

Title: A systematic review of the psychological concerns of Indian women with breast cancer living in different national contexts: the importance of culturally congruent care

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Key words: Breast neoplasms; Stress, psychological, distress, Indian, Transients and Migrants

Word count: 6222 (including quotations)

Abstract

Background: Breast cancer is becoming the most common cancer among women of Indian origin. Little is known about the psychological impact of the disease and its treatment among this population.

Aim: To improve understanding of psychological symptoms of Indian women with breast cancer.

Design: Systematic literature review and critical interpretative synthesis. Searches (7 May 2019;) used MeSH terms and keywords for breast cancer, psychological symptoms and treatment. Reference lists of included articles were examined. Search results were screened against inclusion criteria, data extracted, quality appraised by two independent researchers, with recourse to a third. Narrative (quantitative) and thematic qualitative syntheses were applied followed by critical interpretative synthesis.

Data sources: ProQuest; MEDLINE; Ovid EMBASE; EBSCO; CINAHL; PsycINFO

Results: 18/763 studies from India or Canada were included (13 quantitative; 5 qualitative). Critical interpretative synthesis found similar psychological concerns to “Western” women, but were framed by the common culture of Indian women in either country. Family structure, religion and community appears to protect against and cause distress in relation to the expected core roles of wife and mother, and male-dominance in decision-making. Stigma was amplified by poor knowledge about the nature of cancer. Migrant Indian women had additional problems due to language barriers.

Conclusions: Indian women with breast cancer living in India and Canada experience psychological morbidities which profoundly affect their role in the family and wider community. Culturally congruent care including accessible communication and information may help prevent and alleviate distressing symptoms whether in India or as part of a migrant community.

Introduction

Breast cancer is the most common form of cancer among women of all racial and ethnic groups both in the Global North and the South.¹ According to World Health Organization's Global health estimates published in 2013, over 508,000 women died in 2011 due to breast cancer worldwide.² Psychological symptoms are common in women diagnosed with breast cancer including distress associated with cancer diagnosis, fear of relapse or death, body image issues and treatment related effects.³ Addressing psychological concerns of patients with breast cancer is important to improve quality of life. In addition, psychological symptoms may impact upon survival rates. Patients diagnosed with depression are three times less likely to adhere to treatment regimens as compared to those without depression.⁴ The present treatment modality 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.⁵ Breast cancer is becoming the most common cancer among women in India, accounting for about one-quarter of all the cancers in Indian women, and about half of all cancer-related deaths. These numbers increase when migrant Indian women living in other countries are included.⁶ According to the United Nations International Migration report of 2015, India had the largest "diaspora" in the world with 16 million people living in different parts of the world and women of Indian origin are an important group of migrants.⁷ Therefore, breast cancer affects Indian women all around the world. This is important as women from diverse cultural backgrounds may have differences in cancer care experiences which may be heightened for women who migrate.

Psychological symptoms can be influenced by migrants' level of acculturation (psychosocial adjustment and adaptation to the new culture).⁸ For example, Chinese immigrant breast cancer survivors are known to be at greater risk of distress compared to US-born Chinese survivors.⁹ However, the extent to which Indian women experience psychological symptoms during breast cancer treatment is poorly understood and little is known about how these experiences may differ for migrant Indian women. It is therefore important to understand

the diverse needs of Indian women living in distinct national contexts, both “at home” and on migration, to inform cancer supportive care delivery.

Aim

We undertook a systematic literature review to improve understanding and raise awareness of psychological symptoms of Indian breast cancer patients in relation to treatment and the factors which helped or aggravated distress.

Methods

Search strategy

An initial scoping search of the literature did not yield any reviews of this particular population group. The following databases were then searched, from inception to 7 May 2019: ProQuest MEDLINE; Ovid EMBASE; EBSCO; CINAHL; PsycINFO. MeSH terms and text words, including both US and UK spellings for breast cancer, psychological symptoms and treatment (see Supplementary Table 3) were used, and tailored to each database. The EBSCO host discovery science database was searched on the advice of the librarian at Amrita Institute of Medical Sciences and Research Centre to search for papers in Indian journals inaccessible from the other databases. This search included Indian regional languages (Hindi, Bengali, Malayalam, Punjabi, Sanskrit, Marathi and Urdu) as we were exploring the experience of Indian women. Other searches were limited to English language articles. Reference sections of relevant review articles and included studies were also scanned to identify additional eligible studies.

Inclusion criteria

Studies describing adult women of Indian origin with breast cancer living within and outside the Indian subcontinent who were currently undergoing and those who had undergone any treatment modality for breast cancer and which described or measured the psychological concerns of the study participants were included. Both qualitative studies and quantitative observational studies reporting psychological concerns were included.

Exclusion criteria

Single case history reports, reviews, opinion pieces, experimental or quasi-experimental studies, conference abstracts were excluded. Studies of male breast cancer patients or children were excluded. Studies of effects of treatment for other primary tumours and studies reporting physical adverse outcomes only were excluded. List of all the excluded studies are given in Supplementary Table 6

Study selection

The titles, abstracts and full studies were screened by two independent researchers (SD and JC) against the inclusion criteria. Disagreement was resolved by discussion with access to a third opinion (MJ). Studies that matched the selection criteria were retrieved and their full text version assessed. Results of all the searches were managed using Endnote basic reference management software (EndNote X9)¹⁰ and duplicate reports deleted.

Quality appraisal

Observational studies were appraised using the **Strengthening the Reporting of Observational studies in Epidemiology (STROBE)** checklist¹¹. (See Supplementary Table 5) Although this is designed as a reporting rather than an appraisal tool, we 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 **Critical Appraisals Skills Programme (CASP)** (See Supplementary Table 4) checklist for qualitative studies.¹² Findings were tabulated to demonstrate the key strengths and weaknesses in study design.

Data extraction

The data extraction tool was developed based on the Cochrane Handbook Checklist,¹³ and data independently extracted the included studies by SD and SG. A separate table was developed for quantitative and qualitative studies and piloted in two studies.

Data analysis

Quantitative data were described, tabulating design, participants and main findings and then findings were brought together in a narrative synthesis summarising findings and exploring relationships between and within studies along with quality appraisal of the

robustness of the findings.¹⁴ Qualitative data were subjected to thematic synthesis to form generalizable findings whilst taking the context of each study into account.¹⁵ Direct quotes from patients and researcher comments on the findings were extracted for coding. SD familiarised herself with the data, and then conducted line by line coding of the primary articles. A coding framework was formed following discussion with MJ which SD then used to code all qualitative papers. Descriptive and analytical themes were formed from the codes in discussion with MJ and SD. 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.¹⁶ A theoretical framework (Cultural Distress) was used to inform the analytic themes and final discussion.¹⁷ 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.¹⁸

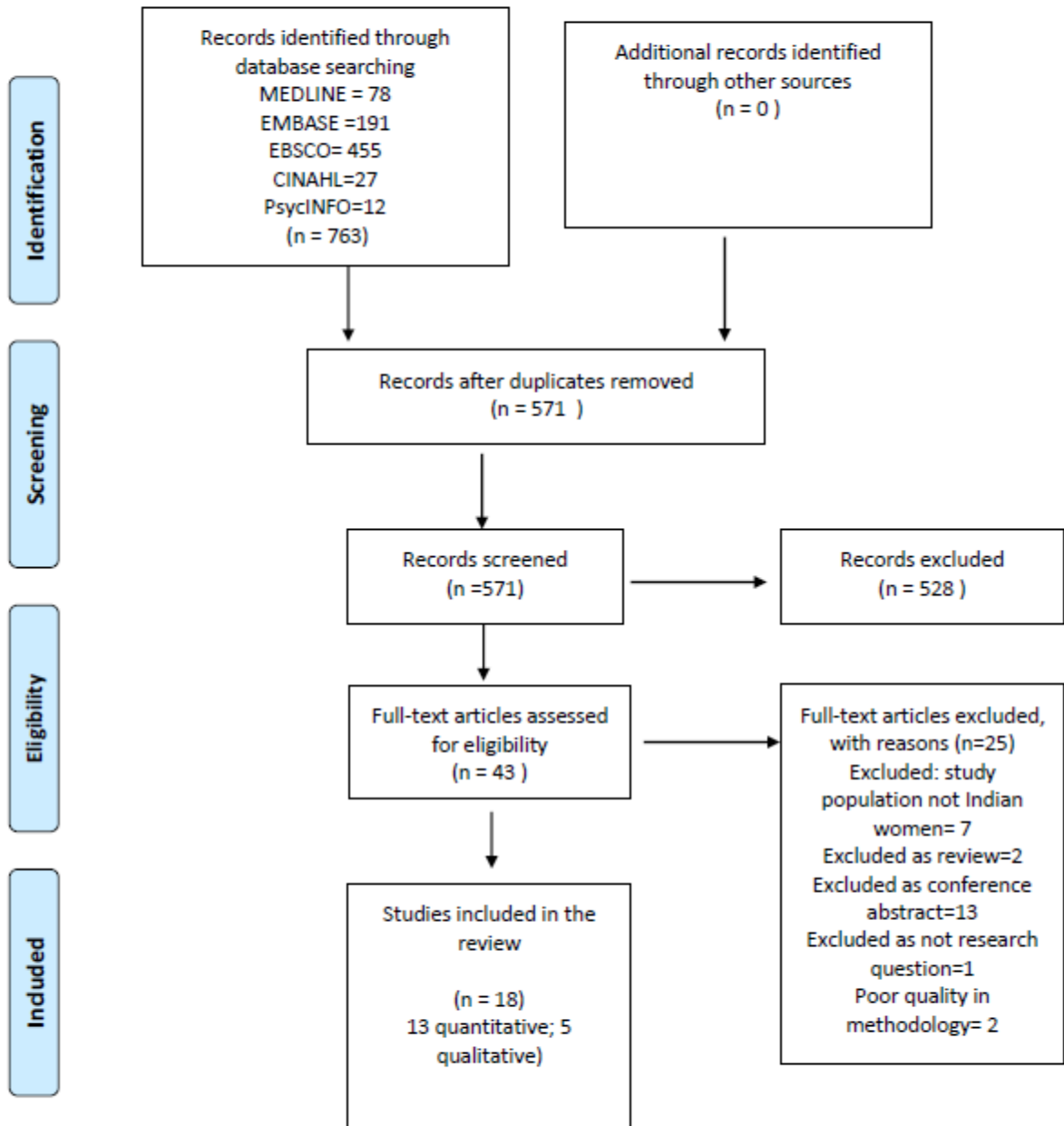
Results

The literature search yielded 763 records of which 20 studies met the inclusion criteria for this review (see Figure 1, PRISMA flow chart). Two papers were excluded due to poor quality. The added search for papers in regional languages yielded no additional results.

Study design and setting.

Out of the 18 included papers, 13¹⁹⁻³¹ were quantitative and five were qualitative studies.³²⁻³⁶ Among the quantitative studies nine were cross sectional^{20-27,29}, three were cohort^{19,28,30} and one was matched case-control.³¹ The summary of characteristics of the included studies are given in Table 1 & 2. The detailed report of the included studies are given in Supplementary table 1 and 2. The participants for 15 studies were recruited from a hospital,^{19-32,36} while three studies recruited participants from Non-Governmental Organisation and community services.³³⁻³⁵ Both North and South India were represented with three Indian studies conducted in Maharashtra,^{19,21,23} two each from Kerala^{22,25} and Delhi^{20,29} and one each from other states.^{26-28,30,31,33,36}

Figure 1. PRISMA flowchart of studies included in systematic review.



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Table 1: included studies: Quantitative studies

Reference/Authors Country	Design	Aims	Measures
PARMAR et al (2005) ¹² 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) ¹³ India	Descriptive cross-sectional study	Investigate the QOL in patients of breast cancer beyond the 1 st 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 et al (2010) ¹⁴ 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 impairment
Pandey et al (2005) ¹⁵ India	Cross sectional	To identify the determinants of QOL of Indian women with breast cancer treated with curative intent.	(FACT-B)
Mahapatro et al (2005) ¹⁶ 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 et al (2013) ¹⁷ 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 of 27 questions
Purkayastha et al (2017) ¹⁸	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-

India			9) WHOQOL-BREF for quality of life
Dubashi etal (2010) ¹⁹ 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) ²⁰ 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 (2012) ²¹ India	Cohort study	To evaluate psychosocial status of patients who underwent surgery for cancer.	GHQ-28 and HADS
Chintamani etal (India) ²² 2011	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 (India) ²³ 2014	Cohort	To evaluate the QOL and affecting factors on it among south Indian cancer patients	EORTC QLQ-C30 EORTC QLQ-BR23
Singh etal (India) ²⁴ 2015	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 2 Included studies: Qualitative

Reference/ Authors Country	Aims	Data collection	Results Summary
Gurm et al (2006)²⁵ 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 et al (2017)²⁶ India	To understand breast cancer survivorship trajectory from an Indian perspective and to understand the impact of the diagnosis of breast cancer and its treatment on body image and sexuality issues	Methodology Descriptive phenomenological approach. Data collection semi-structured interview	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 made, and attitudes held toward sexuality
Howard et al (2007)²⁷ 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 et al (2013)²⁸ Canada	To explore the experiences and concerns of female south 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 age, social situation and culture affect the experiences of sa bcss after treatment, especially as they transition from oncology to community care.	Methodology Thematic and content analysis. Data collection Focus group and one to one interviews	Universal Themes 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)²⁹ India	To explore the cause and manifestation of Stigma in breast cancer patients.	Methodology Thematic analysis Data collection In-depth interviews	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.

SA BCSS:South Asian Breast Cancer Survivors

Observational studies

Cohort studies

There were three prospective cohort studies which included psychological outcomes: body image, global quality of life, anxiety, depression,^{19,28} physical function, role function, future perspective.³⁰ 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.¹⁹ Among the other two studies, one evaluated the quality of life using the tools EORTC QLQ-C30 and BR23,³⁰ while the other used two tools General Health Questionnaire (GHQ-28) and Hospital Anxiety and Depression Scale (HADS)²⁸

Cross-sectional studies

Among the cross-sectional studies, three studies evaluated severity of anxiety and depression^{23,25,29} and four studies analysed domains of quality of life like physical, social/family well-being, functional and emotional well-being.^{20,22,25,26} The other measures evaluated included various somatic symptoms, and social dysfunctions like stigma, vulnerability, transparency, arm concern, body concern,²⁷ dependency, invalidity, restriction and problems with chores, feelings, sadness and inner tension,²¹ concerns, coping mechanism, breast cancer treatment, overall patient satisfaction with follow-up care, information needs at discharge and completion of treatment.²⁴ The various tools used were HADS,^{23,27,29} Functional Assessment of Cancer Therapy-Breast,^{20,22} Concern and Coping Checklist,²³ Patient Health Questionnaire,²⁵ World Health Organization Quality of Life Instruments,²⁵ EORTC QLQ-C30 and Breast Cancer specific module²⁶ and Body Image After Breast Cancer questionnaire.²⁷

Matched case control

Singh *et al* conducted a prospective noninterventive, observational study to evaluate the depression, anxiety, and stress 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, etc using Depression Anxiety and Stress scale.³¹

Qualitative studies

Three of five qualitative studies³²⁻³⁶ used interviews,^{33,34,36} one used focus group discussion³² and one used interviews and focus groups.³⁵ Three studies recruited participants from a migrant community living in Canada^{32,34,35} and two were from Indian women living in India.^{33,36}

Outcomes

Quantitative studies

The main outcomes of the individual studies are summarised in Supplementary Table 1 & 2.

Anxiety/Depression

About a fifth (21.5%) of women with breast cancer undergoing treatment had depression,²⁵ in whom 22% was moderate to severe. A study of patients undergoing surgery for colorectal cancer, breast and head and neck cancer, showed post-surgical anxiety and depression was greater in patients with breast cancer.²⁸ A case-matched control study showed that patients with breast cancer had higher levels of stress than the normal controls.³¹ However this paper did not describe how the controls were recruited or what matching criteria were used. Depression was associated with poor quality of life²⁵ and stigma.²⁷ 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.²⁷ 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]).²⁹ One study explored the relationship between type of surgery and HAD score and found no difference between women who had breast conservation or mastectomy.²³ 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%; $p<0.05$).²⁹

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 (see Table 1). These can be summarised as patient and disease characteristics, treatment-related factors and symptoms.

Patient characteristics

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 ($p=0.04$).²²

Disease characteristics

The disease characteristics affecting the emotional wellbeing of patients were nodal status ($p=0.02$), method of diagnosis ($p<0.001$) and previous treatment ($p<0.0001$).²²

Treatment-related effects

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.²⁶ 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.^{20,26}

Symptoms

Among symptoms affecting quality of life, depression was associated with poor quality of life as described earlier,²⁵ in addition poor quality of life was associated with distress due to hair loss.³⁰

Body Image and stigma

Stigma was more likely in women with worse body image scores.²⁷ Stigma was independently inversely associated with educational attainment ($p=0.01$) and having had breast conservation rather than mastectomy ($p<0.001$). 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).¹⁹ 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 ; $p < 0.05$).²³

Quality appraisal of quantitative studies

Almost all the studies showed deficiencies in various aspects. The study design was not mentioned in the title or abstract in five papers.^{19,21,22,26,29} Singh *et al* described their study as a cross-sectional study but from description of methods it appeared to be a matched case control.³¹ There were missing details of study settings,^{22,27,29} and potential sources of bias^{20,22-30} which was acknowledged as a limitation in only one study.²⁵ Only two^{24,25} papers gave a rationale for sample size, seven^{19-22,24,27,29} explained how missing data were handled, but detailed description of participant selection was provided by only three studies.²⁴⁻²⁶ The detailed reporting is given in supplementary table 3.

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 stigma³⁶ and body image and sexuality.³³ 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.

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.

Community

Most Indian-origin 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.

Talking about their experience with others who understood their cultural context and to whom they could speak fluently was helpful.

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)³⁵

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)³⁵

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)³⁶

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)³⁵

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)³⁶

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)³⁵

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)³⁴

However, not all women had supportive families and the diagnosis of cancer sometimes led to a breakdown in relationships.

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)³⁶

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)³⁵

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)³⁴

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.

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)³⁵

Religion

Religion and faith were important to many women, helping to accept disease, to cope or to change their lifestyle irrespective of country. 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)³⁴

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)³⁵

Several women tried to understand the reason behind the cancer diagnosis by attributing it to fate or ‘karma’.³⁵ This helped acceptance of their diagnosis but led to a “passive fatalism”³² of not going for treatment as “God has already decided the destiny”.³²

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)³²

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.

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)³³

*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)³³*

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)³⁵*

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)³³*

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)³⁵*

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.

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)³²

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)³⁵*

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)³⁵

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)³⁵

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)³⁴

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.

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)³⁵

Quality appraisal of qualitative studies

Four of the five studies were of high quality. One study³³ 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 supplementary table 2.

Critical Interpretive Synthesis (CIS)

CIS combined findings in relation to i) mental health and ii) stigma and body image (see Table 3). 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 3: 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	<ul style="list-style-type: none"> • 21.5 % of patients had depression • Higher levels of anxiety and depression than: <ul style="list-style-type: none"> ○ normal controls, ○ those after surgical procedure for other cancers, ○ those responding to chemotherapy, ○ those from joint families. • Prevalence rates similar to studies from other populations • Emotional wellbeing was directly related to: <ul style="list-style-type: none"> ○ 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 hair loss. 	<p>Overall, support from community, family and religion reduced distress and helped patients to cope in both home and migrant communities</p> <ul style="list-style-type: none"> • However, social expectations have negative impact by increasing pressure: <ul style="list-style-type: none"> ○ to be socially correct, ○ to have children immediately after marriage; fear of infertility prevented some from having chemotherapy. • Though faith supported most, others: <ul style="list-style-type: none"> ○ 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 	<ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> ○ 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

		<p>distress.</p> <p>Lack of information in a language they understand, lack of education, difficulty in gathering information added to the uncertainties and worries about the future adding to their distress.</p> <p>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”.</p>	
Body image and stigma	Worse stigma was associated with poor body image scores, low levels of education and breast conservation surgery	<ul style="list-style-type: none"> • A diagnosis of cancer led to stigma through <ul style="list-style-type: none"> ○ reduced marriage prospects ○ a belief that cancer was infectious • Stigma led to social isolation 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. 	<ul style="list-style-type: none"> • 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 greater stigma perhaps due to social scrutiny of an “unnecessary expense” and fears of recurrence.

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. We 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.

Complexities such as family structure, religion and community affected Indian women distinctly, both in India and following migration, where Indian culture was transplanted to other settings with limited acculturation. Such factors may be supportive to women, but may also be particular causes of distress, 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.¹⁷ 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. 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.³⁷ Exclusion from decision-making, exacerbated by language barriers, was an evident cause of psychological distress of Indian women in Canada.³² 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.³⁸ 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.³⁹

Our 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.³⁵ 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.^{40,41}

Family was an important positive and negative factor for all women in our review. For migrant families, a lack of extended family or wider community system may affect how migrant women cope with cancer.⁴² 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.⁴³ However, familial support may become a “two edged sword” when it is the “nurturing mother” who is affected by cancer. The woman has to address her own issues and support the other family members who are devastated by her diagnosis. A potential loss of their major role of “mother” may lead to non-compliance with treatment.³⁵ 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,⁴⁴ and women may be stigmatised if they remain childless, either voluntarily or involuntarily.⁴⁵

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,²⁷ perhaps because of more fears about recurrence. Irrespective of the type of treatment, the women in our 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. Although in general, breast conserving surgery was associated with reduced stigma¹⁹ in keeping with other work,^{46,47} 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. Many women drew positively on their faith as a coping mechanism and source of spiritual support,⁴⁸⁻⁵² however, women from two studies described '*passive fatalism*'^{32,35} affecting treatment adherence. Such patients need additional support from family and medical professionals.

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,^{53,54} yet migrant Indian women in Canada often declined the support offered by local cancer agencies.³⁴

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.³² 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.³⁵ 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.^{42,55} Similarly, Chinese immigrant women would prefer programs tailored for Chinese cancer patients.³⁹ 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.

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 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.

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 origin. 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.

Strengths and limitations of this study

This systematic literature review was conducted and reported according to the PRISMA process,⁵⁶ 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. Only five qualitative studies were found, with only two conducted in India. 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.

Conclusion

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.

Acknowledgements

The authors would like thank Ms. Jenny Makeham, corporate support librarian at Leeds General Infirmary, for helping with formulation of search terms and Ms. Indira Nair, librarian at Amrita Institute of Medical Sciences and Research Centre, for her help in providing papers from Indian journals.

Contribution of authors

Concept – SD.; design – SD, CV, MJJ; Search-SD; screening, data extraction and quality appraisal – SD,JC,SG ;data interpretation- all; first draft -SD; revisions and final manuscript - all authors

Data management and sharing

All data has been presented in the manuscript with details of full search strategy and excluded papers in Online Supplementary Materials.

Funding

No funding

Supplemental material

Supplemental material for this article is available online.

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Competing Interest

None declared.

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