LOCATING AGENCY AMONG THE PREDICTIVE BREAST CANCER WOMEN OF BANGLADESH

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Abstract

The paper highlights the factors that encourage women to overcome the stigma of performing predictive tests for breast cancer in Bangladesh. It is an interpretive phenomenological study of seven women who had a family history of experiencing breast cancer within the last 10 years. The current study discusses Bangladeshi women's subjective experiences of predictive tests to detect any physiological deviation of the breast. Besides, it confers how early diagnosis of breast cancer is hindered by shyness and discomfort as they exhibited. Women "at risk" for breast cancer, due to genetic affiliation, share their knowledge with their kin network, which works as social capital to build up agency. Moreover, positive experiences with predictive tests need to be ensured by health service providers. In brief, kin networks, determination, information from others, and the involvement of the cohorts could reduce hereditary cancer risk and allow early treatment for many women. Moreover, the communicative behavior of the doctors and their high social capital induces these predictive breast cancer women to act positively towards the predictive tests.

Keywords: Women, Predictive tests, Subjective experience, Stigma

Introduction

Globally, cancer affects all communities regardless of ethnicity, religion, or age. It is the second leading cause of death among the elderly. Although infectious illnesses and hunger are still among the developing world's primary health issues, cancer has become more prevalent and is now the leading cause of death. However, recent research has uncovered some significant variations in cancer incidence in nations with limited resources (World Health Organization, 2002). A medical journal indicates that breast cancer prevalence in Bangladesh was almost 22.5 per 100000 females. Bangladeshi women between the ages of 15 and 44 have been shown to have the highest level of incidence (19.3 per 100,000) of breast cancer. (Begum, Mahmud, Rahman, Zannat, Khatun, Nahar, Towhida, Joarder, Harun,

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Sharmin, 2019). Family history is a major risk factor for several female hormone-responsive cancers, including breast cancer, ovarian cancer etc. There is evidence that several well-known genes are enriched in breast or ovarian cancer families. For instance, 50-85% of women with mutations in the BRCA1 and BRCA2 genes (which cause breast and/or ovarian cancer) will do so throughout their lifetime. Hereditary breast and ovarian Cancer (HBOC) refer to breast/ovarian cancers brought on by abnormalities in certain common genes since these mutations can be passed down through families and cancer rates are higher in these families (Liu, Hao, Song, Zhi, Zhang, & Zhang, 2021).

Thus, a number of people could be considered as "at risk" of hereditary cancer. Only systematic monitoring can reduce the early detection of this deadly disease. There are few techniques which helps women to examine their body, so that the diseases could be detected early, in order to get better chances of survival. The term "clinical breast examination" (CBE) refers to the conventional method of a healthcare professional physically inspecting the breasts. The clinical breast examination or CBE is the breast cancer screening method that has received the least research. There have been a few randomized studies using CBE alone on which to make recommendations, unlike mammography and breast self-examination (BSE), which can be relied on the results of screening trials. But CBE can be advised as a method to detect breast cancer for the benefit of public health due to a significant amount of indirect information from studies (Albert & Schulz, 2003). Since no specialized equipment is needed, the examination itself is affordable. It is simple to do, it is easy to teach medical professionals, and it can be made available anywhere. Any program for the early diagnosis of breast cancer should include CBE, provided that follow-up oncology and medical treatment is accessible (Albert & Schulz, 2003).

This qualitative research paper finds out the strengths of the predictive breast cancer women while interacting with others family members, as they had a fearful experience of the disease and whether they are aware of breast self-examination (BSE), mammography and clinical breast examination (CBE) and their subjectivity. In doing so, the significant role of the female kin association has been interrogated. The study also clarifies the stigma related to breast cancer and its predictive tests.

Literature Review

Women's agency is defined as the ability to identify one's goals and act upon them (Kabeer, 1999). In the context of Bangladesh, women go through obstacles to reach proper health facilities and services. Thus, women's ability to reach health services requires a number of socio-psychological incentives that helps them to build agency. Vizheh, Rapport, Braithwaite, and Zurynski (2023) anticipated that any efforts to increase maternal health service utilization and reduce maternal morbidity and mortality should include the promotion of women's agency. Whereas, Habib (2021) conveyed that women's network through kin are supportive to encourage wellbeing and maternal health care, which assures importance of women's agency to avail health services. Different socio-anthropological studies on women's reproductive health of Bangladesh express that local infra-structure, social awareness, government and non-government engagement, social and cultural capitals help these women to show resilience or agency (Begum, 2015; Hossain, Mondol & Akhter, 2011; Islam, 1985; Tarafder & Sultan, 2014).

However, determining the general level of awareness among the people of Bangladesh, regarding breast cancer prediction testing is crucial in this specific context. Alam, Islam, Ullah, Molla, Shifat, Akter (2021) have investigated the patients of Tangail district, Bangladesh, and they claimed that most participants were aware of breast cancer, though knowledge about risk factors, warning signs and symptoms, early diagnosis and detection was relatively poor. Moreover, awareness about performing BSE was particularly low. Thus, in doing this research, the respondents were selected among those who were aware about the diseases. The engaging of oneself in the cycle of medical observation is not an easy way. It requires several psycho-social factors. Cross culturally, people as patients are infused by the communicative behavior and responsibility of the doctors during their visits. Barbara, Meeuwesen, Tromp and Hans (2007) disclosed that compared to Dutch patients, non-Western ethnic minority patients are less engaged during medical consultations. The degree of patient engagement and patient satisfaction were most influenced by the emotive verbal behavior of the doctors. Moreover, their study shows a considerable reciprocal relationship between patients' and doctors' verbal conduct may bring positive influence. In another study, Bender, Kawachi, Jorgensen and Pisinger (2015) stated that population-based lifestyle intervention's health check phase participation was linked to a greater degree of local social capital. Differences in individual socioeconomic status and degree of neighborhood deprivation can be used to account for the majority of the connection between neighborhood social capital and participation in preventive health checkups. Nevertheless, there appears to be some lingering relationship between social capital and health check participation, suggesting that fostering community social connections may be a way to increase the number of people who participate in population-based health checks.

Women's perceptions of discomfort and pleasure with mammography have been proven to be influenced by their expectations about the mammogram. Participants in different studies reported that removing the discomfort and shame they felt during the mammogram exam would improve their overall experience exam (Ashkar & Zaki, 2017; Ndikum-Moffor, Braiuca, Dale, Gajewski, & Engelman, 2013; Rutter, Calnan, Vaile, Field & Wade, 1992). The most important predictor of discomfort or pain during mammography is a woman's anticipation of pain as Rutter et al. (1992) claimed. Though in another research, Kornguth, Rimer, Conaway, Sullivan, Catoe, Stout and Brackett (1993) indicated that women reported much less discomfort and higher overall satisfaction with the mammography test when compression was regulated by the women rather than by the technician. For women, undergoing mammograms for the first time is based on these expectations, which may be based on information from friends and family who have had mammograms. Thus, medical technologists may serve as an important point of intervention to increase women's satisfaction with mammography as Kornguth et al. (1993) suggested. This study has considered the argument of Kornguth et al. (1993) to see how Bangladeshi women perceive the physical examination to identify their health risks and Barbara and other's (2007) idea of emotive verbal contact to understand the role of the communicative support.

Theoretical Framework

To understand the patients' responses to the bio-medical tests the paper considers the Bourdieu's (1986) social capital theory. According to Bourdieu, social capital is an attribute that belongs to the individual rather than the community. A person with higher social capital can exercise authority over the group or individual that organizes the resources. This study hunches the social strengths and rackets of information the predictive a breast cancer patient accumulates and exhibits in her own experience. Here, it is observed how class, kin relations, education, social experiences assist the women to mount up agency.

For Bourdieu social capital is enduringly attached with not only class but also with other forms of social stratifications. That also ends up with various forms of benefits and advancements (Fine, 2002). Similarly, the study involves the vivid social factors and arrays apart from the economic class to observe the support system and functioning role of the social bodies in this particular context of health care and wellbeing. It has been seen that social capital is inherent in the individual which is the outcome of the social environment embedded. The women under study have common experiences of having close kin with breast cancer, which evokes them non-verbally and keep their activities work as an advancement than their ancestors with cancer. Even metaphorically, social capital climaxes the positive and productive aspects of sociability (Claridge, 2018). However, the following part will elaborate the methodological framework, which in turn engages intensely the respondent's social capitals.

Methodology of the Research

The research is designed within the framework of interpretive phenomenological research method, where human understanding not dictated by a controlled set of procedures or hypotheses (Van der Meide, Teunissen, Visser, & Visse, 2020). According to Desjarlais and Throop (2011), phenomenology has been used to study embodiment and bodily-ness, sickness and recovery, pain and suffering, storytelling and narrative, time and temporality, and perceptions of location. In this qualitative research, there are seven life-span stories of women whose maternal relatives have/had experienced breast cancer. A homogeneous purposive sampling design (Smith, Flowers & Larkan, 2009) was engaged to the predictive breast cancer women, over 35 years old, whose relatives either diagnosed or expired from cancer not more than 10 years ago. The respondents were the city dwellers of Bangladesh and from an educated background. All women were married and belong to the middle class as they mentioned. Respondents have decided where they fit into the social hierarchy, and this subjective social rank subsequently influences other facets of their social behavior (Manstead, 2018). Yet, the current research lacks information from various socio-economic classes of women.

Table 1: The respondents "at risk" and their risk phenomenon

Respondents "at risk"	Age	Education	Economic class	Risk Phenomenon
Monira	36	BA	Middle class	Mother diagnosed 4 years ago, cured after breast surgery
Bithi	42	HSC	Middle class	Mother died 7 years ago, after chemotherapy
Dalia	43	BSC	Middle Class	Sister died 3 year ago, with oral treatment for cancer
Bilkis	43	HSC	Middle class	Sister suffering from stage 2 cancer, had surgery, diagnosed 2 years ago

Aklima	45	BA	Middle class	Mother died 9 years ago, after diagnosis of cancer
Toru	47	BSS	Middle class	Sister died 3 year ago, with oral treatment for cancer
Masuda	50	BSC	Middle class	Mother died 11 years ago, after diagnosis of cancer

Source: Fieldwork, 2023

The data was recorded with the consent of the respondents, where they were assured that the research will exhibit the pseudo name only. The semi- structured interviews were used to initiate the field. Every conversation lasted roughly one hours, after which the respondent was asked to group discursion that were held once a month for the following three months. Recorded data then coded according to the common themes and phenomenon. The narratives of their experiences have been closely related to each other. Data were incrementally gathered and evaluated and discussed repeatedly between field visits.

The analysis and narratives of the study shows the subjective experiences of the respondents which shows their agencies enforcing social capital they exhibit. The following part has been designed accordingly.

Women "at risk" and their Agency of Wellbeing: Understandings from the Cases

The suffering of deadly diseases like, breast cancer not only hampers the affected body, but also the surroundings of the body experience stiff time. The women of Bangladesh are little aware of their body, but the lethal bodily sufferings, mental trauma and loss of their dear ones sometimes shake them to be sensitive to their bodily uncomforting situation. Most of my respondents shout with sadness that they were not espoused about the cruelty of breast cancer earlier. They women who have seen their close relatives' distress experience anticipate their bodily discomfort prior time. These women are considered as breast cancer patients "at risk" by the medical practitioners. However, though they have witnessed the traumatic death and bodily pain of their relatives they hesitate to visit medical practitioners. This hesitation is rooted from the gendered experience of the body. Women's bodies have been constructed both physically and mentally for procreation, lactation and for male pleasure. The cultural orientation to these bodily constructions has not only objectified a body but also initiate subjective experience of the body. Subsequently, women's intervention towards pain or discomfort in distinguished body part is not often acknowledged.

Women who are considered as breast cancer "at risk" by the medical practitioners have seen life from a different lens. However, they do not hold homogenous social experience in dealing with the predictive disease and tests with their social world and show agency. The young most respondent of the study, Monira said that it was quite "shameful" for her to discuss such issues of her mother. Though her mother was cured after the surgery, they are often asked by relatives not only about her health but also about the portion of breast that has been eliminated through surgery (mastectomy). The opinion polls by the relatives were harsh and appalling according to her. Many were interested how her father reacted to the surgery of breast of his wife; some were even predicted about her father's remarriage, when her mother has to eliminate a portion of the breasts, as a process of the treatment. Thus, mastectomy as the surgical treatment of breast cancer results negatively about the bodily self-image and conjugality (Konan & Gursoi, 2016). The treatment of breast cancer may trigger sexuality and fertility, which challenges femininity as respondents foresee. Most of the respondents corresponded to Monira's experience and expressed similar integration from the society. Although people have a tendency to express empathy and compassion toward the sick and their associates, this does not ensure acceptance of rehabilitation in the community of breast cancer patients as normal sick individuals.

However, during the fieldwork, Monira's mother was under observation and she visits clinics regularly. Monira was suggested to go through clinical breast examination by the medical practitioner as a "at risk" person while she accompanied her mother. She considered the suggestion and started to examine afterwards. She assumes that the life as a breast cancer survivor without breast would be physically, mentally and socially challenging.

The case of Dalia and Toru are associated, because they are siblings. They lost one of their sisters three years ago. However, none of them came had any regular check-up after the early demise of their sister. Just a few months ago, Toru identified a *chaka* (lump) over her breast; she reported that to her doctor. Afterwards, she was advised to have mammogram then, FNAC and biopsy. However, her *chaka* (lump) was not malignant. But, consulting with the medical practitioners she came to know the urgency of SBE and CBE. As Toru stated,

> I did not know about it earlier. May be my ordinary lump helped me to get the information. Now I know as my sister died of cancer, we may also carry same genes or diseases. And it took several months for me to convince another sister, Dalia, to come for a clinical breast examination. It was hard to encourage her. Moreover, other family members, especially in-laws do not like us coming to the clinic for these types of tests.

Dalia further added to her sister's conversation,

> Once your (Toru's) mother-in-law strongly discouraged us to have such checkup! That lady (Toru's mother-in-law) also said that we should not chat about these tests and probabilities of having those deadly diseases with neighbors, if we do, then it would be hard to find groom for our daughters.

Thus, sometimes the family members and neighbors who fail to understand the urgency of the medical investigation hinder the former detection of the test. The sisters predicted that another sister (who died) was not diagnosed early and well treated not only for the expenses but also for the social stigma to the disease. So, women "at risk" are more aware and acquainted about their wellbeing and strategically play role to circulate the knowledge to their female offspring, they are having from the clinics. Here, family bondage, intimacy among the sisters, trust and experience serve major part in persuading the practice of the investigation among these predictive breast cancer women.

Chart1: The factors that leads to women's agency building to predictive tests of breast cancer (Source: Fieldwork 2023)

These women were informed by the physicians at their different stages of life about their vulnerability to the deadly diseases, and sooner than later they silently provoked the other blood related fellows to get closer and associated them in order to have early diagnosis for better chances of life. Despite the humiliation, disapproval and defamed behavior from some members of the family, women who experienced the pathetic loses of the breast cancer patients screech and provoke one another for medical checkup, which works an agent of their welling. Strong female kin networks serve as a lifesaving factor to support the women's agency for the awareness about the predictive tests. Apart from this, these women's subjective experience and sharing their experience with their cohorts influence their further awareness.

Subjective Experience of Bodily Examination

Medical as well as public health utility of medical tests generally corresponds to the diagnostic certainty they provide. However, the sociology of diagnosis has long emphasized the ambiguities and concerns that diagnostic testing may cause, particularly when used to screen ‘healthy’ people (Gillespie, 2012; Armstrong & Eborall, 2012; Timmermans & Buchbinder, 2010; Lupton, 2012). Accordingly, diagnostic uncertainty might generate anxiety and ambivalence for the persons undergoing testing. People combat about whether its results are reliable, but also over the aims and interpretations of test results, as well as their clinical, social, economic, and personal consequences (Street & Kelly, 2021). So, predictive examinations and results are valuable for a better understanding of one’s bodily status.

In Bangladesh most of the women still lack the information of BSE (Alam et al., 2021). Even those who know about these predictive tests do not give importance to it. Thus, vast women are ignorant and negligent about the BSE. However, those who were coming for checkup informed that though the process of self-examination had been demonstrated to them by the medical associated, they feel less motivated and lack confidence to understand their own body. All of the respondents affirmed about their uttermost negligence and discomfort to understand the BSE. However, they also explained their fear and hesitation in visiting the doctors for CBE. Some of them took a year to induce and mentally prepare oneself. The reasons are not homogenous. As mentioned, these women with a ‘somewhat’ healthy condition do not emphasize the upcoming threat to them. Women of the third world often neglect their health threats. Moreover, women’s health is subservient in the development projects of these countries (Mohindra & Nikiéma, 2010). Another factor is that these women held that receiving any type of clinical examination makes them think negatively or pessimistically and makes them believe that they are ill. All of the respondents were not only fearful and uncomfortable about the procedure of these predictive tests, but also has a stigmatized notion towards it. However, the assumption of discomfort, stress and painful experience of the CBE and mammography affect their first attempt. One of the respondents timidly stated that,

> It was not easy to come for tests. The memories of my sister make me weak and fearful. Moreover, it seems painful…shameful (hesitantly uttered) to the soft part of body.

Only two respondents mentioned about the cordial medical technician who keep trying to make them comfortable, while others were not pleased with the behavior of the medical technician. The environment of the clinic where diagnosis takes place, presence of male, communicative behavior of the medical technician and doctors, cost of the test and influence of the doctor play role in the subjective experience of these women.

Women are more predictive and have vivid imaginations before their first attempt of CBE or mammography. All of the respondents experienced stressful days after they decided to have the predictive diagnosis. Some of them had sleepless nights, while others tried to resolve their apprehension by meeting near ones and shared their anxiousness. According to them, sharing emotional breakdown or anxiety helps them to release negativity, which is fairly similar to Kornguth and other's findings (1993). However, the presumption of bodily suffering significantly affected their experience. Unlike Rutter and others (1992), it was observed that most of the respondents felt less pain as they assumed. But those, who didn't assume about bodily pain, suffered more, as they stated. Thus, the preconception toward pain played role to accommodate and experience these predictive tests. However, the subject experiences of these "at risk" women were far and wide shared with their cohorts, where they share their knowledge and influence others to overcome stigma toward SEB and CBE.

Supports of Cohorts and overcoming Stigma

> Boinrai (sisters from different mothers) are of work. They provide information. Yes, some may misguide, but they light up the trouble and way to solution….and the more we discuss…the more it becomes clear and relatively fearless.

The above statement from a respondent makes clear how the cohort of sisterhood works in the context of women's health care. The sisterhood of women comes with a positive influence towards health care behavior. There are female groups of breast cancer survivals, where they work on coping strategies and try to spread social awareness. Though the "at risk" women have seen their relatives having cancer, it has been observed that it does not aware them about SEB and CBE at all. In most cases, their personal experience of bodily discomfort allows them to visit doctors. It is also observed that not all the respondents have shared about their relative's cancer with the doctor. They observe cancer as a stigma, thus don't feel ease to discuss about the disease. However, it seems education and kin affiliation work as social capital to influence their view about the deadly disease, cancer and thus, social capital plays significant role to understand that it is vital to discuss about family illness to the doctors. Additionally, the women who are visiting doctors for CBE also play effective role in encouraging others, especially women who had seen relatives having cancer. The survivals of breast cancer patients have originated a number of collective groups to increase the social awareness about the disease and eliminate stigma towards it.

The place where the CBE takes place is important for these women. They interact with one another, build not only sisterhood but also confidence. As mentioned, women usually probe three questions to another woman who already had CBE. Firstly, they ask "was the experience painful?" The respondents comforted themselves by observing others who completed their CBE and mammography from the same place they are going to visit. While waiting for their serial they tried to reach those women and asked about their experience. Hitherto, they feel shame and discomfort, conducting the diagnosis. Secondly, they interrogate about the person who will conduct the diagnosis. So, they tend to know about the surrounding inside the examination room. The people associated with mammogram and CBE are so important that it is also associated with the decision making of this diagnosis. The decisions made by Muslim women of all races and ethnicities in America about mammograms are influenced by their religious convictions (A. I. Padela, M. Vu, Muhammad, H., F. Marfani, S. Mallick, M. Peek, & M. T. Quinn, 2016). Consequently, the respondents being Muslim were not only aware of their *purda* but also rebellious about the presence of any male technicians inside the premise. All of the respondents seek provision from female doctors and female monographers to conduct CBE. The women do not want other male to take over control of their sensitive body part, because of *purda* and embarrassment. Moreover, the overall environment and behavior of the medical associates also provide deep insights of the diagnosis and work as an agent to overcome the stigma. Thirdly, they query about the report or wellbeing of the woman who completes the diagnosis. The fear, anxiety and stigma of being "at risk" cancer patients reduce when they see many women are coming up with watery lumps and minor cists. They also observe that the chance of inheriting cancer is not alarming, but early diagnosis eliminates the level of severity of the deadly disease. The social gathering of women inside the clinical premise creates openness among the women who visit, thus it builds agency against the stigma on these predictive tests.

Discussion and Conclusion

The paper identifies the factors that encourage the women to overcome the stigma of performing predictive tests for women, who have seen their relatives suffering or had suffered from it. Like other third world women, the women of Bangladesh lack sufficient information about the diseases and hold superstitious thoughts about it. The shyness and discomfort related to the diseases and its predictive tests hinder the early diagnosis, which could be lifesaving. The women who have been regarded as "at risk" to breast cancer due to family history poses little information about the predictive tests, whereas they are not always prompt to health services. However, the doctor's suggestion somewhat invokes them to circulate the information within their kin network. These women are more likely to share their understanding with the women who had experienced homogenous memory of dealing with breast cancer patients. Yet, their subjective bodily experience and the gathering to women at the clinics often encourage them to earn the ability to restore mental distress, though bodily pain and discomfort depends on their persuasions of previous thoughts. The study has seen similarity with the research of Barbara and others (2007) and states that doctor's attention and communicative behavior encourages these women to start and continue CEB on a regular basis. However, the positive or negative attitude of social surrounding of the women "at risk" initiates the stigmatic response towards these predictive tests. Thus, the social capital has the control over these women in persuading clinical tests. It has been observed by Bender and others (2015) that high social capital engages positive health behaviors and ensures general health checkup among Danish people which is similar with the women of Bangladesh who maximize their bonds with sisterhood. The kin networks, determination, information from others, involvement of the cohorts are the social capital and avenues of agencies for these women. Furthermore, these "at risk" women could be influential for others, the social capital for many; if the health service providers ensure a positive experience of predictive tests. So, this could reduce the possibility of hereditary cancer and a large number of women could be taken under the umbrella of early treatment if any anomaly in the cell diagnosed.

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