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Seeking Healthcare at Their 'Right' Time: The Iterative Decision Process for Women with Breast Cancer

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Research article

Keywords: advanced breast cancer, health seeking behaviour, care seeking pathway, delay

Posted Date: July 1st, 2020

DOI: https://doi.org/10.21203/rs.3.rs-39123/v1

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Version of Record: A version of this preprint was published on October 19th, 2020. See the published version at https://doi.org/10.1186/s12885-020-07520-x.

Abstract

Introduction: About 85% of breast cancer patients attending Komfo Anokye Teaching Hospital (KATH), Ghana, present with stage III/IV disease. In spite of great investments into the early diagnosis and management of breast cancer, late presentation persists and poses a barrier to realising the possible benefits of the gains made in breast cancer management. This study assessed the symptom appraisal and medical health seeking behaviour of women with either locally advanced or metastatic breast cancer attending breast clinic at KATH

Method: In-depth interviews of women presenting with clinical stage III/IV breast cancer were conducted to explore the women's care seeking pathways after symptom identification until arrival at KATH from May 2015 to March 2016. Thematic data analysis was conducted using the Andersen behavioural model for health service use.

Results: Fifteen women aged 24 – 79 years were interviewed. The time from symptom identification to reporting to KATH was 4 - 24 months. The initial symptom was a breast lump or breast swelling which all the women identified themselves. These were initially appraised as not serious because most importantly, they did not interfere with their daily function. Symptom progression such as prevented them from undertaking their usual economic, social and family function triggered seeking care from health facilities. The availability of money to pay for care and diagnostic investigations influenced the time taken to navigate the referral pathway. While the women initially deferred healthcare for reasons related to their ability to perform economic, family and social roles, ultimately, aggressively pursuing healthcare was also for the same economic, family and social reasons or goals.

Conclusion: Deciding to seek care and pursue treatment for breast cancer symptoms may be much more complicated than it appears. Economic, family and social function significantly drive the health seeking process both at the personal and health facility phases of health seeking. Breast cancer education messages must be adapted to incorporate these functional goals and their influence on symptom appraisal and decision making to seek help and not just focus on the breast symptom as an isolated entity.

Background

In low and middle-income countries, 30–98% of breast cancer cases are diagnosed at stage III or IV [1]. Some evidence from African countries indicate 70–80.6% of breast cancer patients present late [2–4]. According to the World Health Organisation (WHO), out of an estimated 1.38 million women diagnosed with breast cancer annually, almost 50% of cases and 58% of resulting deaths are from developing countries [5]. Advanced stage at diagnosis, aggressive tumour type, poor differentiation and triple negative hormone receptor status found among most African women are all contributing factors[1, 6, 7]. Furthermore, initiating definitive treatment more than three months after patient's discovery of symptoms

contributes to the high mortality rates [8]. At the Komfo Anokye Teaching Hospital (KATH) in Ghana, about 85% of breast cancer patients present with stage III/IV disease [7].

Many women discover their breast symptoms themselves [9]; and mostly by chance [10] during activities such as bathing, dressing, or breast feeding [11]. After identifying the symptom or sign, personal interpretation is the first step of the health seeking process [12]; where the individual may conclude whether the discovered symptom or sign is normal or serious and needs medical attention. Women have delayed seeking care because they initially interpreted their breast symptoms as not serious [10, 12–17]. Breast symptoms have been attributed to hormonal changes [16] trauma [18], and breastfeeding [12], and if the symptoms do not meet a woman's expectations of how breast cancer should present, it can be evaluated as not being serious. Women's expectations of how breast cancer symptoms present have also been found to vary. For example, while some women consider breast cancer to be a painless pea-sized lump [13], others consider pain rather than a lump in the breast as harmful [16]. Yet the absence of pain has been interpreted as an unserious symptom by other women [12, 16, 18]. Some women also believe that breast lump turns into cancer if it is often pressed or touched [19]. Poor knowledge about early signs of breast cancer aside a breast lump contributes significantly to delayed health seeking [4, 20–23]. Besides symptom appraisal outcomes, poverty [4, 24–26], psychological factors like fear and denial [12, 18, 23, 27, 28] and use of complementary and alternate medicine [4, 22, 23, 26, 27, 29] have been identified as contributing to late health seeking behaviours. Socio-demographic and economic factors such age, education, marital status, area of residence and income level have however been reported to be equivocal [4, 14, 30–36] in how they influence breast cancer health seeking behaviour.

Andersen et al. [37] assert that symptom interpretation is the most important step in the health seeking process for cancer diagnosis and posit that it contributes 60–80% of the health seeking process. It has been found that women who delayed seeking help actively monitor their symptoms and seek care when they perceive their symptoms to have become serious [12, 13, 16]. Eventually, there is always a trigger that drives women to seek help, albeit too late in most cases. Such triggers include the onset of pain [12, 16, 18, 38], increasing severity, and the persistence of the identified symptom such that it interferes with daily activities [18, 39]. For women who only seek help when they perceive worsening symptoms, what informs such behaviour? What goes on during that period of active monitoring of their symptoms? There has been great investments into screening, early diagnosis, and management of breast cancer. However, late presentation poses a barrier to realising the possible benefits of advanced breast cancer screening and management modalities available today. Thus, it remains a healthcare challenge that some women still present to healthcare facilities with advanced breast cancer – localised or metastatic. We assessed the symptom appraisal and medical health seeking behaviour of women with either locally advanced or metastatic breast cancer attending breast clinic at KATH.

Methods

Study Design and setting

We conducted a descriptive qualitative study among breast cancer patients accessing care at the breast clinic of the Komfo Anokye Teaching Hospital (KATH), Ghana from May 2015 to March 2016 to assess the symptom appraisal and medical health seeking behaviour of women with either locally advanced or metastatic breast cancer. Komfo Anokye Teaching Hospital is a 1300-bed capacity tertiary hospital that provides surgical, chemotherapy, and radiotherapy treatment for breast cancer. The Hospital has a dedicated breast care centre manned by Surgeons where women with breast symptoms are first seen. All decisions on breast cancer treatment are taken by interdisciplinary tumour board comprising: surgeons, oncologists, pathologists, radiologists, nurses, and social workers.

Participants, recruitment and sampling

We purposively selected 15 women presenting for the first time to the breast clinic of KATH with breast disease clinically suggestive of Stage III or IV breast cancer as defined by the American Joint Committee on Cancer [40]. The clinical stage was determined by the attending physician based on history, physical examination, and prior laboratory or radiological investigations the women may have done. These women would have invariably observed overt changes in their breast during the period before seeking care at KATH breast clinic. Eligibility also included reporting to KATH breast clinic at least 3 months after identifying the symptom. Age was not a limitation to inclusion. Women who were too frail, such as those who were visibly tired out after the routine clinical consultation and examination were not selected for interviews. Eligible women were identified by the clinic nurse and an explanation of the study and its purpose was given using the participant information leaflet. Women who voluntarily expressed their interest to participate were directed to contact the researcher.

Data collection

We obtained informed written consent prior to the conduct of the interviews. The in-depth interview was conducted using open questions on how they noticed their breast symptoms; how the symptom had evolved since; the experiences that influenced the decision to seek medical care and the activities they had undertaken until arriving at the breast care center. In order to promote a dialogue that could explore the issues that came up, the questions were used flexibly and the order adapted and elaborated to suit each interview context[41]. The interviews were conducted in the local dialect of Twi and translated into English during transcription. Back-translation was used reiteratively during the transcription and analysis process to ensure the meaning of the original responses was not lost [42].

Data analysis

We performed thematic data analysis deductively using priori themes guided by the Andersen Behavioural Model of Health care utilisation [43]. According to the model, the determinants of health service use include individual characteristics such as demographic factors, cultural norms, education, occupation, social relationships, health beliefs, personal and family income/wealth, individual perceived need for health care; and health service factors such as cost and accessibility to care and patient's satisfactions and perception of the care provided.

Results

Fifteen (15) women aged between 24 – 79 years, were interviewed. Ten (10) of them had clinical stage III and five (5) had clinical stage IV breast cancer.

The health seeking journey for the women unfolded in two phases: the personal phase and the health system/facility phase. These phases unfolded either separately or concurrently.

The personal phase of health seeking

Symptom identification

All the women identified the breast change themselves except for one whose lump was noticed by her friend. Breast campaign messages, a sense of discomfort/pain or unusual asymmetry provoked self-breast examination (SBE). The first sign identified by most of the interviewees was a lump whilst others first experienced a breast swelling, or breast pain as the index symptom.

> *"I saw it myself that the breast looked a bit swollen" [Int. 11]*

> *"There was something in it something hard and they have been announcing that when there is something in your breast go and have it checked" [Int. 4]*

Personal beliefs and appraisal

One of the initial impressions many had was that it was nothing serious. Reasons for this included the small size of the lump that was unapparent to others, and the normal gross appearance of the breast. More importantly, 'serious signs' they expected to be associated with serious illness such as pain or interruption of one's normal activities were absent.

> *"It wasn't big and I thought it won't worry me" [Int. 5]*

> *"It was hard but it was not paining me and I could wear a dress and go to the farm" [Int. 1]*

The breast symptom was appraised regularly, and several issues played a role in deciding what is was and what action to take. Common knowledge (cultural/traditional) of breast illness, lumps, or body swellings and how they are commonly managed influenced appraisal. Swellings were commonly regarded as boils and were expected to discharge pus and subsequently resolve, sometimes with the application of locally prepared topical treatment. This expectation was heightened if there was previous personal/friend/family/ experience of similar change.

> *"The way it was hurting I was thinking, as for something that is swollen it will burst and discharge then you are free and that's all" [Int. 6]*

> *"I had seen women with breast disease, some their breast became very huge* [and] *they used herbal medicine at home and for the majority it resolved" [Int. 10]*

Breast cancer campaign messages on symptom appraisal

Nine (9) of the women had been exposed to breast cancer messages via media (television, radio, posters) or local church/social groups. They had acquired knowledge such as breast lumps could be cancer, and reporting to the hospital if they found a lump in their breast; and skills in performing routine examinations of their breasts. Their account did not include information of how different or similar breast cancer symptoms could be to what they traditionally knew breast swellings and lumps to be, and how different breast lumps evolved. Also, their volunteered knowledge base did not include information on what other signs or symptoms could be present or absent in addition to a breast lump to suggest that breast cancer was more likely.

"I hear always about breast diseases….as for the breast I did not really see anything in it. It was my armpit that I noticed something" [Int. 9]

"Our pastor's wife is a nurse and taught us periodically to examine our breast. She said breast can develop cancer so you must take the right steps else you can die. I had heard this on radio and TV too." [Int. 12]

'The tipping point' - Deciding to seek help

Some important triggers that emerged from the interviews were symptoms disrupting daily function and symptoms affecting quality of life or perceived as potentially doing so:

> *"I see that the illness keeps getting worse, it is growing bigger and now my neck is also hurting so bad I just sit till morning comes so I decided to go and see the doctor" [Int. 4].*

> *"So when it started paining me and I could not go to the farm I could not do anything that is when I went to tell my brother and the same day we went to the doctor" [Int. 1]*

The health system/facility phase

The time from symptom identification to reporting to KATH ranged from 4 - 24 months.

Six of the women had their first contact with a health facility less than 3 months after identifying their symptom. The initial contact for all the women was with a non-specialist physician. The referral to KATH was not straightforward. Some of the women saw up to 3 other physicians, including travelling to other towns for diagnostic investigation before finally coming to the KATH breast clinic.

The time taken to navigate the course from the point of initial healthcare contact to KATH was closely linked to economic, family and social roles as women. For example, hospital appointments were deferred in order to work for more money; treatment for illnesses perceived to affect functionality was prioritized over the breast condition; taking care of an ill child caused seeking care for the breast symptom to be relegated.

"I had heard about breast disease so even though it was not paining me I had to do something about it…..but it was not worrying me and we had entered the Christmas season too so I wanted to work small" [Int. 12]

"*It has been swollen for over a year, I did not do anything about it…. I was seeing the doctor monthly for my hypertension medication" [Int. 6]*

"The child's illness was more serious and so I had to take care of him first before, I didn't consider mine as that serious [Int. 3]

The availability of money to pay for care and diagnostic investigations also significantly influenced the time taken to navigate the referral pathway.

"You see by the time I was discharged about my leg problem, I had no money on me that is why it took me so long" [Int. 5]

"By the time we got to the regional hospital, all our money was finished so the doctor asked us to go back home and mobilise some money for the tests." [Int. 14].

"*Well I wanted to come but the money issues, **the money issues**" [Int. 2]*

Even when money was available, it was prioritised for other economic, social or family use.

"Recently too I had gone to pay school fees for two of my children so the money on me if I came was not enough" [Int. 15]

The women did not seem to have any problems with their health seeking journey. They believed their decisions and the timing of actions taken was justified; it could not have been any other way. At the time they had decided to seek medical care, the breast symptom was a singular priority, and nothing was considered a hindrance.

"Well the time I felt the pain I did not delay, I went to the hospital. They gave me a referral on Tuesday, only Wednesday passed and I travelled here on Thursday. I am okay with how things have gone" [Int. 15].

"I am pursuing this because of the children, if I die they will become miserable" [Int. 9]

"W*ell if you want good for yourself you must spend money" [Int. 7]*

"I was not bothered about coming here because I want my good health back" [Int. 3]

"The distance is far but if it will help me then there is no problem" [Int. 12]

Essentially, while deferring healthcare was related to ability to perform economic, family and social roles, pursing healthcare was also for the same economic, family and social reasons or goals.

Discussion

The personal phase – the prioritization cycle

It is not the physical characteristics of a breast symptom, but how it affects a woman's function that provokes health seeking. As observed in this study, breast symptoms that interfere with daily activity or function is a significant factor in deciding that breast disease is serious and needs medical attention [18, 39]. This suggests that the breast symptom is not appraised as an isolated entity, but with regard to its effects on function. How the symptom interrupts economic, family and social function is an important factor in defining severity/illness requiring urgent medical attention. The mere presence of the breast symptom is not alarming enough until it is perceived as a threat to, or actually impacts functionality.

Breast cancer campaign messages in Ghana generally encourage screening, especially self-breast examination for early signs of breast cancer and where detected, to immediately seek care. The general expectation is that appraisal of a breast cancer symptom should culminate in the decision to seek treatment, and this health seeking action is again anticipated to be immediate – without delay. Reasonably, the responsibility to appraise and classify breast symptom as needing medical attention and following through with the health seeking behaviour cannot be taken away from the individual. This desired health seeking behaviour has been communicated in diverse ways. In spite of this, delayed health seeking persists. It appears that having the information does not guarantee timely health seeking behaviours. From their exploration of the cultural model of breast cancer among low-income African American women, Barg and Grier [44] attribute this to the different cultural beliefs and experiences that exist about breast cancer. Thus, the intended meaning (i.e. the cognitive and affective response to be evoked) to be conveyed in breast cancer communication may not be the actual meaning created during a woman's interpretation of the message [44]. Even where the intended and actual meanings are congruent, Granek and Fergus [45] in their discussion of issues of agency and liminality of women's symptom appraisal and help-seeking behaviour upon discovery of a breast symptom assert that women who are not ready to present their breast symptoms to a physician remain 'deliberately ignorant' of it because they have other areas in their life that needs attention and that are not hindered by the threat of breast cancer, or the early symptoms of breast disease. Whilst this assertion may be true, the findings from this study suggest that women are not necessarily deliberately ignorant. Rather they remain aware of their symptoms but make active choices of prioritising other areas in their life needing attention until such time that seeking care for their breast symptoms is the means to achieve those other previously prioritised choices. In other words, when their perceived priorities are latterly threatened by the breast symptom, seeking medical attention to treat the breast symptoms becomes a means to ensure that those previous priorities are maintained or restored.

The decision-making process of health seeking is thus part of an ongoing process of iterative priority setting process, the ultimate goal of which is to maintain important economic, family and or social function.

Acting on the breast symptom is thus one of the other means (e.g. work, child care) to achieving some economic, social or family goal, such that its place on the activity priority ladder depends on how it is directly related to achieving these goals. There is an awareness of the breast condition, but this 'joins the queue' of other important things that also need to be done. As such, for some women, the timing for health seeking is not delayed. *The timing is right*; the time when the symptom is beginning to threaten economic/family/social goals; the time when if the symptom is not dealt with, other priorities cannot be achieved; the time when health seeking for the breast symptom becomes the means by which the other activities can be sustained; the time when in the regular priority setting agenda, it has become the number one activity to be done in the daily pursuit of economic, family and social function.

The health facility phase

Breast cancer treatment tends to be offered in specialised centres. Referrals are therefore necessary for many women in the health seeking journey. For the women in this study, referrals were not just for treatment but also for investigations to establish diagnosis. This journey translates into time, money and the use of other resources, competing with daily efforts to maintain their economic, family and social function. Having to commit these resources to health seeking further affects the decision of when to pursue healthcare, especially when the symptom is not perceived as a threat to function. This initial inertia could be further entrenched by already existing narratives about breast cancer care – cost, time etc. Even when the health seeking journey has been initiated, activities such as diagnostic investigations may be deferred as economic, family or social goals come up and compete for resources.

Probably, a clear understanding of the false economy of delaying treatment in competition with the very economic, family and social goals they hold so dear could have led to different health seeking choices.

Conclusions And Recommendations

Deciding to seek care and pursue treatment for breast cancer symptoms may be much more complicated than it appears. Economic, family and social function significantly drive the health seeking process both at the personal and health facility phases of health seeking.

It may be useful if breast cancer campaign messages delivered by national and local public health agencies are adapted to incorporate these functional goals and their role in symptom appraisal and decision making rather than focus on the breast symptom as an isolated entity. A national document on breast cancer education approved by all stakeholders should be developed to serve as the basis for breast cancer campaign messages delivered on all media and local group platforms to ensure uniformity and consistency of the information given to women.

Further, there is need for more research to explore how health workers, non-governmental organizations and other stakeholders who are involved in breast cancer campaigns and treatment can provide targeted communication and counselling support to women to undergo breast cancer investigations and treatment.

Limitation

There was likely some recall bias as the women were recollecting activities that had occurred several weeks to months prior to arriving at the breast clinic.

Abbreviations

WHO – World Health Organisation

KATH – Komfo Anokye Teaching Hospital

CHRPE – Committee on Human Research, Publication and Ethics

SBE – Self breast examination

Declarations

Ethical approval and consent to participate

Ethical approval for the study was obtained from the Committee on Human Research, Publication and Ethics (CHRPE) in Ghana (CHRPE/AP/386/14). All the study participants signed a written informed consent before proceeding with the interview.

Availability of data

We do not have participants' consent to share their data – including anonymized forms of complete interview recordings and their transcriptions.

Competing interests

All the authors declare that they have no competing interests

Funding

This research was funded by the authors. We did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Author contribution

- AEA – Conception, design, acquisition, analysis of data and initial draft of manuscript
- JA – Substantively revised the manuscript
- JB – Substantively revised the manuscript
- BBK – Substantively revised the manuscript
- IK – Substantively revised the manuscript

Acknowledgements

We are grateful to Dr. Sara Morris and Dr. Anne Grinyer, both formerly of the Faculty of Health and Medicine, Lancaster University UK who co-supervised this research.

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