal, political or other appropriate representative in addition to the consent of the participant *(e.g. HM Prison Service for research with young offenders, Head Teachers for research with children etc.).*

N/A

c

) If participants might not adequately understand verbal explanations or written information given in English, describe the arrangements for those participants (e.g. translation, use of interpreters etc.)

d N/A

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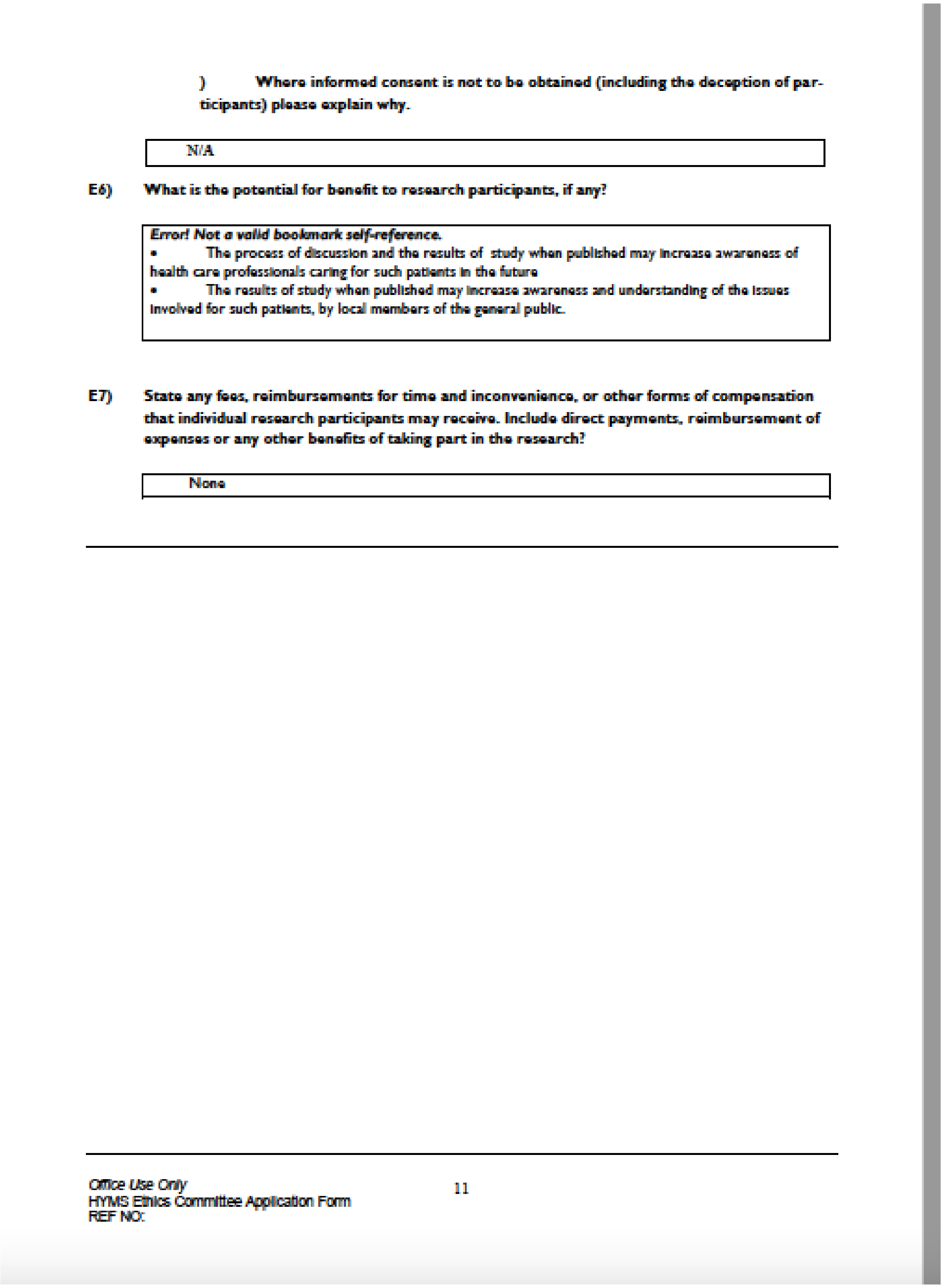

)   Where informed consent is not to be obtained (including the deception of participants) please explain why.

N/A

E6)   What is the potential for benefit to research participants, if any?

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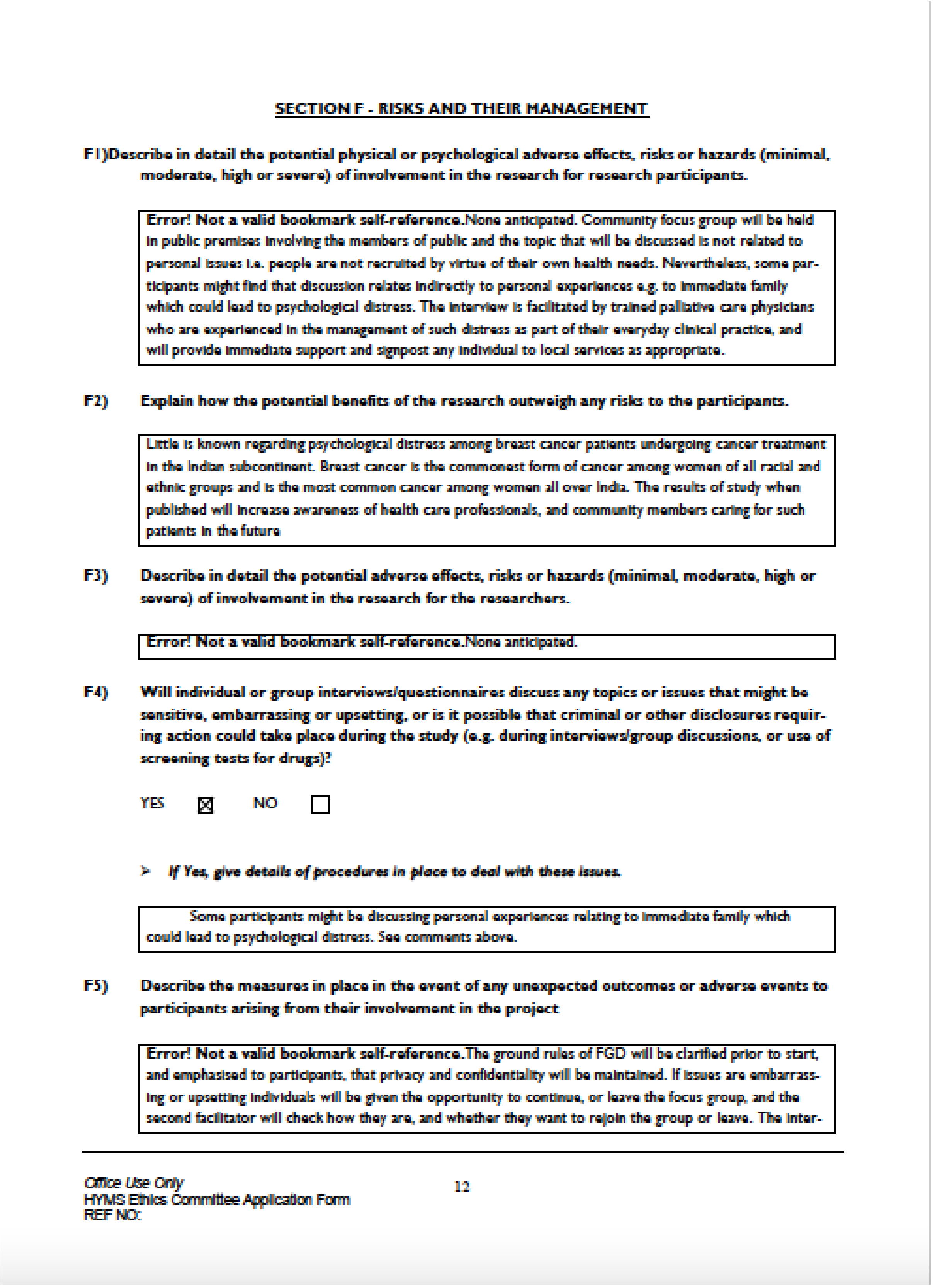
- The process of discussion and the results of study when published may increase awareness of health care professionals caring for such patients in the future
- The results of study when published may increase awareness and understanding of the issues involved for such patients, by local members of the general public.

E7)   State any fees, reimbursements for time and inconvenience, or other forms of compensation that individual research participants may receive. Include direct payments, reimbursement of expenses or any other benefits of taking part in the research?

None



SECTION F - RISKS AND THEIR MANAGEMENT

F1)Describe in detail the potential physical or psychological adverse effects, risks or hazards (minimal, moderate, high or severe) of involvement in the research for research participants.

Error! Not a valid bookmark self-reference. None anticipated. Community focus group will be held in public premises involving the members of public and the topic that will be discussed is not related to personal issues i.e. people are not recruited by virtue of their own health needs. Nevertheless, some participants might find that discussion relates indirectly to personal experiences e.g. to immediate family which could lead to psychological distress. The interview is facilitated by trained palliative care physicians who are experienced in the management of such distress as part of their everyday clinical practice, and will provide immediate support and signpost any individual to local services as appropriate.

F2) Explain how the potential benefits of the research outweigh any risks to the participants.

Little is known regarding psychological distress among breast cancer patients undergoing cancer treatment in the Indian subcontinent. Breast cancer is the commonest form of cancer among women of all racial and ethnic groups and is the most common cancer among women all over India. The results of study when published will increase awareness of health care professionals, and community members caring for such patients in the future

F3) Describe in detail the potential adverse effects, risks or hazards (minimal, moderate, high or severe) of involvement in the research for the researchers.

Error! Not a valid bookmark self-reference. None anticipated.

F4) Will individual or group interviews/questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews/group discussions, or use of screening tests for drugs)?

YES ☒ NO ☐

- ***If Yes, give details of procedures in place to deal with these issues.***

Some participants might be discussing personal experiences relating to immediate family which could lead to psychological distress. See comments above.

F5) Describe the measures in place in the event of any unexpected outcomes or adverse events to participants arising from their involvement in the project

Error! Not a valid bookmark self-reference. The ground rules of FGD will be clarified prior to start, and emphasised to participants, that privacy and confidentiality will be maintained. If issues are embarrassing or upsetting individuals will be given the opportunity to continue, or leave the focus group, and the second facilitator will check how they are, and whether they want to rejoin the group or leave. The inter-

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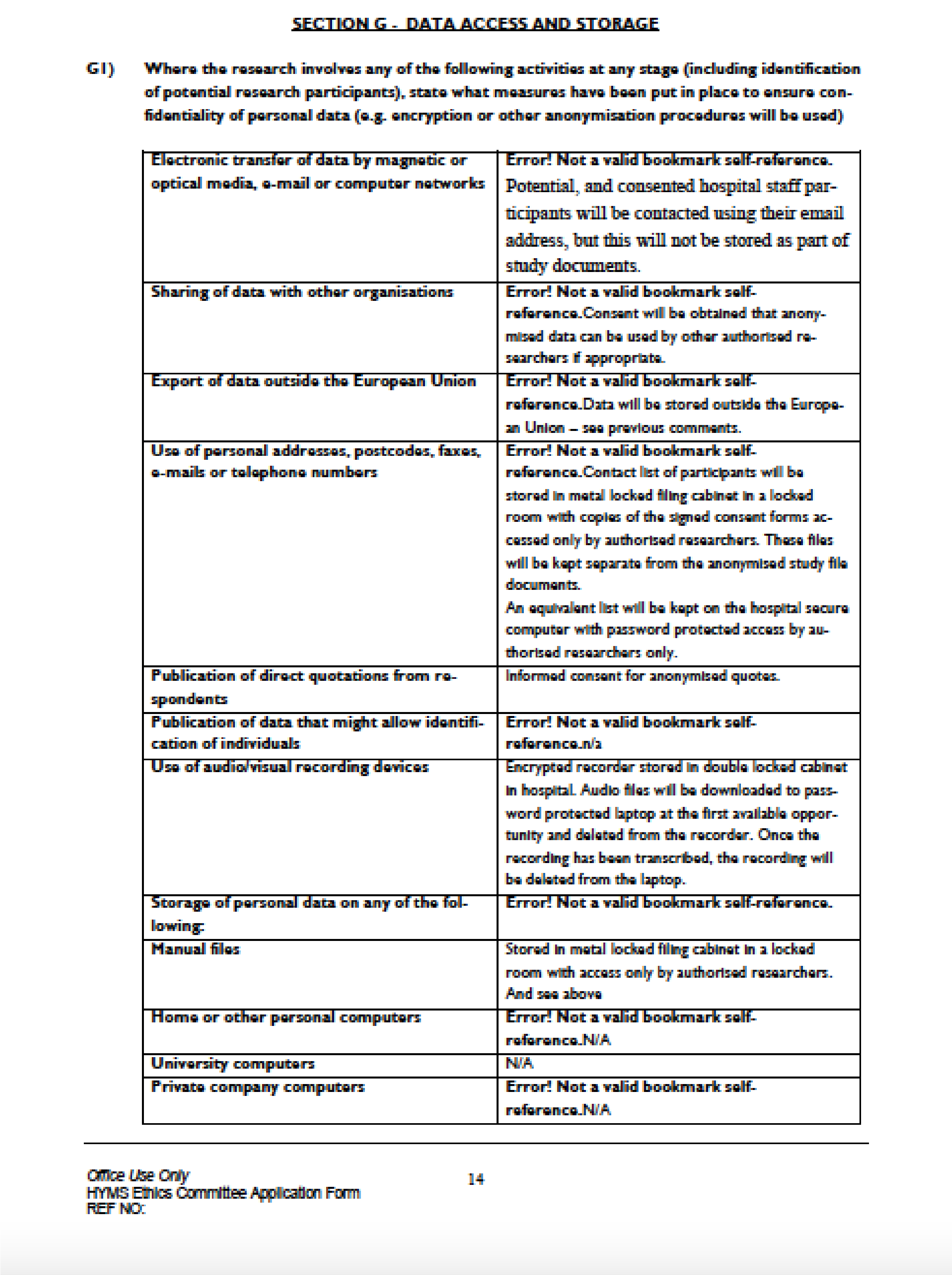
view is facilitated by trained palliative care physicians who are experienced in the management of such distress as part of their everyday clinical practice, and will provide immediate support and signpost any individual to local services as appropriate.

F6) Explain how the conduct of the project will be monitored to ensure that it conforms with the study plan and relevant University policies and guidance.

The project will be conducted as part of MD project under the regular guidance of thesis advisory panel.



SECTION G - DATA ACCESS AND STORAGE

G1) **Where the research involves any of the following activities at any stage (including identification of potential research participants), state what measures have been put in place to ensure confidentiality of personal data (e.g. encryption or other anonymisation procedures will be used)**

Electronic transfer of data by magnetic or optical media, e-mail or computer networks	**Error! Not a valid bookmark self-reference.** Potential, and consented hospital staff participants will be contacted using their email address, but this will not be stored as part of study documents.
Sharing of data with other organisations	**Error! Not a valid bookmark self-reference.**Consent will be obtained that anonymised data can be used by other authorised researchers if appropriate.
Export of data outside the European Union	**Error! Not a valid bookmark self-reference.**Data will be stored outside the European Union – see previous comments.
Use of personal addresses, postcodes, faxes, e-mails or telephone numbers	**Error! Not a valid bookmark self-reference.**Contact list of participants will be stored in metal locked filing cabinet in a locked room with copies of the signed consent forms accessed only by authorised researchers. These files will be kept separate from the anonymised study file documents. An equivalent list will be kept on the hospital secure computer with password protected access by authorised researchers only.
Publication of direct quotations from respondents	Informed consent for anonymised quotes.
Publication of data that might allow identification of individuals	**Error! Not a valid bookmark self-reference.**n/a
Use of audio/visual recording devices	Encrypted recorder stored in double locked cabinet in hospital. Audio files will be downloaded to password protected laptop at the first available opportunity and deleted from the recorder. Once the recording has been transcribed, the recording will be deleted from the laptop.
Storage of personal data on any of the following:	**Error! Not a valid bookmark self-reference.**
Manual files	Stored in metal locked filing cabinet in a locked room with access only by authorised researchers. And see above
Home or other personal computers	**Error! Not a valid bookmark self-reference.**N/A
University computers	N/A
Private company computers	**Error! Not a valid bookmark self-reference.**N/A

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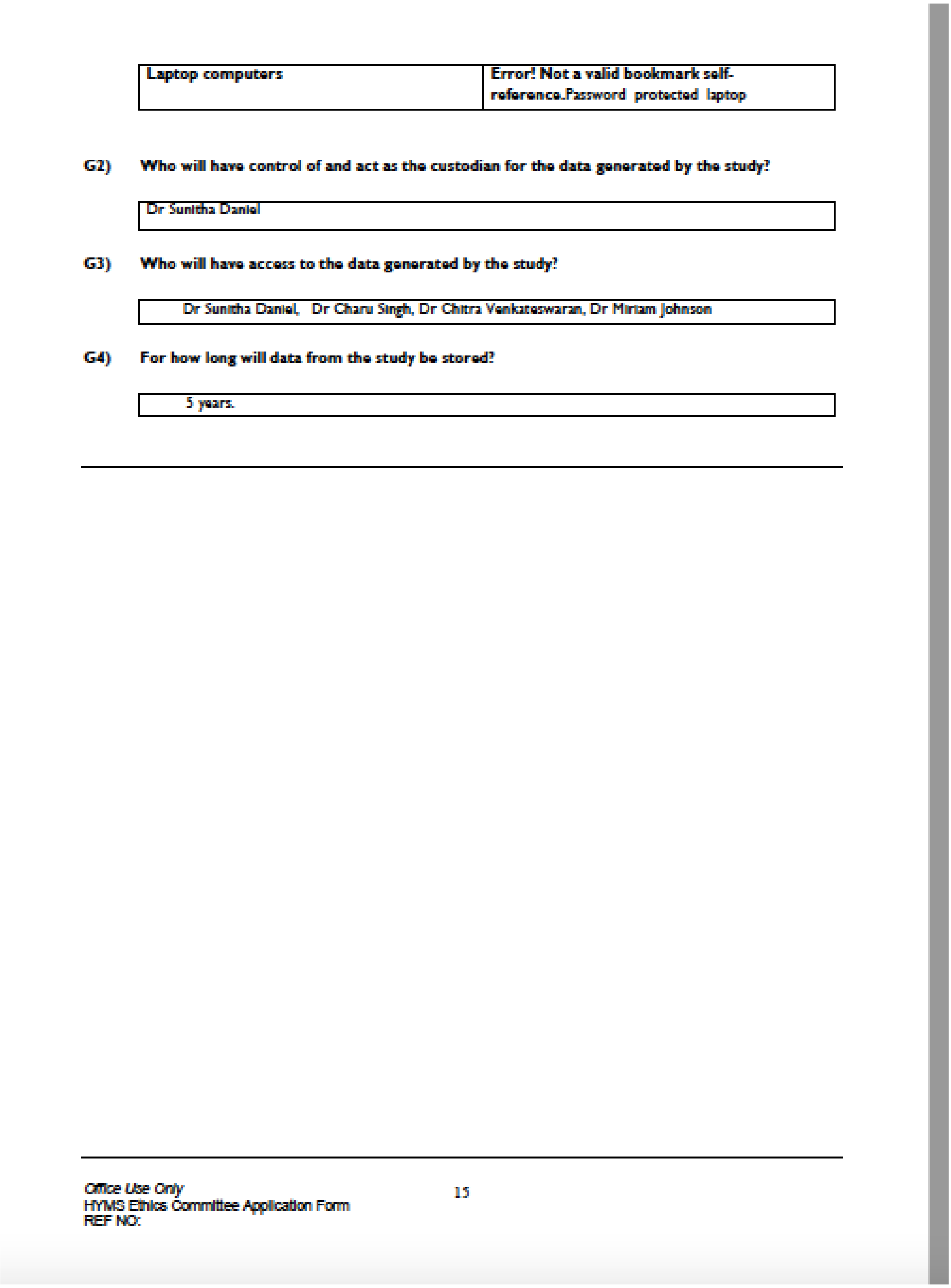


Laptop computers	**Error! Not a valid bookmark self-reference.**Password protected laptop

G2) **Who will have control of and act as the custodian for the data generated by the study?**

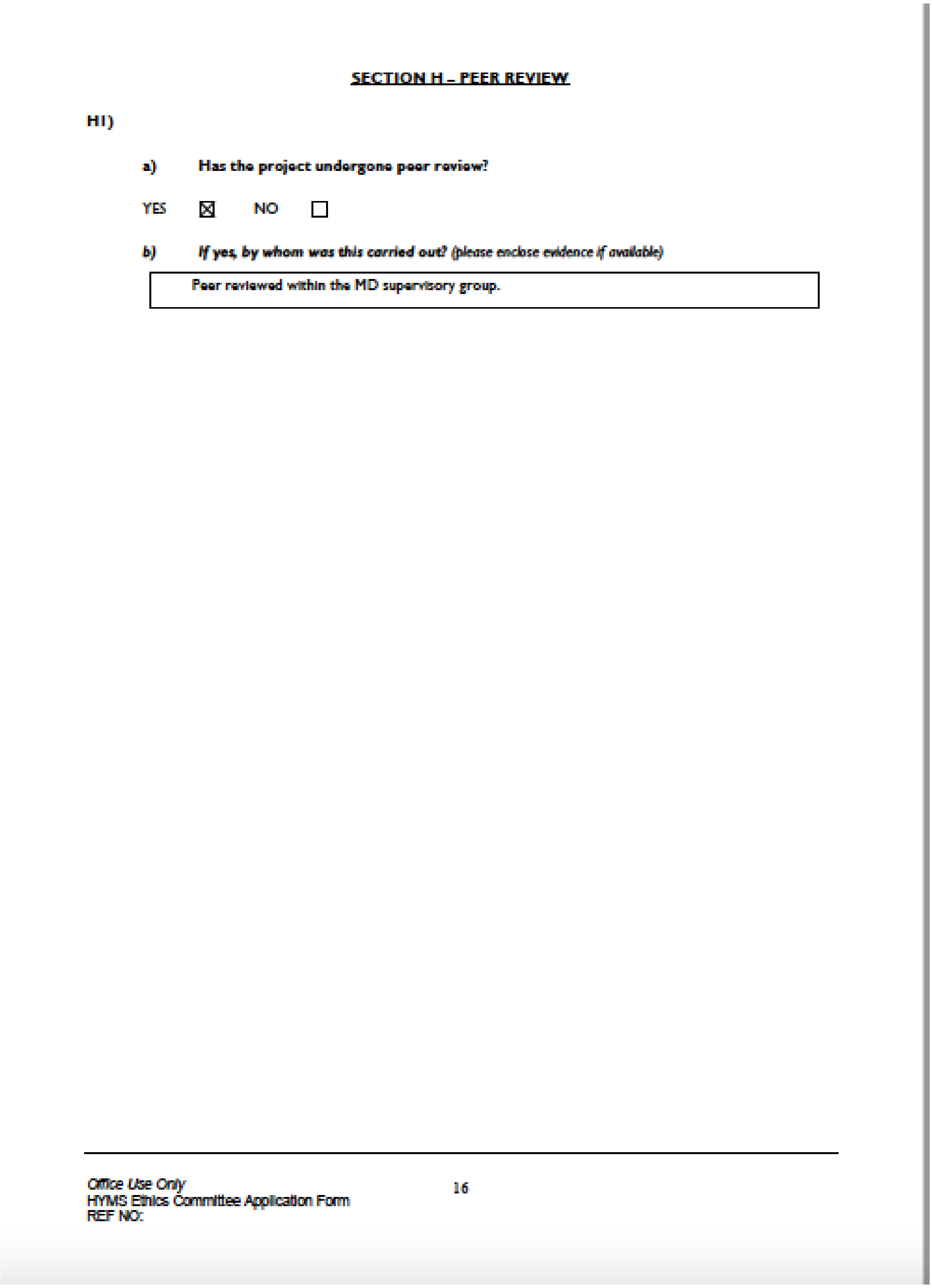
Dr Sunitha Daniel

G3) **Who will have access to the data generated by the study?**

Dr Sunitha Daniel, Dr Charu Singh, Dr Chitra Venkateswaran, Dr Miriam Johnson

G4) **For how long will data from the study be stored?**

5 years.



SECTION H – PEER REVIEW

H1)

a) **Has the project undergone peer review?**

YES ☒ NO ☐

b) ***If yes, by whom was this carried out?*** *(please enclose evidence if available)*

Peer reviewed within the MD supervisory group.