

Exploring perceptions and practices of cancer care among caregivers and care recipients of breast cancer in India

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Abstract

Objective: Cancer care is physically and psychologically challenging for both care recipients and caregivers. Caregiving in cancer is an area that needs urgent attention in India. Much of caregiving literature in India is limited to mental illnesses. This study thus examines the perceptions and practices of psychological caregiving among caregivers and care recipients of breast cancer in India.

Methods: Participants were interviewed with the aid of a semistructured qualitative interview guide. Participants included 39 caregivers and 35 care recipients in different breast cancer stages. Interviews were transcribed, translated to English, and coded, and themes were derived for further analysis. Informed consent from participants and ethical clearance and permission from a tertiary hospital were obtained prior to data collection.

Results: Psychological caregiving as perceived by the participants included actions such as encouraging, convincing care recipients, companionship, and maintaining a stress-free environment. Caregivers in particular felt that psychological caregiving meant reacting calmly to sensitive queries of nonfamily members, providing emotional support to other family members, and involvement in religious activities. Taking on such diverse responsibilities gave rise to several unmet psychological needs such as motivation and support in decision making from other family members.

Conclusions: Irrespective of the status (caregiver or care recipient), participants in this study felt the need for structured counselling services to be incorporated into the standard care protocol. This is an area that needs to be further explored in the context of the breast cancer caregiver and care recipient dyad.

KEYWORDS

breast cancer, breast oncology, caregiver, caregiving, India, psychological care, qualitative study

1 | BACKGROUND

Caregivers, especially family members, perform diverse caregiving activities at all stages of illness, additionally to their routine work.¹⁻⁴

Providing emotional or psychological support is one of the inherent caregiving activities⁵⁻⁷ and crucially includes managing psychological needs⁸ and feelings about having cancer.⁹ Literature suggests that about 74% to 80% of the cancer caregivers provide psychological

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caregiving.^{6,9} There is lack of consensus on explicitly defining psychological caregiving.¹⁰ Nevertheless, some researchers defined it as an act directed towards resolving psychological conflict¹¹ or improvement in psychological well-being (such as positive affect and life satisfaction)¹² or fulfilling the psychological needs of the patient.¹³

Priest terms needs associated with emotion, behaviour, and cognitive functioning of an individual as psychological, psychosocial, or emotional needs that affect thoughts, behaviour, and feelings.⁸ Negative psychological needs are triggered in physical illnesses such as cancer that have a reciprocal effect on their informal caregivers.¹⁴ During the course of cancer, there are many triggering factors, which generate the need for psychological care for patients¹⁵ and caregivers.⁹

In India, much of the caregiving is performed by family members.^{4,15} Most often, this is a cultural obligation, and they either do not have the means or feel the need to employ professional caregivers. Cancer caregiving research in India is limited to quantitative studies, and few focus on breast cancer.¹⁶⁻²⁰ Furthermore, literature is focused more on assessing the caregiver burden and other caregiving effects.¹ There is a considerable gap in the literature that focuses on the experiences of caregivers caring for women having breast cancer, and almost none that have corroborated the experiences of care recipients on the same topic.

Hence, there is a need for more in-depth information on the lived experiences of caregivers and the care recipient's experiences to have a holistic perspective. In India, breast cancer is mostly diagnosed in reproductive age group of women and in advance stage of illness.²¹⁻²³ As incidence of breast cancer increases,^{21,24,25} there is an urgent need to examine the contexts, in which they receive care. Empirical studies have demonstrated that psychosocial care enhances patient outcomes.¹³ Therefore, psychosocial oncology is gaining to be an essential service in the management of patient,²⁶ but it is mostly overlooked.¹³ Therefore, this study aimed at investigating the experiences of caregivers and breast cancer care recipients on psychological caregiving in India. These psychological caregiving practices need to be performed by caregivers towards care recipient and do not include self-care by care recipients.

2 | METHODS

A qualitative study was undertaken at a tertiary hospital in the coastal district of Karnataka, India, and participants were recruited from the cancer super specialty wing of the hospital.

Women with breast cancer were selected during or after cancer treatment, between July 2015 and June 2016, and their informal caregivers who were willing to participate were recruited. Informal caregivers included spouse, offspring, siblings, parents, distant relatives, friends, or neighbours. There was no restriction on the number of caregivers per care recipient. The first author approached participants in the outpatient department and admission wards and purposively selected the women coming for follow-up and admitted on the day of visit. Care recipients and caregivers were contacted, and their willingness to take part in the study was inquired. An attempt was made to recruit participants from different prognostic stages of breast cancer,

marital status, treatment types, ages, religion, and socio-economic status. In-depth interviews were undertaken at the participant's residence or in the hospital.

In view of the complex nature of the research question, it was felt that an in-depth interview was the best method to acquire the perspectives of the participants. This "special kind of knowledge-producing conversation" to understand the insider's (emic) perspective is the backbone of qualitative research.²⁷ A semistructured in-depth interview guide (Supporting Information) was developed and was pilot tested prior to administering to the study participants. Participants were queried on the changes in their life post breast cancer diagnosis and the perception of the caregiving roles that were performed and sharing of activities.

After the purpose of the study is explained, informed consent from each participant was obtained. Interviews were recorded with prior permission and conducted either in Kannada, Tulu, Konkani, Hindi, Marathi, or English. Information was obtained till the point of saturation, and interviews lasted for 20 to 90 minutes. In-depth interviews were conducted for a total of 39 caregivers and 35 care recipients. Participant sociodemographic details, efforts made to enhance the rigour of qualitative methods, and positionality of interviewer are provided in Supporting Information.

2.1 | Data management and analysis

The recordings were transcribed and translated into English. The data were managed using Atlas.ti software. A two-stage coding cycle was undertaken. Initially, the transcripts were read and reread by one of the investigators, to identify a list of deductive and inductive codes pertaining to caregiving. Subsequently, under the second cycle of coding, discussion was held between the authors, and similar codes were grouped together to ascertain code families. A list of themes and sub-themes was decided and is provided in Table 1. Some of the quotations from the participants' interviews are supplemented in the description. Each participant is assigned with pseudonyms to ensure anonymity.

2.2 | Ethical approval statement

Ethical clearance was obtained from the Kasturba Medical College and Kasturba Hospital Institutional Ethics Committee (IEC: 430/2016) Karnataka, India, and due permissions were obtained from relevant institutional heads.

3 | FINDINGS

3.1 | Caregiver's understandings of care provision and perceptions on the role of the caregiver

Choice of primary caregiver depended on the amount of time a person could offer and not necessarily on gender. However, some participants perceived that women should be caregivers, because of the

TABLE 1 List of themes and subthemes of psychological care

Main Themes	Codes
Caregiver's understandings of care provision and perceptions on the role of the caregiver	Providing motivation
	Convincing the care recipient
	Normalizing the situation
	Disclosing the cancer diagnosis
	Psychological care to other family members
	Dealing with sensitive queries of the people
	Keeping care recipient stress free
	Companionship
	Reminding to take adequate rest
	Talking and listening to care recipient
Offering prayers	
Care recipient's understanding of caregiving and their care needs	Providing motivation
	Companionship and talking
	Suggesting care recipient to rest
	Showing concern
	Taking care of minor children
Psychological caregiving to other family	
Caregiver's needs	Encouragement
	Providing company

comfort level they share with the care recipients. Deeksha, 23-year-old daughter, notes, "We three discussed (brothers and Deeksha) who should stay back to look after (the mother). Then I suggested that I would stay, as I am the daughter Women should look after the sick family member Women may be shy to express their problems to men ... (...) Men don't know how to look after. So only women can be a caregiver." Women, in this study, bore a larger burden of care within the household. In the absence of support from the immediate family, distant family, such as nephew, niece, or sister-in-law, felt obligated to provide care.

Psychological care was crucial in all phases of cancer trajectory. Care recipients experienced distress especially during diagnosis and the beginning of chemotherapy. They were wary of consuming medicines because of the side effects and were hesitant to visit the doctor for a follow-up, so caregivers played crucial role in motivating and convincing the women to initiate treatment and adhere to it. Premananda, a 50-year-old husband, recounts his role, "After first treatment she (wife) informed us that she doesn't want the treatment. Later, I convinced her that she would be better and next time would not have that much problems (chemo side effects) but second time effects were worse. Then, again we convinced her that only two cycles were remaining Now, I convince her by telling that she will have (her) hair back."

Caregivers and other family members tried to normalize the situation and behaved as if cancer was similar to any other disease. In spite of knowing the diagnosis and having financial and psychological stress, pretending to be normal was a skill caregivers acquired. A 30-year-old Hina, daughter-in-law, shared her experience, "If we have to look after her nicely, we have to see to it that she doesn't take tension. If she takes tension her illness might worsen. Therefore, we have to behave the same way like the way we used to before cancer diagnosis."

Caregivers revealed that care recipients should be strategically made aware of the diagnosis and other health-related details, by either caregivers or the doctor, in order to take care of themselves. Yeshwanthi shared her experience of how she disclosed the cancer status to her mother, "... while going for operation, I had given a clue to her that if it was just a lump, i.e. fibroid, then only lump would be surgically removed and if it had turned cancerous, then the whole breast needed removal. ... Later, after surgery we disclosed the cancer diagnosis." Collusion is a common practice in India, wherein family members usually hide the diagnosis from the sick individual but prefer to know all facts themselves.¹⁴ Some caregivers were of the opinion that disease severity may be hidden. However, others were reluctant to disclose the diagnosis to the care recipients as they presumed, and it would affect the care recipient's mental state.

Cancer diagnosis affected the entire family. Therefore, caregivers were involved in providing psychological care to other family members as well. A 30-year-old daughter-in-law, Hina, mentioned that informing and educating children while providing care were equally important. She narrated how her husband and her mother shared the responsibility of caring for her children while she was tending to her mother-in-law in the hospital. "I have a son (age, 5 years) and daughter (12 years). I sent them at my mother's place My husband made it a point to be with the children at night especially, my son felt comfortable with his father being around... but, in the morning, when the father left for work he would start missing me and often cried over phone"

Participants expressed that they had to deal with the sensitive queries from people, some of which did not have an answer. Premananda, a middle-aged spouse, stated, "People kept asking why she had lost her hair and each time we had to start from the very beginning They would then grouse as to why we had kept them in the dark all this while. They would come home while she was resting and continue their questioning, what happened? and why? and so on." The constant questioning left the caregiver and care recipients emotionally drained.

3.2 | Care recipient's understanding of psychological caregiving

Care recipients shared that the family member whom they love should be a caregiver. Most married women expected husband to play the role of caregiver, as shared by Anusuya, "To whom they (care recipient) love more, provide accompany and care, then they can cure earlier For me, if my husband is there along with me then I get courage compared to other people. So, I stayed at my home. My sister and mother called me but I didn't go."

However, older women shared that children should be taking up the responsibility of caregiving, but those who had daughters were of the opinion that daughters were preferred caregivers. A 62-year-old Kamamma shared that she has one son married and living separately. She also has two married daughters, living in different states of India, and one unmarried daughter, working in the city. Her unmarried

daughter took leave from work to be her caregiver; however, her other daughters took turns and looked after her. She stated, "Children should look after the women, is it not? Who else will do it? In our case, my husband goes for work. Then children only, that too daughters take care. Will the sons be the caregivers? No, they will not. I have one son, he is also outside."

Providing motivation was the main caregiving activity. Some of the care recipients reported that they were not dependent on physical care but expected encouragement. Women shared about experiencing shock, anxiety, and distress after diagnosis. A 44-year-old married Shanti shared, "Doctor directly told me that I got cancer. People used to tell me earlier that those who got cancer die sooner. I developed that fear. After hearing diagnosis I was in shock, I came out from hospital ... If he (husband) hadn't come at the right time I would have met with an accident ... I was worried, also thought of committing suicide." The aforementioned example shows the care recipient's experience of shock and agony, suggesting the need for psychological care soon after diagnosis.

Care recipients expected their caregivers to provide psychological caregiving to other family members as well. Care recipients perceived that children were emotionally affected as a result of separation from mother and needed attention and care. During hospitalization, some care recipients expressed that the husband used to go home to take care of the child(ren) while other relatives stayed with them. Care recipients expressed that their children were affected because of the mother's illness and feared that it may have a lasting effect on their mind, as shared by Vinni, "... when I lost all my hair, he (son, 9 years) did not come near me for ten days. He was saying 'Maa (mother) is not looking good. What happened, you lost all your hair'" After that, her husband explained the problem and encouraged him to be supportive. This case clearly highlights the need for holistic family counselling for cancer care.

3.3 | Caregiver's psychological needs

It was observed and reported that the caregivers themselves needed psychological support in terms of motivation. Caregivers often felt overwhelmed while caregiving and experienced psychological concerns such as anxiety, distress, fears, and uncertainty. Psychological support was usually provided by other family members, friends, and sometimes by care recipients. A 44-year-old Marcus expressed, "If I was alone it would have been difficult. Because I have family (siblings and in-law's family) here (native place) it is better for me, I can ask them anything or share my feelings." However, some caregivers did not receive any support. Caregivers reported that the treating physician and other cancer survivors encouraged them. Absence of professional psychological support to caregiver-patient dyads, in India, warrants the caregiver to undertake the role of a counsellor. In the current study, psychological care was perceived as a need; however, unprepared and without any skills, most caregivers provided utmost efforts to undertake it.

Caregivers expected empathy and guidance with regard to illness and treatment, encouragement, and hope that their loved one would

be cured of cancer. Caregivers pointed that extended family should help during emergencies but the person should do it voluntarily. A 48-year-old husband, Chadrappa, shared, "... They (siblings) should feel the need to help and should always be there around the family for any help They should not help for the sake of helping (katachara) They should have that feeling (manasirbeku) that 'I will look after.' Some people do not have family, to them an outsider can provide help with a true feeling to help."

4 | DISCUSSION

Examining the lived experience of a cross section of breast cancer care recipients and caregivers, the study elicited distinctive perspectives towards caregiving and receiving. To the best of our knowledge, ours is the first qualitative study focusing on the intensity of psychological caregiving conducted in India.

A previous study conducted among caregivers of cancer patients reported that it is the duty of children to look after sick parents,^{28,29} which was similar to our study. Offspring, who were the caregivers, considered this to be a duty and privilege and an opportunity to express their gratitude to those who had supported them through their growing up phase. Literature on caregiving suggests that family, especially women, undertakes the responsibility of a sick individual,³⁰ particularly psychological caregiving.³¹ In addition to women being the preferred caregiver, our study has distinctively demonstrated that caregiving was not limited to a woman centric activity and that spouses in general were perceived as better caregivers and equal number of men were involved in caregiving. Previous studies conducted among caregivers provided evidence of family, friends, and health professionals as a source of support and strength.^{28,32-35} The current study was congruent with this finding and demonstrated that caregiving was not limited to a single individual. However, some of the participants belonging to nuclear families and those who did not disclose the cancer status to others perceived to have lack of psychosocial support.

Care recipients experience internal, repetitive, and cumulative trauma throughout the cancer trajectory, which is analogous to that of trauma experienced by people living in war zones, natural disasters, or abusive homes.³⁶ Additionally, diagnosis of cancer leads to identity disruption.³⁷ Similarly, our participants expressed their cancer journey as traumatic and life changing, especially the treatment component. This finding points towards unmet psychological needs of the breast cancer patients.

Family systems theory provides evidence of psychological distress having an effect on the entire family, and this effect is reciprocal,³⁸ thus generating a need for psychological care. Some studies measured psychological caregiving as a single component.^{6,7,31} However, others^{5,32,39,40} described it as multifaceted. Psychological caregiving components that emerged from the present study were found to be congruent with the findings of existing literature as being multifaceted, suggesting that these caregiving mechanisms might be common across all cancers. Conversely, care components such as dealing with

sensitive queries, necessitating gradual disclosure of the disease status to the care recipient and other family members, and caring for others in the family specially minors in addition to full-time caregiving were unique findings of our study. This finding suggests the influence of sociocultural factors in the psychological caregiving, thus making it distinct.

In our study, caregivers and care recipients shared common understanding about psychological caregiving except some components. Convincing the care recipients, disclosing cancer diagnosis, dealing with sensitive queries by others, and keeping care recipient stress free were shared by caregivers and not by care recipients.

The review by Thompson et al on psychosocial oncology stresses the effectiveness of psychosocial interventions during the course of illness.³⁵ It was found that although reassurance was important in coping the illness, standard care seldom stressed the need for psychological care in the management and prevention of distress and promotion of well-being.^{30,36} These findings are in keeping with those of the present study wherein the participants were hardly ever referred to a mental health professional for counselling despite the presence of the facility within the same hospital.

Informal caregivers are important stakeholders of care management, but in many instances, their personal aspirations are sacrificed to accommodate patient care as that takes centre stage.²⁻⁴ While patient care is of paramount importance, caregiver's well-being could have an impact on patient's health outcomes. Therein lies the need to recognize the caregiver and care recipients dyad, both requiring psychological care for better patient outcomes. This generates the need for a structured psychological intervention to relieve stress.

5 | CONCLUSION

The study was intended to understand the psychological caregiving among caregivers and care recipients of breast cancer in India. Participants were acutely aware of the need to deal with multiple stakeholders in the community and communicating effectively in such instances. In addition, disclosing the disease status at an appropriate time to the patient and the family was another aspect that found a special mention. The caregivers found the additional responsibility of caring for a minor in the family during the difficult phase to be psychologically taxing. Irrespective of their status as a caregiver or care recipient, participants felt the need for structured counselling services to be incorporated into the standard care protocol. This is an area that can be explored in the future, and follow-up studies could be designed to assess the impact of this recommendation.

5.1 | Study limitations

This being first qualitative study on breast cancer patients and their caregivers in India, findings could resonate for people in a similar setting. However, as the participants in this study had a higher educational level as compared with certain other regions in the country,

some of the findings may be region specific and not generalizable. We did not include ancillary caregivers such as school going children, friends, and other family members as our intent was to focus on primary caregivers. This would, however, have prevented us from gathering certain information that would have been specific to this group and would have affected overall caregiving as most often, it was found to be a shared responsibility. We included caregivers having various relationship with care recipient; therefore, differences in intensity of providing psychological caregiving may vary. Some of the interviews were held in a hospital setting, and this could have influenced certain responses.

5.2 | Clinical implications

Study generates the need for routine practice of disclosure of cancer diagnosis, counselling services for patient-caregiver dyads, and improving quality of doctor-patient-caregiver communication.

ACKNOWLEDGEMENTS

Authors would like to acknowledge the Transdisciplinary Centre for Qualitative Methods, MAHE, for providing a small grant to undertake this research in addition to training the lead author in qualitative research and providing access to Atlas.ti software. We would like to recognize the internal support provided by Kasturba Medical College and MAHE, Manipal, to carry out this study. We are deeply indebted to Ms Shashiprabha, medical social worker, and Ms Sushma Marita D'Souza, master's student, for assisting with the field work and the participants of this study who spared valuable time to generously share their experience.

CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on demand from the corresponding author.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

How to cite this article: Parsekar SS, Bailey A, V. S. B, Nair S. Exploring perceptions and practices of cancer care among caregivers and care recipients of breast cancer in India. *Psycho-Oncology*. 2020;29:737–742. <https://doi.org/10.1002/pon.5326>