Psychological concerns of Indian women with breast cancer in different national contexts: a systematic review and mixed-methods synthesis

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ABSTRACT

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

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

Design This is a systematic literature review and critical interpretive synthesis. Medical Subject Headings (MeSH) terms and keywords for breast cancer, psychological symptoms and treatment were used to search databases from inception to 7 May 2019. The reference lists of the included articles were examined. Search results were screened against the inclusion criteria, data were extracted, and quality was appraised by two independent researchers with recourse to a third. Narrative (quantitative) and thematic qualitative syntheses were applied, followed by critical interpretive synthesis.

Data sources ProQuest, MEDLINE, Ovid EMBASE, EBSCO, Cumulative Index to Nursing and Allied Health Literature, and PsycINFO.

Results 18 of 763 studies from India or Canada were included (13 quantitative, 5 qualitative). Critical interpretive synthesis found psychological concerns similar to ‘Western’ women, but were framed by the common culture of Indian women in either country. Family structure, religion and community appear to protect against and cause distress in relation to the expected core role of being a wife and a mother and the 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 their family and the wider community. Culturally congruent care, including accessible communication and information, may help prevent and alleviate distressing symptoms whether in India or in 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 South. According to WHO’s global health estimates published in 2013, over 508 000 women died in 2011 worldwide due to breast cancer. Psychological symptoms are common in women diagnosed with breast cancer, and include distress associated with cancer diagnosis, fear of relapse or death, body image issues, and treatment-related effects. Addressing the psychological concerns of patients with breast cancer is important to improve their quality of life. In addition, psychological symptoms may impact on survival rates. Patients diagnosed with depression are three times less likely to adhere to treatment regimens as compared with those without depression. 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 the assessment of prognostic and predictive factors and the potential benefits and side effects of the treatment. Breast cancer is becoming the most common cancer...
among women in India, accounting for about a quarter of all 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. 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. Therefore, breast cancer affects Indian women all around the world. This is important as women from diverse cultural backgrounds may have different experiences in cancer care, which may be heightened among those who migrate.

Psychological symptoms can be influenced by migrants’ level of acculturation (psychosocial adjustment and adaptation to the new culture). For example, Chinese immigrant breast cancer survivors are known to be at greater risk of distress compared with USA-born Chinese survivors. 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 among 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 among Indian patients with breast cancer in relation to treatment and the factors which help or aggravate 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, Cumulative Index to Nursing and Allied Health Literature, and PsycINFO. Medical Subject Headings (MeSH) terms and text words, including both US and UK spellings for breast cancer, psychological symptoms and treatment (see online supplementary table 1), were used and tailored to each database. The EBSCO host discovery science database was searched on the advice of the librarian at the 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. The reference sections of relevant review articles and of the 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, and conference abstracts were excluded. Studies of male patients with breast cancer or children were excluded. Studies on the effects of treatment on other primary tumours and studies reporting on physical adverse outcomes only were excluded. The list of all the excluded studies is given in online supplementary table 2.

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 (MJJ). Studies that matched the selection criteria were retrieved and their full-text version assessed. The results of all searches were managed using the EndNote basic reference management software (EndNote V.X9), and duplicate reports were deleted.

Quality appraisal
Observational studies were appraised using the Strengthening the Reporting of Observational studies in Epidemiology checklist (see online supplementary table 3). 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 Appraisal Skills Programme (see online supplementary table 4) checklist for qualitative studies. Findings were tabulated to demonstrate key strengths and weaknesses in study design.

Data extraction
The data extraction tool was developed based on the Cochrane Handbook checklist, and data from included studies were independently extracted by SD and SG. A separate table was developed for quantitative and qualitative studies and was piloted in two studies.
Data analysis
Quantitative data were described, tabulating the design, participants and main findings. The findings were then brought together in a narrative synthesis summarising the findings and exploring the relationships between and within studies, along with quality appraisal of the robustness of the findings. Qualitative data were subjected to thematic synthesis to form generalisable findings while taking the context of each study into account. 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 MJJ, which SD then used to code all qualitative papers. Descriptive and analytical themes were formed from the codes in discussion with MJJ and SD. 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. A theoretical framework (cultural distress) was used to inform the analytical themes and final discussion. This framework identifies that cultural distress is experienced when patients receive care which does not take into account their beliefs and if they experienced ‘otherness’. A critical interpretative synthesis (CIS) approach was then used to identify and synthesise the findings pertaining to the research question from both quantitative and qualitative studies.

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

Study design and setting
Out of the 18 included papers, 13 were quantitative and 5 were qualitative studies. Among the quantitative studies, nine were cross-sectional, three were cohort and one was a matched case-control. A summary of the characteristics of the included studies is given in tables 1 and 2. A detailed report of the included studies is given in online supplementary tables 5; 5; 6. The participants for 15 studies were recruited from a hospital, while 3 studies recruited participants from non-governmental organisation and community services. Both North and South India were represented, with three Indian studies conducted in Maharashtra, two each from Kerala and Delhi, and one each from other states.26–28 30 31 33 36

Figure 1 PRISMA flow chart of studies included in the systematic review. CINAHL, Cumulative Index to Nursing and Allied Health Literature; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Observational studies
Cohort studies
There were three prospective cohort studies which included psychological outcomes: body image, global quality of life, anxiety, depression, physical function, role function and future perspective. One was a validation study of the European Organisation 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. Among the other two studies, one evaluated quality of life using EORTC QLQ-C30 and BR23, while the other used General Health Questionnaire-28 and Hospital Anxiety and Depression Scale (HADS).

Cross-sectional studies
Among the cross-sectional studies, three evaluated severity of anxiety and depression, and four analysed domains of quality of life such as physical, social/family well-being, functional and emotional well-being. Other measures evaluated included various somatic symptoms and social dysfunctions such as stigma, vulnerability, transparency, arm concern, body concern, dependency, invalidity, restriction and problems with chores, feelings, sadness and inner tension, concerns, coping mechanism, breast cancer treatment, overall patient satisfaction with follow-up care, and information needs at discharge and completion of treatment. The various tools used were HADS, Functional Assessment of Cancer Therapy-Breast, Concern and Coping Checklist, Patient Health Questionnaire, WHO Quality of Life.
Instruments, EORTC QLQ-C30 and BR23, and the Body Image After Breast Cancer Questionnaire.

Matched case–control
Singh et al conducted a prospective, non-interventional, observational study to evaluate depression, anxiety and stress levels in surviving cancer patients receiving chemotherapy as compared with normal control, and explore the associations with clinico-demographic characteristics such as age, gender, duration of cancer diagnosis, chemotherapy cycles, cancer types and so on using the Depression Anxiety and Stress Scale.

Qualitative studies
Three of five qualitative studies used interviews, and one used focus group discussion, and one used interviews and focus groups. Three studies recruited participants from a migrant community living in Canada and two were from Indian women living in India.

Outcomes
Quantitative studies
The main outcomes of the individual studies are summarised in online supplementary tables 5 and 6.
### Table 2 Qualitative studies included in the review

| Authors | Aims | Data collection | Results summary |
|---------|------|----------------|----------------|
| Gurm et al. | To understand the experience of Canadian Punjabi-speaking South Asian women in order to inform healthcare practices. | Methodology: inductive and deductive processes of analysis. Data collection: focus group methodology. | Two themes expressed by all women: Spiritual beliefs as a dominant context for understanding cancer. Distress at diagnosis. Other themes: patient inclusion, family systems and emotional expression. |
| Barthakur et al. | 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: semistructured 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 towards sexuality. |
| Howard et al. | To explore women’s stories of breast cancer in order to uncover how they made sense of their experiences. | Methodology: narrative analysis. Data collection: indepth interviews. | Four storylines emerged: 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. |
| Singh-Carlson et al. | To explore the experiences and concerns of female SA BCSS 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 on the experiences of SA BCSS after treatment, especially as they transition from oncology to community care. | Methodology: thematic and content analyses. Data collection: focus group and one-to-one interviews. | Universal themes: Physical impact: 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. | To explore the cause and manifestation of stigma in patients with breast cancer. | Methodology: thematic analysis. Data collection: indepth interviews. | Three major themes: Drivers (causes) of stigma, including cancer as contagious, punishment, death sentence. Manifestations of stigma described: isolation, verbal abuse, harassment, loss of employment, reduced marriage prospects. Consequences that follow stigma. |

SA BCSS, South Asian breast cancer survivors.

### Anxiety/Depression

About a fifth (21.5%) of women with breast cancer undergoing treatment had depression,25 of which 22% were moderate to severe. A study of patients undergoing surgery for colorectal cancer, breast cancer, and head and neck cancer showed postsurgical anxiety and depression were 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 The type of treatment was related to the presence of psychological symptoms. A cross-sectional study of women following surgery for breast cancer found on univariable analysis that anxiety disorder (p=0.03) and depression (p<0.01) were associated with stigma, 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 well-being 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 4–20) vs responders mean average 5.6 (range 1–16)).26 One study explored the relationship between type of surgery and HAD score and found no difference between women who had breast conservation and mastectomy.23 Lack of social support was also related to the presence of depression, with those from nuclear families more likely to have depression compared with 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 well-being of patients was directly related to the distance travelled to reach the treatment centre (p=0.04), religion of the patient (p=0.006), marital status (p=0.002), education (p=0.04),...
patient's occupation (p=0.02) and spouse occupation (p=0.04).22

Disease characteristics
The disease characteristics affecting the emotional well-being 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 patients with breast cancer (<35 years), type of surgery was related to quality of life: those who had mastectomy reported overall good quality of life with better global health status (p=0.04) compared with those who had 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 earlier25; 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 at 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 of 9 months after surgery).19 Sexual role and performance concerns were fewer in patients who had lumpectomy rather than mastectomy (1.12±0.44 and 1.38±0.56; p<0.05).23

Quality appraisal of quantitative studies
Almost all 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 the description of methods it appeared to be a matched case–control.31 There were missing details on study settings22 27 29 and potential sources of bias,20 22–30 which was acknowledged as a limitation in only one study.25 Only two papers24 25 gave a rationale for sample size, seven19–22 24 27 29 explained how missing data were handled, but detailed description of participant selection was provided only by three studies.24–26 A detailed report is given in online supplementary tables 1; 3.

Findings from qualitative synthesis
Out of the five studies, three were from Canada and the rest from India. The two qualitative studies from India were aimed at evaluating 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 the 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 women of Indian origin 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 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 the family, lack of hope given by the community or the pressure to be ‘socially correct’. These negative effects were 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, which is an additional burden not faced by 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 bear the cancer diagnosis and treatment. (Researcher, Canada)\textsuperscript{35}

There was also ignorance with regard to the nature of the illness and how it is spread among women living in India, for example, 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)\textsuperscript{36}

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

It is understood, however, that this concern is not unique to sabc, (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)\textsuperscript{35}

**Family**

Family was described as a strong support system for many women, helping them practically go through treatment as well as providing them 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)\textsuperscript{34}

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

Some family members they have neglected us... Before they will come very often but now it was wasn't the right time. (Patient, Canada)\textsuperscript{35}

For some, problems that are already existing in the family worsened after cancer diagnosis, with others due to lack of support from partners. Some children also 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)\textsuperscript{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)\textsuperscript{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)\textsuperscript{31}

**Religion**

Religion and faith were important to many women, irrespective of country, helping them in their acceptance of the disease and helping them cope or change their lifestyle. Some women felt that their faith was strengthened following their 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)\textsuperscript{34}

However, others felt it was God’s punishment for not being religious enough, and so changed their lifestyle 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)\textsuperscript{35}

Several women tried to understand the reason behind the cancer diagnosis by attributing it to fate or ‘karma’.\textsuperscript{33} This helped acceptance of their diagnosis, but led to a ‘passive fatalism’\textsuperscript{32} of not going for treatment as ‘God has already decided the destiny’.\textsuperscript{32}
As one woman said: “Nobody could change the time and cause of my death, it is God’s will. So I avoided the cheemo treatment.” (Patient, Canada)

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 with and to alleviate distress.

Psychological response
Some women found that it was difficult to cope with breast cancer treatment and that it has affected their femininity, that is, loss of hair and breast. Women described changes in their body and expressed their desire to have better cosmetic results or to use wigs and prosthesis to address 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)

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)

Sharing experience with other patients with breast cancer 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)

Several women expressed concern about how their sexual life was affected, with their partners finding them less attractive or losing 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)

However, in some cases, partners were very understanding and waited until 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)

Information seeking
Most women wanted information about their disease, treatment and side effects, which had both positive and negative impacts on any psychological distress as they had difficulty in accessing information due to language barriers. 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)

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

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

Language was felt to be a major barrier to understanding 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)

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)

For some women, this lack of communication, compounded by poor education, language barriers and a culture where individual autonomy in healthcare 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)

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 that they were excluded from decisions, thereby adding to their psychological distress.

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

Although some sabcbs (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)\textsuperscript{33}

\textbf{Quality appraisal of qualitative studies}

Four of the five studies were of high quality. One study\textsuperscript{33} was found to be of low quality in various aspects, including poor methods and lack of clear research aims, making it impossible to see whether these have been achieved. Although there were some interesting data from the qualitative interviews, the implications of the findings were not satisfactorily discussed. A detailed report is given in online supplementary tables 4; 6.

\textbf{Critical interpretive synthesis}

CIS combined findings in relation to (1) mental health and (2) stigma and body image (see table 3). Although Indian women had significant depression and anxiety with similar rates as 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 described their community, family and religion both as supportive and as cause of distress, sometimes enough for them to refuse treatment. Those in migrant communities had additional sources of distress: difficulty in accessing host country community support, further reduced participation in decision making due to language barriers, and financial distress if the disease or treatment disrupts a necessary secondary source of income. In addition to language barrier, support groups for women with breast cancer in Canada were seen as not culturally relevant or congruent with the needs of Indian migrants.

Stigma and body image were related to and amplified by the foundational role of women in Indian society as a wife and a mother and poor knowledge about the nature of cancer. Fears that cancer was transmissible led to social isolation and with the whole family becoming stigmatised in terms of marriage prospects for 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 on the role as a home maker and on the provision of care to children, in-laws and husband, was serious. Even for Indian women in India, experience of the response of the family and the community was not always seen to be culturally congruent for the individual women concerned, preferring societal expectations to personal choices.

\textbf{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 further significant 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 brought to other settings with limited acculturation. Such factors may be supportive to women, but may also be particular causes of distress, especially in terms of decision making and the role of women in households and in the 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.\textsuperscript{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 on factors such as age, gender and community influences. Indian women grow up in multigenerational 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.\textsuperscript{37} Exclusion from decision making, exacerbated by language barriers, was an evident cause of psychological distress among Indian women in Canada.\textsuperscript{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.\textsuperscript{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, avoiding isolation and having a positive attitude.\textsuperscript{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 non-migrant women they observe in clinics.\textsuperscript{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.
## Table 3: Critical interpretive synthesis

| Mental health | Relevant findings from qualitative studies | Synthesised findings |
|--------------|------------------------------------------|----------------------|
| **What are the psychological concerns of Indian women with breast cancer?** | | |
| ▲ Overall support from community, family and religion reduced distress and helped patients to cope in both home and migrant communities. | ▲ Women reported significant psychological distress—both helped and aggravated by their community, family and religion. | |
| ▲ The psychological concerns were anxiety/depression, body image issues, stigma and factors affecting mental health component of quality of life. | ▲ Indian women have significant depression and anxiety with similar rates as those in other populations. | |
| | ▲ Indian women in India and in migrant populations described their community and religion as supportive for them to deal with distress. Sometimes, support from their community and religion was inadequate. | |
| ▲ To be socially correct. | ▲ To have children immediately after marriage or fear of infertility prevented any treatment. | |
| ▲ Emotionally well-being was directly related to: | ▲ Emotional well-being was directly related to: | |
| ▲ Distance to reach the treatment centre. | ▲ Distance to reach the treatment centre. | |
| ▲ Patient’s religion, marital status and education. | ▲ Patient’s religion, marital status and education. | |
| ▲ Patient and spouse occupation. | ▲ Patient and spouse occupation. | |
| ▲ Extent of disease and method of diagnosis. | ▲ Extent of disease and method of diagnosis. | |
| ▲ Cancer treatment, for example, type of surgery. | ▲ Cancer treatment, for example, type of surgery. | |
| ▲ Poor quality of life also associated with depression and distress due to hair loss. | ▲ Poor quality of life also associated with depression and distress due to hair loss. | |
| ▲ Stigma and body image were related to 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 security of an unnecessary expense and fear of recurrence. | ▲ Stigma and body image were related to 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 security of an unnecessary expense and fear of recurrence. | |
| ▲ Breast image and stigma were associated with poor body image scores, low levels of education and breast conservation surgery. | ▲ Breast image and stigma were associated with poor body image scores, low levels of education and breast conservation surgery. | |
| ▲ Stigma and body image were related to 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 security of an unnecessary expense and fear of recurrence. | ▲ Stigma and body image were related to 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 security of an unnecessary expense and fear of recurrence. | |

### Body image and stigma

| Body image and stigma | Relevant findings from qualitative studies | Synthesised findings |
|----------------------|------------------------------------------|----------------------|
| ▲ Worsen stigma was related with poor body image scores, low levels of education and breast conservation surgery. | ▲ Worsen stigma was related with poor body image scores, low levels of education and breast conservation surgery. | |
| ▲ Stigma and body image were related to 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 security of an unnecessary expense and fear of recurrence. | ▲ Stigma and body image were related to 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 security of an unnecessary expense and fear of recurrence. | |
| ▲ A diagnosis of cancer led to stigma through: | ▲ A diagnosis of cancer led to stigma through: | |
| ▲ Reduced marriage prospects. | ▲ Reduced marriage prospects. | |
| ▲ Stigma led to social isolation and delays in presentation to doctors. | ▲ Stigma led to social isolation and delays in presentation to doctors. | |
| ▲ Women felt that the loss of breast and hair diminished their femininity, especially in a male-dominated society. | ▲ Women felt that the loss of breast and hair diminished their femininity, especially in a male-dominated society. |
Mental health issues in migrants are recognised, including the challenges faced due to language and cultural differences; the effects of culture and society on the occurrence of symptoms and on shaping their behaviour towards diagnosis, coping and treatment; the effects of employment, social status and integration; the differences in family structure; and the process affecting adaptation, acculturation and inter-generational conflict.

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. 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 such as younger age, previous psychological problems and non-cancer-related difficulties. However, familial support may become a ‘two edged sword’ when it is the ‘nurturing mother’ who is affected by cancer. The woman both has to address her own issues and to support the other family members who are devastated by her diagnosis. A potential loss of their major role as a ‘mother’ may lead to non-compliance with treatment.

Family and community expectations may also influence 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 1 year of marriage, and women may be stigmatised if they remain childless, either voluntarily or involuntarily.

The choice of type of treatment 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, perhaps due to greater fear of recurrence. Irrespective of the type of treatment, the women in our review were significantly affected by the loss of breast and hair, although wearing cultural dress enabled them to hide their lost breasts and make them less noticeable. Although in general breast conserving surgery was associated with reduced stigma, in keeping with other work, women who chose to have breast conservation may have found themselves under social scrutiny, as the process is seen as an unnecessary expense, highlighting the conflicting pressures women must go through 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, however, women from two studies described ‘passive fatalism’, 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, yet migrant Indian women in Canada often declined the support offered by local cancer agencies.

Findings identified by this review are highly likely to have relevance in 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. Peer support groups who share their unique cancer stories within their own cultural and social context, in their mother tongue, make the exchange more meaningful and supportive. 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. Similarly, Chinese immigrant women would prefer programmes tailored to Chinese patients with cancer. Future research should seek to identify the particular challenges faced by migrants with different healthcare problems and from different cultural backgrounds 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, culturally competent clinicians should 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, clinicians must not assume that they know all culturally relevant influences, and must also allow for differences in regional language spoken, especially in tertiary hospital settings. Early support, which can help through the diagnosis and treatment decisions and side effects, with access to appropriate language, is important, especially for immigrants or those accessing healthcare outside of an Indian state.

A family-centred approach to care but one which includes the woman in decision making will help overcome the barriers women face in India and elsewhere.
Compared with their Western counterparts, migrant Indian women suffer from additional stigma, and thus careful discussions are needed with individuals with regard to treatment choices and accessing support, including access to wigs made from their own hair. The importance of motherhood and parenting should be kept in mind among young patients with breast cancer. 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 to all people, regardless of their culture or origin. Future research should also focus on 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 Preferred Reporting Items for Systematic Reviews and Meta-Analyses process, 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 that were 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. CIS 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 in immigrant communities.

Correction notice  This article has been updated since it was first published. The article type has been changed to Systematic review.

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