

Qualitative study to explore reasons for 'no-show' after diagnosis of breast cancer in a private teaching hospital in Kerala

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ABSTRACT

Background and Objectives: Breast Cancer is the commonest cancer among women both in developed and developing world. Exploring the reasons involved in 'no-show' at the health facility, which is also a teaching hospital, after being diagnosed with breast cancer can aid as a problem identifier, act as an add-on for continuous quality improvement in healthcare and open avenue of understanding about participation that women have in decision-making. This study aims to explore the reasons for 'no-show' after diagnosis of breast cancer in a teaching hospital. **Method:** A hospital-based cancer registry was used to extract the number of patients from the medical records department (MRD) who were diagnosed with breast cancer but did not show up for the treatment offered. Qualitative study method of in-depth interview was employed to understand the reasons for not following up after diagnosis. Interviews were audio taped, transcribed verbatim, analyzed for thematic contents using the standard content analysis framework. **Result:** Personal, familial, social, and hospital-related factors were involved in not following up in the health facility. The major themes were financial difficulties, general inconvenience, others' decisions, alternative therapy, acclaimed oncologists, and awful occurrences, which were categorized under three heads as perceived barriers to continuing treatment in the health facility of study, perceived benefits of treatment in other facilities, and influence of family, friends, and society on decision-making. **Conclusion:** The study throws light on the multitude of reasons behind 'no-show' behavior among patients with breast cancer from the facility where the diagnosis was made, highlighting the requirement for a more patient-centred approach that considers financial, social, and psychological factors in healthcare delivery. Addressing these barriers could significantly improve treatment adherence and outcomes in breast cancer care.

Keywords: Breast cancer, care approach, decision making, exploratory study, no show after diagnosis, patient behavior, qualitative research

Introduction

Cancer is categorized under a terminal disease group that demands an expeditious remedy. The life-threatening and unruly

nature of cancer and its emotional fall-outs make it difficult for the patients to arrive at decisions regarding the kind of treatment and the hospital where the treatment is to be taken.

Globally, breast cancer is ranked second in incidence and fourth in mortality rate among all cancers. In India, it is ranked first with 13.6% and 10.7%, incidence and mortality rates, respectively, among all cancers.^[1] A person diagnosed with breast cancer, not showing up at a health facility following the diagnosis, is a behaviour that draws attention. The prognosis for breast cancer

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can be greatly affected by the time of treatment commencement. Missed visits could lead to healthcare delays that can worsen the condition and lower the likelihood of a successful outcome.^[2] Follow-up appointments give medical professionals the chance to closely monitor patients, modify treatment plans as necessary, and address any potential side effects or complications.^[3] A “no-show” may result in gaps in care that may negatively impact the health of the patient. Cancer diagnosis and treatment, though overwhelming to patients, regular follow-ups can provide an opportunity for healthcare providers to offer psychosocial support.^[4] “No-shows” disrupt this coordination, potentially leading to fragmented care and suboptimal outcomes. Exploring and examining the reasons involved in no-show by patients diagnosed with breast cancer therefore becomes pertinent.

A subjective study to explore reasons for no-show of cancer-diagnosed patients, therefore can aid as a problem identifier and also act as an add-on for continuous quality improvement in healthcare.

One of the important dimensions in modern cancer care is the approach to care, that gravitates toward patients’ needs. A gradual transition from a paternalistic doctor–patient relationship to a more patient-centered treatment planning is now noted.^[5,6] Understanding and studying patients’ behaviors, needs and expectations, thus become increasingly relevant. ‘No-show’ in the study refers to the behaviour of the patient of not continuing with the treatment for breast cancer in the hospital from where the diagnosis was made. The patient might have undergone the same treatment option elsewhere or might have pursued an entirely different line of treatment.

Materials and Methods

An exploratory study was conducted using qualitative methods in the Department of Cancer Registry of the Teaching Hospital from February 2020 to May 2020 after obtaining Institutional Ethics Committee clearance, IRB-AIMS-2020-039. From the hospital-based cancer registry, Medical Records Department (MRD), the numbers of patients who were diagnosed with breast cancer from 2014-2018 were extracted. As the second step, a list of names and contact details of patients who did not show up after the treatment was prepared. Of the total 1,163 patients diagnosed during the period, 157 were no-show.

Broad areas of knowledge relevant to deciding on no-show was arrived at by extensive formative research, and an interview guide based on probable themes that evolved was prepared.

The study participants were contacted over the telephone by the researchers, the purpose of the interview was explained and the study was initiated on receiving informed consent. Efforts were employed to incorporate the maximum variation and include participants from diverse socioeconomic, cultural, religious and geographic milieu. This ensured the data were enriched diversely. In a few cases, the patients were no longer alive and information

was gathered from the respondents; in the majority of cases, from husbands and children.

An interactive conversation style was employed to attain and maintain rapport to ensure the smooth conduct of the interview. After piloting the tool, needful probes were added iteratively. Follow-up questions were used as prompts when needed. The duration of the interview averaged around 35 to 45 min. Data were collected until saturation was attained and the researchers continuously monitored the emergence of new themes during the process. It was considered that data saturation was attained when no new themes, codes, or concepts emerged in the interviews, the researchers could anticipate responses to the questions being asked and realized that no new information that could enhance the study was forthcoming. Researchers independently reviewed the interview transcripts followed by regular discussions to evaluate the point of saturation.

The telephonic conversations with the participants were audio-recorded after obtaining informed oral consent. The data were transcribed verbatim and then translated into English.

Data familiarization was attempted by reading and re-reading transcripts multiple times. The data were manually coded. The emerging categories were identified by data reduction and condensation. Thematic analysis of the data was performed by standard content analysis framework, to identify, analyze and report themes within it. Potential themes and subthemes were identified. The thematic framework of the interview guide coupled with the data-driven analysis by inductive approach enabled capturing of the widest possible theme involved. Independent analysis by two researchers was employed to verify that the themes identified were an exact reflection of the data. A comparison between participants’ data was done to identify similarities and differences in patient narratives. Data filtration through a feminist lens was also attempted to help understand how patriarchy operated through patient–society, and patient–relatives’ interactions in no-show decision-making.

Results

The patient flow chart in Figure 1 depicts how the participants were included in the study, and the socio-demographic characteristics are given in Table 1.

As defined earlier, the ‘no-show’ behaviour refers to non-continuance with the treatment offered for breast cancer in the concerned facility of study. The patient could have carried out treatment elsewhere. Researchers thus attempt to categorise the reasons for no-show as barriers to continuing treatment in the hospital of study and facilitating factors to treatment elsewhere.

1. Perceived barriers to continuing treatment in the health facility of study:
 - a. Non-affordability of healthcare facility:
The majority of the participants decided to ‘no-show’ in the hospital of study as the treatment expenses were not

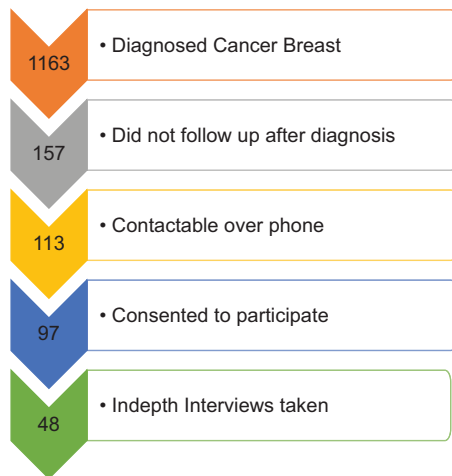


Figure 1: Patient flow chart

Table 1: Characteristics of participants

Variables	Categories	n=97
Age	Range	31-77 years
	≤ 50	32
	≥ 50	65
	Mean±SD	55.4 +/- 10.7
Religion	Hindu	55
	Christian	25
	Muslim	17
Education	Primary	22
	Secondary	20
	Diploma	17
	Graduation	31
	Post-graduation	7
Occupation	Home maker	70
	Employed	25
	Retired	2
Income Class	Lower	28
	Lower middle	29
	Upper middle	27
	Upper	13
Patient Alive	Yes	78
	No	19
Treatment Continued At	Government hospital	47
	Other private facilities	42
	Adjuvant therapy	7
	No treatment	1
Adjuvant Therapy Break Up	Ayurveda	4
	Homeopathy	2
	Naturopathy	1

affordable to them. Out of 48 participants interviewed, 13 had financial difficulties as the primary concern and a few others had it as the secondary reason in view of either low income in the household or other financial liabilities within the family. There had been narratives that treatment in private hospitals seemed non-affordable and the costs involved in the diagnosis alone were a huge burden. Government insurance schemes such as Rashtriya Swasthya Bhima Yojana (RSBY) and Karunya

being non-available at the study site were another factor that made the treatment available non-affordable.

b. Non-accessibility of family and relatives:

Family and familial ties remain a major element, around which many decision-making processes revolve. Many participants were found deciding on which hospitals to take treatment, based on the ease, availability and access for their family and relatives. This originates either out of love and desire for nearness or else out of compulsion and set standards and expectations.

c. Difficulty in long-distance travel and in compromising jobs:

The hospital where the study was carried out is known for its latest technology and has attracted patients from across the globe. However, subjective exploration throws light on how distance can be an impeding factor to a few patients who prefer carrying out their treatment in hospitals nearby. When balancing out with many factors, there are times when distance and difficulty involved in long-distance travel weigh the balance down.

Treatment as such was time-consuming and hence compromised the balance between work and household for many working women. They preferred being treated at hospitals nearby to conserve the time involved in travelling. The kind of success that a few participants had achieved in their professional lives was motivating and a ray of hope for them.

d. Beliefs, fears, and perceptions:

A few participants had a fear of surgery and chemotherapy. When a few feared the procedures involved in surgery, others had concerns about its eventualities. Loss of hair and breast, including size reduction, had been a major concern. They feared losing their feminine looks. This disturbed the patients and their husbands equally and hence they looked for alternative treatment options.

e. Late stage of disease and old age:

This sub-theme evolved from conversations with the patients' spouses or children. The patient had already lost their lives in these cases. When the diagnosis was made, it was already the last stage according to them. They did not have the hope of survival and hence did not go after complicated treatment options. Similarly, age was also a factor in seeking alternative therapy. Many found it wise not to go for surgery and chemotherapy in old age.

f. Hospital-related factors:

The study site being a teaching hospital, the patients visiting there could turn as a utility for the students. Similarly, in hospitals where many patients enter and leave

Table 2: Evidence Chart

Themes	Subthemes	Evidence	Participant code
Perceived barriers to continuing treatment in the health facility of study	Non-affordability of health care facility	“The family had been in a big debt trap, kids’ education, together with parents’ medical care, had been a burden on my husband. To top it all the expenses for treatment of this disease in a private hospital would be large”	P11
		We expected RSBY and Karunya insurance to be available when we came for screening, however, we couldn’t avail them	P07, P18, P24
		Screening test, in itself, was so costly, how could I go for more	P12
	Non- accessibility of family and relatives	Always convenience of relatives matters a lot, for them to visit, or else it will remain a complaint forever	P05
		It has been really difficult for me to travel such a huge distance	P03, P14, P23
	Difficulty in long-distance travel and in compromising job	Teaching students and keeping myself engaged boosted me up. Didn’t want to compromise my job for the treatment. So, I preferred the hospital nearby.	P20
		The very term surgery scared me to death, Loss of consciousness and removal of body parts gave me a very uneasy feeling	P17
	Beliefs, fears, and perceptions	Loss of hair following chemotherapy was my biggest concern I am continuing with Ayurveda still. The feeling was the same about the removal of breast	P33
		Had been diagnosed at the last stage and my wife did not encourage me to spend money on surgery	S40
	Late stage of disease and Old age	My mother was 70 years above when the diagnosis was made, she did not want us to spend money on surgery and radiation.	C42
		I had this feeling of not being consoled for the predicament I had been into....	P15
	Hospital-related factors– Treated as a case, Medical College Culture, Unprofessionalism, Being a good diagnostic center	I was just a case for them....	P19
		That is a Medical College, I did not like myself being exposed and to being studied.... it caused unease...	P19
		I strongly believe there is a mode of conduct in each profession and the way the disease was disclosed on my mother’s face is condemnable	C46
		I had this very awful experience when my mother was treated and the people in charge of data entry had entered the wrong X-ray in my mother’s file	C45
Perceived benefits of treatment in other facilities	Affordable healthcare facilities	Had been to that hospital for diagnosis, as it is well-known for it	P26
		When we have good quality govt hospitals why is it that we should spend such a humongous amount here	P02
	Accessible healthcare facilities and Accessibility of family & relatives	When we have such good hospitals nearby, why strain ourselves, it is an inconvenience	P13
		My son is working in Delhi and to get his support there was no other way but to join him and get treatment there	P01
	Other alternative/adjunct therapy, faith in faith	Always convenience of relatives matters a lot, for them to visit, or else it will remain a complaint forever	P08
		My husband had a chronic kidney disease that could only be treated by Homeopathy, hence I have faith so firm in it	S38
	Help from Sisterhood	Just place your faith in God. Dhyanam (meditation) helped me in curing my illness	P10
		“My community provided me with a huge support and that enabled my treatment in a hospital elsewhere”	P03, P09
Influence of family, friends & society on decision making	Spouse/Children	... it is their decision which is later made to as ours.	P12, P36
		My relatives had good experience elsewhere and wanted me to follow as well	P28
	Relatives	When my friend wanted me to see a doctor who treated her relative quite well, I couldn’t resist	P25
		My husband’s niece is a nurse working in a Govt Medical College and she helped me get treatment there	P08
	Friends	Acclaimed oncologist: His/her name, Easy access to home, Availability in many hospitals	P04
		There is no other reason, but the name of this well-known doctor! For any cancer, he is equated to God, comes to our rescue.	P32
		Availability of this acclaimed doctor near my house was the only reason, why should I go elsewhere then!	P16
		This famous doctor is available at more than one place and hence easily accessible	P16

daily, it is not uncommon to reduce them into cases. This might seem natural for a person working with a number of patients. However, from the perspective of a patient, it is denying their subjectivity and questioning their dignity and being reduced to an object.

Diagnosis of cancer is overwhelming for patients. The shock and uncertainty carried along are tremendous.

Taking this into consideration, the way diagnosis is delivered requires an art. The study could capture the angst and torment that the patient had to go through when the diagnosis was given on the face. This had been a deterrent toward continuing the treatment there for a few participants. There had been voices on the unprofessional way of working among the data entry operators in the

hospital. When dealing with medical data, especially involving a disease such as cancer, meticulous, careful, and scrupulous handling of data is expected.

2) Perceived benefits of treatment in other facilities:

a) Affordable healthcare facilities:

The availability of good-quality government healthcare facilities with good doctors and the latest medical technologies in the state made healthcare affordable for many and hence facilitated treatment seeking in government facilities.

b) Accessible healthcare facilities and accessibility to family and relatives

Availability of good health facilities near the patients' place of stay and work. When a few participants preferred to get treatment in hospitals nearby due to difficulty in travelling, there were a few who were forced to travel longer distances. The patients who had their children settled or spouses working at a distant place had no option but to travel and get treatment from there. The access therefore is not just the availability of healthcare facilities nearby but of family and relatives as well.

c) Other alternative/adjunct therapy, faith in faith:

When most of the participants did not show up for treatment in the hospital of study or followed the allopathic treatment options in other private or government hospitals, there were a handful who had followed alternative therapies such as Ayurveda, Homeopathy, and Naturopathy. They mentioned having followed adjunct therapies for most disease conditions and had positive outcomes from it. Thus, such positive experiences with alternative therapies such as Ayurveda and Homeopathy, in curing other diseases have been a factor. The years-long acquaintance participants had with these alternative therapies also had been a stronger reason for this trend.

One of the participants had resorted to faith in God and claimed to heal through meditation and spirituality. She had rested her faith in God and through prayers and strong faith, she claimed a complete cure.

d) Help from sisterhood:

A few participants had received financial and emotional support from community sisterhoods. The camaraderie that evolved had helped in tiding through the difficult time both with financial help and emotional support.

3) Influence of family, friends, and society on decision-making

This broad theme evolved after data filtration through a gender lens. The majority of the contact numbers the researcher obtained were generally either of participants' spouses, children, and rarely their brothers. Only in a handful of cases, the researcher could directly contact the patients.

There had been instances when the participants palmed off the call to their children or spouses.

On a few occasions, participants fondly remembered the doctor who diagnosed the disease in the tertiary care hospital. One among them who wished to continue the treatment in the hospital, however, had to relent to the decision of her husband to continue treatment elsewhere. A few of the participants after discussing with their close relatives decided to get the treatment done from hospitals, where their relatives had undergone treatment with a positive outcome. For many, the experience of relatives did not require a credibility check. The human nature of trust in close relatives is expressed here. Apart from the experience of relatives as patients, their presence in other hospitals as healthcare professionals also attracted the participants to such hospitals.

There had been a few oncologists whose names were repeatedly mentioned by participants in the study. The name and acclaim that these oncologists had been one of the reasons. Thus, apart from relatives and friends, the general opinion that society maintains also influences decision-making among individuals. More details of evidence provided as a chart in [Table 2].

Discussion

Literature abounds with studies that discuss factors influencing older adults' decision to accept or decline cancer treatment. There are, however, limited studies involving patients with breast cancer, particularly, and including female participants exclusively. In the same vein, there is a dearth of studies focusing on no-show in a health facility where a cancer diagnosis was made. Most studies in the literature deal with factors influencing no-show altogether, where the patients have not carried forward with the treatment elsewhere.^[7,8] Hence, the present study is particularly specific with the facility involved would aid as an add-on for continuous quality improvement in healthcare provision. Similarly, the study being exclusively on women participants could elicit the participation of females in their life decisions.

Decision-making is a complex procedure that involves several dimensions. There are multiple factors that can lead to a particular decision. The study could elicit a multitude of themes and subthemes toward deciding to not follow up in the facility where breast cancer was diagnosed.

The predominant barrier identified was the non-affordability of treatment at a private hospital. This aligns with existing literature that highlights financial constraints as a significant determinant of healthcare access in low- and middle-income countries (LMICs). The absence of government insurance schemes at the study site exacerbated this issue, reinforcing the need for broader insurance coverage in private facilities.^[9] This theme could elucidate how the cost involved in cancer treatment could disturb the financial tightrope traversed by families and overburden the already weighed-down family.^[10] This is of

enhanced importance, especially when the disease under concern is affecting a vulnerable population, as in this case the women. There were sub-themes that pointed to the cost involved in the test for the diagnosis of breast cancer. Relatedly, there are studies in the literature that state that problems with insurance and lack of personal insurance act as barriers to cancer treatment.^[11]

The study could elicit general inconvenience as a major theme that captured many sub-themes under it. Distance or difficulty in travelling and compromising work were a few sub-themes that evolved. In a similar vein, studies by Ciambone *et al.*^[12] and Petrisek *et al.*^[13] have mentioned travel and transportation issues as reasons for no-show.

In our study, we identified several familial factors that influence decision-making behaviors. Upon closer examination, it becomes evident that these factors are deeply intertwined with gender roles, norms, and social constructs, which play a pivotal role in shaping individual and collective behaviors. Many participants described decision-making processes that align with traditional gender roles, where men are often observed as the primary decision-makers, especially in matters related to finances and major life decisions. This dynamic reflects longstanding societal norms that ascribe leadership and authority to men within familial contexts. Others' opinion was a broader theme that evolved on filtration through a feminist lens. Going with the trend, abiding by the societal norms and yielding to familial decisions were the themes that reflected the limited voice the patients had in deciding on their own treatment. The patients in this study being women opens the discussion to consideration of a participatory decision-making process with an emphasis on hearing their voice. The importance of familial support in healthcare decision-making, particularly in Indian society, cannot be overstated. Previous studies have shown that family dynamics play a crucial role in treatment adherence, often outweighing the patient's personal preferences.^[14] There had been evidence of women fondly remembering the oncologists at a health facility where a diagnosis was made. A few studies on breast cancer treatment decision-making among women had reported the opinion of family and relatives being a factor in treatment decisions, especially when they are healthcare workers as reflected in this study.^[15,16]

The emotional and financial support from community sisterhoods highlights the critical role of social networks in coping with illness. This finding is consistent with the broader literature on the importance of social support in cancer care. Strengthening community-based support systems could be an effective strategy for improving treatment adherence.^[17] The influence of well-known oncologists and societal opinions also underscores the role of social capital in healthcare choices.

Adjunct therapy has been a major theme with many interesting sub-themes. The role, experience and faith play in decision-making could also be elicited. The use of alternative therapies and faith-based healing reflects cultural influences on health behaviors. Although the efficacy of such therapies remains debated, their

popularity underscores the need for healthcare providers to engage with patients' beliefs and offer integrative care options where appropriate.^[18] The fear of consequences and experiences of relatives and peers, following surgery and chemotherapy, had also compelled patients to opt for other treatment alternatives. Fears related to surgery and chemotherapy, including concerns about body image and femininity, were prominent among the participants. This aligns with the Health Belief Model (HBM), which posits that perceived severity and susceptibility, along with fears of negative outcomes, significantly influence health behaviors. These findings highlight the importance of addressing psychosocial aspects of cancer care, particularly through counseling and patient education.^[19,20] Many studies in the literature have also reported negative treatment experiences of significant others as the reason to refuse treatment. A few of these studies were, however, with men with prostate or lung cancer. A few studies in the literature have reported losing sex life, especially among men with prostate cancer as reasons for declining treatment.^[21] This study also revealed age as a factor for adjunct therapy, ageism had forced a few patients to opt for alternative treatments such as Ayurveda and homeopathy. Older patients were reported to be less confident than their younger counterparts concerning their ability to be assertive in treatment discussions with physicians, older people have been found to be less likely to believe in the rights of patients to make medical decisions or to question the physician's authority.^[15] Decisions to forgo aggressive treatment in the late stages of the disease or old age reflect a rational consideration of the quality of life, as observed in other studies where patients prioritize comfort over curative treatments in advanced stages. This underscores the need for palliative care options and clear communication about prognosis and treatment goals.^[22]

Personal factors are to a greater extent within the control of an individual and may need a reflective behavioural study for continuance. The value and relief, the profession bestows in the lives of women are revealed by the study. Similarly, the idea of compromising or losing a job had been a deterrent to pursuing treatment. The positive treatment experience of friends and family in other hospitals was a reason for no-show in the institution under study.

The depersonalization of patients in teaching hospitals and the unprofessional delivery of cancer diagnoses were significant deterrents to treatment continuation. These findings resonate with the literature on the importance of patient-centered care, where respect for patient dignity and compassionate communication are essential for fostering trust and adherence.^[23]

One of the important dimensions in modern cancer care gravitates toward the spectrum of patient's needs, which is a continuum and ranges through social, physical, mental, psychosocial, functional, cultural and even spiritual needs.^[5] Under patient-centered treatment planning, patients' behaviour, needs and expectations, become increasingly relevant.^[24] The

study also unveils the significance each individual holds to their subjectivity and individuality. Being reduced to mere 'cases' and objectification are factors that triggered no-show behavior.^[25]

In a patient-centered approach to healthcare, exploring patient needs and expectations becomes pertinent. Exploring each of the factors individually, especially those that are hospital-related is essential for better patient compliance and the smooth functioning of healthcare institutions.

This study has a few limitations. Having conducted in a single private teaching hospital may limit the generalizability of the findings. Additionally, the reliance on self-reported data can introduce the possibility of recall bias. Future research should explore these issues in a larger, more diverse sample, including public and private hospitals across different regions. Investigating the long-term outcomes of patients who choose alternative therapies could also provide valuable insights.

In conclusion, the study throws light on the multitude of reasons behind 'no-show' behavior among breast cancer patients from the facility where the diagnosis was made, highlighting the requirement for a more patient-centered approach that considers financial, social, and psychological factors in healthcare delivery. Addressing these barriers could significantly improve treatment adherence and outcomes in breast cancer care.

Authors' contribution

Concept, design, definition of intellectual content: RM, CT, LG

Literature search: RM

Data acquisition: RM

Data transcription: RM, CT

Data triangulation: RM, CT, LG

Manuscript preparation: RM, LG

Manuscript review: RM, LG

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Conflicts of interest

There are no conflicts of interest.

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