

Disease, woman-health and a cultural perspective: A Study on Breast Health Seeking Behavior of Women in Sylhet, Bangladesh

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ABSTRACT: One of the biggest health concerns for women is breast cancer. Late diagnosis and low survival rates in breast cancer cases are partly caused by patient delays in seeking medical care. Determining the variables that affect patient delays may help in shortening the time delay (Khakbazan, 2014). There are lots of social conditions which influence the patients delay in help seeking as well as less attention has been given to the patients with benign breast diseases. This study employed a qualitative technique to explore the forces that affect the breast health seeking behaviour of women in breast diseases (both breast cancer and benign breast diseases) in Kulaura, Sylhet. Data were gathered from the purposively chosen respondents through 1 key informant interview and 8 in-depth interviews. The social elements that influence patients' quality of life will be the main focus of this investigation. Women with breast diseases face several complications which delay their breast health seeking. Vulnerability affects their self-perception. Inadequate primary health care at the rural level, distance of hospital from the village, poverty, lack of knowledge, interpersonal relationships are the major causes of the women's health crisis. There should be effective breast diseases awareness programs in rural areas so that women can learn about their condition and choose an appropriate course of treatment.

Keywords: Breast diseases, Breast cancer, Health seeking behavior, coping mechanism, culture

Introduction

Breast cancer is the most frequently occurring invasive cancer in women in both the developing and developed worlds (Stewart & Kleihues, 2003 cited in Allahverdipour et al. 2011). Breast cancer accounts for only 3% to 6% of clinical breast changes in women; the majority of alterations are benign. With the focus being on the diagnosis and treatment of breast cancer, no evidence-based recommendations for the management of benign disease have been produced, despite the fact that only 3% to 6% of women with clinical symptoms have breast cancer detected, and most of the time the cause of the symptoms is benign (Arztebl, 2019). The increased life expectancy, urbanisation, and adoption of western lifestyles have all contributed to an increase in the incidence, morbidity, and mortality rates of breast cancer in

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both high- and low-resource countries (Alam et al., 2021). Breast cancer affects around 11.7% of all new cancer cases worldwide, with 2.1 million females receiving a diagnosis globally in 2018 and rising to exceed 2.3 million by 2020. In 2018, 15% of all cancer deaths worldwide were attributable to breast cancer, according to the World Health Organisation (Mehejabin & Rahman, 2022). South Asia, the home of approximately 588 million women over 15 years of age, faces a growing breast cancer epidemic, as the incidence of breast cancer is increasing dramatically (Hossain, 2014). In Bangladesh, there were 22.5 new cases of breast cancer for every 100,000 females. Bangladeshi women between the ages of 15 and 44 have been shown to have the highest prevalence rate (19.3 per 100,000) of breast cancer (Begum et al., 2019). Therefore, the actual incidence and mortality of breast cancer is mostly unknown (Alam et al., 2021). The risk of breast cancer linked to specific benign breast diseases (Arztebl, 2019).

The Sustainable Development Goals (SDGs) seek to cut the death rate from non-communicable diseases (NCDs) by one-third between 2015 and 2030. Twenty-two percent of deaths from NCDs are related to breast cancer, which is the leading cause of cancer mortality among women. Therefore, it is crucial to lower the number of women who die from breast cancer. Recently, low- and middle-income countries have been the focus of development initiatives and agendas (Value In Health, 2020). The Breast and Cervical Cancer Prevention and care Act, passed by Congress in 2000, gave states the authority to provide Medicaid care to individuals diagnosed with cancer as part of the NBCCEDP. The CDC assists low-income individuals without sufficient insurance in getting timely breast and cervical cancer screening, diagnosis, and treatment services through the NBCCEDP (CDC). Bangladesh's mortality rate from cervical and breast cancer can be lowered by prevention, screening, early detection, diagnosis, and treatment. Bangladesh accepted the clinical breast examination (CBE) method for screening for breast cancer, while the visual inspection of the cervix with acetic acid (VIA) method is used to screen for cervical cancer. VIA is a low-cost, straightforward method that can be used in low-resource settings and allows for quick provider training (WHO, 2020).

Over time, women encountered a number of intersecting obstacles that combined to postpone diagnosis and restrict access to care. Women stated that these attitudes and beliefs influenced not only their own treatment decisions but also those of their husbands and family members. When appropriate care is available, fear, fatalism, and stigma all serve to influence and postpone decisions about medical treatment. They can also be rooted in illogical attitudes and beliefs (Steiness et al., 2018). Ineffective communication between the patient and the provider, as well as patterns of unequal interpersonal power dynamics, led to a pattern of interpersonal apathy and dissatisfaction that hindered treatment compliance and the patient's ability to

follow up on future sessions (Bowen et al., 2013). The majority of respondents stated that they were unable to pay for necessary surgeries or diagnostic tests, or that they did not have enough money to cover these costs. Poor extended relatives and having a husband with no or little income were the most often mentioned reasons for not being able to afford care (Steiness et al., 2018). The dynamics of body image elaboration involve a variety of sociocultural contexts and cultural symbols, particularly when physical characteristics associated with ideals of beauty are altered as a result of illness or treatment (Santos and Vieira 2011 in Schwartz & Glascoe, 2020).

In Upazila Health Complex, Kulaura there also adopted the clinical breast examination method to detect breast diseases. Women may encounter a variety of obstacles and enablers to timely presentation, according to data from earlier investigations on the factors associated with symptomatic help-seeking behaviour in FBC (Brand et al., 2019; Kailemia et al., 2020 as cited in Kailemia et al. 2023). As a human being we are vulnerable. Vulnerability affects people's perception of self and relation to others (Gammeltoft et al., 2021). This study will explore the forces that affect the health seeking behaviour of women in breast diseases and focus on how vulnerability can play a significant role in breast health seeking in Kulaura, Sylhet.

Research Methods

Study setting

This study was performed according to the qualitative approach for in-depth analyses of the forces that affected health seeking behaviour of women in breast diseases. We studied women who were registered in Upazila Health Complex, Kulaura from 2022 to 2023 and were reported as CBE(Clinical Breast Exam) positive through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in upazila level, which provided free screenings. The respondents who were diagnosed with breast diseases (Benign breast disease/ Breast cancer) and service providers of Upazila Health Complex were the target population of this study. The selected participants were subjected to both In-depth interviews (IDIs) and key-informant interviews.

Study participation

Eight women who were registered in Upazila Health Complex and diagnosed with breast disease participated in In-depth Interviews. Among them 2 women were diagnosed with breast cancer, the rest of the women were diagnosed with benign breast disease (2= breast tumour, 1= hormonal imbalance, 3= couldn't find out actual disease). One hospital Nurse was recruited as a Key Informant.

Table 1: Summary of the respondents and interviews

Method	Participants	Interview
In-depth Interview (IDI)	Breast cancer patients	2
	Benign breast disease	6
Key Informant Interview (KII)	Service provider	1

Data collection methods

Three different methods were used to collect data. These included key informant interviews (KIIs) and In-depth Interviews (IDIs). In-depth Interviews took place at a convenient location for participants and included a women's home (n=5) and telephone interview (n=3). At first a verbal informed consent was received from the respondent. The interviews began by asking about their demographic information. Thereafter, interviews were directed by open-ended questions relating to the experiences of symptom detection, health seeking procedures of both benign breast disease patients and breast cancer patients. Probes were used as required to encourage the women to share their experiences. The interviews were tape-recorded and ranged in length from 25-55 minutes. The participants who didn't give the consent for tape-recording, hand note had taken in their case. By selecting key informant techniques, I had tried to find out the basic information and existing knowledge about the patients and the health providing procedures. The study period for the fieldwork was October 23, 2023 to January 2, 2024 and this study was conducted at Kulaura in Moulvibazar district.

Data analyses

All the interviews were fully transcribed verbatim. After transcribing the data, it was then coded, analyzed, interpreted, and verified. Coding the data began when all the data was fully transcribed. The codes applied keywords that were used to categorize or organize text and were considered an essential part of qualitative research (Sarantakos, 1998). The data was then analyzed, categorized, and organized into themes and further sub-themes which emerged through the coding process. The themes which emerged were assigned a specific code accordingly. The next stage involved interpreting the data by identifying any recurring themes throughout and highlighting any similarities and differences in the data. The final stage involved data verification, this process involved a process of checking the validity of understanding by rechecking the transcripts and codes, thus allowing the researcher to verify or modify hypotheses already arrived at previously (Sarantakos, 1998).

Finding of the study

Forces affect decision making of treatment

Interpersonal relationship

Vulnerability is bound to relationships with others which is constructed through interactions. It can be understood in terms of relationships. Something is always at risk when a relationship develops. Friendship and love expose our vulnerabilities (Coeckelbergh, 2013). In this study most of the respondents showed their concern about the children. They constantly thought about what would happen to their children after their death.

One respondent said,

I can't eat. One day I have to die but now my children are small, this is not the right time I need to survive for them" (P=6).

Another respondent said,

"My son gave me blood for my operation, if I knew about this incident before the operation I can't go for operations. They hid this incident from me"(P5).

A patient-practitioner relationship also constructed through medication. Vulnerability could be created by their interaction. The patient's experience of discrimination and mistreatment could be the reason for vulnerability.

Economy

This study shows that most of the respondents were in control of resources such as money. They couldn't go for medical treatment timely as they were dependent on their husband and son, in some cases other family members. Most of the time they were delayed in decision making for the financial problem. Study showed that four of the respondents were scared about the monetary expenses of the treatment.

One said,

I didn't fear much as I knew treatment would recover me. I had just one fear about the report of cancer positive. If cancer was positive I had to go for several therapy sessions" (P7).

Another respondent said,

My son wanted to sell our land. I forbade him to do so. I would survive taking this medicine as long as I could"(P1).

Health seeking behavior before diagnosis

Priority in Help seeking

As the research has already shown, women's knowledge and views have an impact on HSB (Help Seeking Behaviour). Most women knew that having a

breast lump was a serious condition, which is consistent with earlier research showing that the symptom's nature (breast lump) makes HSB easier (Bish et al., 2005; Burgess et al., 2001, 2008; deNooijer et al., 2002a; deNooijer et al., 2002b; Grunfeld et al., 2003; Meechan et al., 2002, as cited in O'Mahony et al., 2011). In this study, the women were not so concerned about the symptoms and for the lack of knowledge, general belief about diseases, they delayed in seeking help. They just waited to see if anything happened to them, they knew the process of healing themselves.

According to the Respondents,

.....I thought it could be something like Bishfuri (boil). If it is Bishfuri, I know how to treat myself by using Lap(herbal medicine) on that and the Lap will recover it.....Six month later I can realise jhinjhini (enormous pain) in my back and breast then I went to the hospital for check-ups.....then I didn't think about it" (P5, P7)

Moreover, they preferred to take medicine which healed pain instead of going to hospital without any prescribed medicine.

The respondent said,

Most of the time I can feel pain in my breast. I used to tell my son to bring medicine when I felt pain. After taking those medicine I feel better"(P=1)

Instead of going to the hospital and taking advice from an expert they prefer to heal their own selves by taking herbal medicines or the medicines which lessened pain. When the diseases become harmful for them they visit the doctors.

Social Interaction

Failure in symptom disclosure with someone else is considered to be proportional to delay the seeking of help. The early presentation was significantly influenced by the approval of asking for help from close friends or relatives. (Khakbazan et al., 2014). Respondents discussed the symptoms with their close relatives including son(n=2), daughter-in-law(n=1), husband(n=5), husband and other family members(n=1). Most of the decisions were taken by the women after asking the male members of the family.

According to one Respondent

Outsiders won't give you any advice, the family members will give advice about treatment"(P=6).

Health seeking behavior after diagnosis

Social Interactions

Social interaction means interaction with family members, relatives, neighbours can both trigger and barrier to seek help (Khakbazan et al., 2014). Respondents who interacted with others sometimes faced dilemmas in decision making about treatment and fear about their health.

Dilemma

From a social and cultural perspective, Bangladesh too has diversity in its health care system. Socio-economic infrastructure encouraged them in making decisions about treatment. It was necessary to take permission from the husband for most of the respondents. In the case of a widow, they depended on their son's decision because they were dependent on them financially. If the husband, son didn't provide money they couldn't go for medical treatment. In making decisions the female members of in-laws also gave advice about treatment and most of the time they motivated themselves to take herbal medicines and homoeopathy, as there was a matter of money. There could be a fear of spending lots of money. They preferred to take herbal medicines or any medicines which drove them into better feelings.

The respondent said,

I delayed going to the hospital as I can't make any decisions. My sister-in-laws gave me advice about taking herbal medicines or homoeopathy before making a big decision about operations”(P7).

Another respondent said,

Her grandmother said I should try puria(Homoeopathy medicines)” (p6)

One respondent stated that she had gone for a medical checkup. The doctor provided medicine. After finishing the medicine she had started to take herbal medicine for economic problems.

“We didn't have so much money. I had taken medicine for one month and I felt better. Now I am taking herbal medicine, I made these medicines following youtube videos. Whenever I felt pain I took the medicine made by me and after taking the medicine I felt good.” (P4)

Fear

Fear is not something extraordinary but is part of our human existence. If we fear a risk, we fear it because it presents itself as a (real) possibility (Heidegger 1927 as cited in Coeckelbergh 2013). Interacting with other relatives and doctors made them scared about their existence.

One respondent said,

When my relatives talked about other patients' conditions I felt so scared...Seeing my condition, my sister told me I would die by stroke now. I should go to the room.....Doctor couldn't find out the reason for my suffering from pain. If there were no diseases then how could I cure myself from this pain? It scared me”(P=6).

Satisfaction

By interacting with others the patient felt good, sometimes helping others gave them a sacred feeling. It helped them to cope with the vulnerability and risks. By motivating others they motivated themselves.

According to the respondents, .

Many Breast cancer patients come to me and seek help. I help them to find out the place where blood is tested, where the ultrasono is. I motivate the patient. It will benefit you to conduct good deeds for others. I've never had to overcome difficulties” (P5, P1).

Experiences of health service

The respondents' access to healthcare and ability to lead healthy lifestyles are limited by structure (Bourgois, 2017). They have to face several complications while seeking health services. At present, all districts of Bangladesh have 271 Upazila Health Complexes (UHC) with VIA and CBE centres set up to provide broader screening coverage and treatment linkage (WHO, 2020). This study showed in Upazila level there were no breast diseases diagnosis centres. The nurse manually checked if there were any lump and other problems in the breast. Then referred the patients to the district hospital. Many respondents shared their experiences of not getting enough support from the Upazila Health Complex.



Figure 1: Breast screening in Upazila Health Complex

The Respondent said,

They just manually checked my breast and told my sister to take me to the district hospital as soon as possible. If It would have been nice if there was a good hospital in Kulaura, it would have been easier for us to come and go” (P5, P7, P2).

The respondents had faced so many difficulties in health seeking. One respondent couldn't go for a check-up as she had not enough knowledge about the other areas where she could be better treated. It increased the fear and stress of the patient instead of faster treatment.

According to the respondent,

“ They told me to go to the Shadar hashspatal (District Hospital located in moulvibazar) and to go to Sylhet for treatment but I didn't know anything, anyone. Where should I go? That's why I didn't go for treatment” (P8)

Every person was a part of a variety of distinct yet recognisable power structures and hierarchies, which could restrict access to resources and influence people's choices and behaviours in ways that were occasionally outside their control or impossible to alter without outside assistance. In this study we found out that all the patients were not treated equally. Some patients got extra privileges whereas the others didn't get much attention. They faced discrimination in case of seeking help. One respondent said about her interaction with a breast cancer patient,

“ Patient said to me, sister there had so many doctors, they came and checked you up but we couldn't find doctors when we needed them”(P5)

Discussion

Finding demonstrated that most of the respondents delayed going to the hospital for check-up. They didn't take the symptoms as seriously. Then after finding out the disease they also were in dilemmas of taking medicines. The main barriers to women's health seeking were interpersonal relationships, lack of knowledge, economy and distance from the hospital, dilemmas with the health system. These factors made them vulnerable emotionally and structurally.

A structural vulnerability perspective has shed light on the social dynamics that make certain people more vulnerable to health problems than others. Specifically, it has shown how socioeconomic disadvantages and different types of discrimination interact to raise people's chances of being unwell (Gammeltoft, 2021). This study showed that the patient's previous experience of treatment (discrimination, mistreatment) in hospital demotivated them to

take medical support from the hospital. Moreover, through another respondent, it was understood that even if she was given good treatment, other breast cancer patients were not properly checked up. This type of treatment made the patient more vulnerable which further influenced their decision making in health seeking.

Social structure makes people sick. It constructed the mind of the people. Residence is a prominent structural vulnerability assessment tool for the clinical encounter (Bourgois, 2018). The setting of the medication system made people vulnerable. This study showed that the clinical breast exam was done only in Upazila Health Complex which was situated so far from villages. The nurse manually checked the breast and if they were CBA positive, they were referred to Moulvibazar Shodor Hospital or Sylhet hospital. Most of the patients didn't know where, to whom they would go. One respondent didn't go for further treatment for the communication barrier. The medication system created a vulnerable state and fear about the diseases on the respondent's mind that they wanted to be treated but didn't know the way.

The social environment makes it more difficult for patients to obtain healthcare, follow their treatment plans, and successfully change their lifestyles (Bourgois, 2018). Bangladesh has health care pluralism from a social and cultural aspect. Among the three sectors of health care: the popular sector, the folk sector, and the professional sector (Helman, 2007), most of the respondents in this research found that they relied on the professional and popular sectors for their fundamental health care needs. Most of the respondents, before diagnosis depended on the popular sector like self treatment. But after diagnosis of breast disease most of them preferred professional sectors but they had to face dilemmas in decision making. Patterns of belief about the origins of sickness; norms regulating the selection and assessment of therapy; socially-legitimated roles, statuses, power dynamics, settings, and institutions are all potential components of health care systems (Kleinman 1981 as cited in Miskelly, 2006). This study showed that the decision was driven by financial vulnerability. Respondents didn't fear about their health; they had a fear related to the financial cost of the treatment. After taking modern medical facilities one respondent was taking herbal medicine which could reduce her pain. Thus the economic vulnerability affects health seeking behaviour.

With the help of the existential vulnerability concept, how people experience and respond to the larger forces that affect their lives can be easily understood (Gammeltoft, 2021). Existential vulnerability affects people's self perception. They thought of themselves as a burden to others and decided to not take any medication for their poverty. Various explanations might be offered for why women tend to exhibit emotional fragility more than men: partially as a result of a societal emphasis on women's roles in maintaining families (e.g. Schuler et al. 2006). This study shows that respondents' relationship with their son

affected them much. They felt scared about the future of their children. The relationship with their close one gave them the fear of losing them. Thus interpersonal relationships affect health seeking behaviour.

Limitation of the study

This qualitative study explored the forces that affect health seeking behaviour of women in breast diseases. This study aimed to highlight the experience of patients. Clinicians experience can give us another point of view which is not assessed in this study. Therefore, The list of the respondents which was collected from the Upazila Health Complex, was full of wrong information. For this reason I couldn't contact some respondents. Moreover, I had faced difficulties in conducting In-depth interviews through mobile phones.

Conclusion

Late diagnosis and low survival rates in breast cancer cases are partly caused by patient delays in seeking medical care. Determining the variables that affect patient delays may help in shortening the time delay (Khakbazan, 2014) Patterns of belief about the origins of sickness; norms regulating the selection and assessment of therapy; socially-legitimated roles, statuses, power dynamics, settings, and institutions are all potential components of health care systems (Kleinman 1981 as cited in Miskelly, 2006). Conflicting goals, limited funds, the high expense of healthcare, unfavourable earlier experiences with healthcare, anxiety about receiving a cancer diagnosis, and the shame of physical examinations all contributed to their delay in presenting their case (Khakbazan, 2014). Making decisions about one's health is a highly complex process that is frequently done in the background, with significant support from cultural, familial, community, and national elements. These variables include constraints and "real world" scenarios, perceptions of risk due to involvement and authority, family history that interacts with firsthand experience, and interactions with carers (Davison et al., 1992). The social environment makes it more difficult for patients to obtain healthcare, follow their treatment plans, and successfully change their lifestyles (Quesada, 2011). This study investigated the experiences of women in breast diseases, and found out the forces which affected their breast health seeking behaviour. Findings showed that social forces like economy, interpersonal relationships affected health seeking behaviour of women in breast diseases. Even the medication system itself created vulnerability among patients in kulaura. These forces influenced the behaviour of the patients. Fear and dilemmas were the outcome of the forces which result in continuous psychological pressure among them. These forces played an important role in decision making about the treatment.

Recommendations

Based on the findings from this study, several recommendations have been formulated-

- Women must be provided knowledge/ much information about breast diseases. Nurses have a significant role to play in educating women in both clinical and community settings, about breast cancer and early detection practice.
- Seminars must be established to provide knowledge about breast diseases.
- Access to cancer treatment in Upazila level must be revised.
- Clinical Breast Examination must be adopted in Health community centres.

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