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# **BMJ Open**

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## An exploratory study of illness perception and coping among women with breast cancer in Ghana

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#### Abstract

**Objective:** Illness perception has been shown to have significant influence on the wellbeing and coping strategies of persons living with chronic medical conditions. Understanding of how women living with breast cancer cognitively and emotionally represent their illness and coping strategies utilized is likely to help in designing focused psychosocial interventions aimed at improving their health and wellbeing. This study explored the illness perceptions and coping strategies among women receiving care for breast cancer.

**Design:** A qualitative study-phenomenology (using semi-structured in-depth interviews)

**Setting:** Oncology department of a tertiary hospital in Ghana

**Participants:** Eleven (11) women receiving breast cancer treatment were purposively sampled and in-depth individual interviews were conducted with questions based on previous illness perception and coping literature.

**Results:** In terms of illness perceptions, it emerged that most of the participants lacked adequate factual knowledge about breast cancer and perceived causes but believed in the curability of their illness through the medical treatments and the help of God. Spirituality, social support, diversion coping and self-care practices were the key resources for coping among the participants.

**Conclusion**: Breast cancer patients lacked adequate factual knowledge of breast cancer and their perception about the causes of breast cancer is rooted in biopsycho-spiritual model of illness. The reliance on spirituality and social support as the main coping strategies suggests the need for psychosocial interventions tailored to the spiritual and psychosocial needs of the patients.

### Strengths and limitations of this study:

- This study is the first of its kind which comprehensively explored illness perceptions and coping strategies among breast cancer patients.
- Findings from this study have laid the foundation for more psycho-oncology research focused on understanding bio-psychosocial issues associated with living with breast cancer to inform evidence-based interventions.
- The sample included only breast cancer patients receiving oncology care at only one referral hospital and findings may not represent the views of patients located at other parts of Ghana.

**Keywords**: Illness perception, coping strategies, breast cancer, Ghana

#### INTRODUCTION

Living with breast cancer presents women with significant challenges that they must deal with as the illness interferes with their physical, social, psychological, economic and spiritual lives [1, 2]. These challenges have been found to be the major contributing factors to decreased health-related quality of life among women living with breast cancer [3-5]. Evidence suggests that women diagnosed with breast cancer differ in their reaction to the illness and that these reactions in turn influence their coping strategies and disease management [6].

Breast cancer patients' cognitive and emotional representations of their illness becomes a critical aspect of the healthcare delivery process which cannot be overlooked. This is because patient-centered care requires health professionals to take the needs and views of patients into consideration to ensure satisfaction and thus, improved health outcomes [7]. Illness perceptions among breast cancer patients have been linked to several health outcomes including depression, anxiety, physical and mental quality of life [8-10].

However, the specific socio-cultural and economic contexts may influence patients' perception and understanding of their illness which are inextricably linked with their lived experiences. The interrelationships among the entire experiences of the women suggest that the socio-economic and cultural factors may impact on how patients make meaning of their illness and these illness representations may influence the lived experiences of the patients. Thus, the relationships among these factors are multidimensional and may sometimes revolves in a cycle as the lived experiences may also influence the socio-economic status and illness perception of the patients. These represent significant challenges confronting women living with breast cancer.

In dealing with the multitude of challenges, various coping strategies are employed. It has been argued that coping plays a major role in the lives of persons diagnosed with chronic medical conditions including breast cancer [11]. As noted earlier, the illness representations of the women are likely to influence the type of coping strategies they adopt in trying to adjust with the burden of the medical treatment and living with the disease. Evidence suggests that spirituality, social support, acceptance, cognitive restricting and avoidance are common coping strategies among women living with breast cancer [12-14]. These coping strategies among breast cancer patients significantly influence their health outcomes [15].

However, contextual and cultural differences may influence the illness representation and coping strategies that are employed by women living with breast cancer in a low-resourced healthcare setting like Ghana. Studies among Ghanaian women diagnosed with various cancer types have showed that surrendering to God, illness acceptance, the will to live and self-care practices as key coping strategies [16, 17]. These studies did not consider the cognitive and emotional representations of breast cancer and how these perceptions may influence coping strategies. There is paucity in the literature regarding illness repression and coping strategies utilized by women living with breast cancer and the current study explored the illness perception and coping strategies used by women living with breast cancer in Ghana. It is believed that this information would provide practitioners and researchers with the roadmap to improving the health and wellbeing of women living with breast cancer as their illness perceptions are most likely to inform treatment choice and overall health seeking behaviours.

#### **METHODS**

## Research design and research setting

A qualitative research design (phenomenology rooted in the interpretivist paradigm) was employed to understand the lived experiences of breast cancer patients regarding their illness representation and the coping strategies they adopt in their breast cancer journey. The population for this study consisted of all women diagnosed with breast cancer and receiving treatment at the Radiotherapy and Nuclear Medicine Department of the Korle-Bu Teaching Hospital (KBTH) in Ghana, West Africa. The Korle-Bu Teaching Hospital is one of the Tertiary Hospitals and the oldest in terms of healthcare provision in Ghana. Patients who access healthcare at the KBTH are usually referred from the smaller health facilities. This hospital caters for all patient groups regardless of socioeconomic status. The National Health Insurance Scheme covers part of the cancer treatment but patients still bear some of the cost not covered by the scheme.

#### Participants and sampling

A total of eleven (11) women receiving treatment for breast cancer were purposively sampled after they were initially recruited for a quantitative study [4, 5, 11]. In terms of the demographic characteristics of the sample, it was observed that most of the participants were younger than 60 years and all of the participants except one reported to be a Christian. The details of the distributions in terms of marital status, years of marriage, number of children, employment status, educational level, duration of illness and the types of treatment received are summarized in Table 1.

### [INSERT TABLE 1 HERE]

### Patient and public involvement

There was no patient or public involvement in setting the research agenda.

### **Data collection procedure**

An interview guide was used to conduct in-depth individual interviews with the women living with breast cancer to explore their illness perception and coping strategies within the Ghanaian context as culture influences the perceptions causal attributions and experience of illness [18]. All the participants were visited in their homes and their informed consents were sought after the purpose of the study was explained to their understanding. Permission was also sought to record the interviews using an audio recorder. An interview guide was used and it focused on two key topics: illness perception and coping strategies. The responses from the participants were used to generate further probing questions for clarifications as the interview guide allowed for flexibility. The data collection lasted between September, 2017 and January, 2018. The individual interviews lasted between 30 and 60minutes.

#### Data analysis

Verbatim transcription of the audio recording was done. This was to ensure that the views expressed by the participants are not distorted. Most of the participants could speak English and thus, all the interviews were conducted in English with few local language interjections to emphasize their views. These interjections were appropriately translated as the researchers understand the predominant Ghanaian language which is Twi. The Interpretative Phenomenological Approach (IPA) which involves exploration of participants' own subjective real-life experiences with no attempts at measuring the objectiveness of the experiences of the

women living with breast cancer were used [19]. The analysis utilized the four principles and guidelines (gaining an understanding of the transcribed interview by reading and re-reading of the data and identifying points of interest, linking identified and harmonized quotes together to form themes, making connections with identified themes, and summarizing main themes together with their sub-themes with their appropriate quotations) recommended by Storey [20]. In following the guidelines stated above, the researchers read and re-read the transcribed data which allowed for an in-depth understanding of the views of the participants. The researchers proceeded to make meaning of the data and developed themes to encapsulate the views expressed by the participants. Sub-themes were developed to elaborate on the dimensions of the major themes that emerged from the data. The sub-themes were supported with direct quotes from the narratives of the participants for emphasis. 6/6/

#### **RESULTS**

#### **Illness representation**

This main them describes participants' cognitive and emotional representations of their illness. Participants understanding and meanings of breast cancer are likely to influence their lived experiences. Under this theme, three main sub-themes were found which are breast cancer knowledge, perceived causes of breast and duration/curability of breast cancer.

#### Knowledge of breast cancer

Factual and accurate knowledge about breast cancer is likely to help patients in their adjustment to their illness as it may minimize the uncertainties surrounding breast cancer. Two key dimensions of what participants think breast cancer emerged. That is, those who have no factual knowledge

and those who have some factual knowledge about breast cancer. The majority of the participants do not have any factual knowledge about breast cancer as illustrated by a narrative from one of the participants:

"as a matter of fact, if you ask me, I wouldn't know even before the thing (breast cancer) happened, I had not heard of the name before and in my family, I had not heard that anyone has had that disease before" (P6).

Contrary to the above, some of the participants had some factual knowledge about what breast cancer is with emphasis on the biological changes cells of the breast as illustrated below:

"It starts with the lump. I think when you go earlier, they can just take the lump out for you. When you don't see it and it spreads, that's when it becomes cancerous...Like I told you, at the initial stages, I thought it was meant for old ladies who'd given birth already, sixty years upwards. That was what was in my mind. That was how I knew breast cancer to be. Nowadays in your thirties and forties, if you're not careful, you'll get it" (P4).

### Perceived causes of breast cancer

Participants in the study had varied views about their perceived causes of breast cancer. Whereas a substantial number of the women stated that they did not know how their breast cancer came about or they have no ideas as to what might have caused their disease, others mentioned supernatural forces, physiological and stress as the possible causes of their illness.

"I do not know my child (referring to interviewer). As for me...hmmm...I do not know. Sometimes, they say it is a family sickness or runs through the family but my mother did not experience this, neither did any member from my father's family experience this.....hmmm...so my child (interviewer)....I don't know ooo" (P8).

Some of the participants perceived their illness to have some underlying supernatural causes and these perceived causes were influenced by what they have heard from people and their own beliefs.

"... well my sister was saying as for breast cancer, it is an evil spirit people give it to people and so on. And you see this superstition me I told her that me I don't know o... so she was preventing me not to go for the surgery because she thought if I go for the surgery, I will die so I told her that, sister let me go if I die praise God, I will die with my fine body unlike sitting down this thing (breast cancer) will get worst, spread over my body, I don't know how I will look like when I will die... (P4)".

Another participant emphatically stated that she is convinced that extreme stress from her work might have caused her breast cancer.

"...as for mine (breast cancer), I suspect stress...high level of stress... I am not someone who lives a careless life. By nature, I am the prudent type in all aspects of life...eating...whatever. I have never even taken alcohol before in my whole life. I do not even know how it tastes...and I am not someone who leads reckless life. You see...they said this disease is a lifestyle related problem. My psychologist sat with me trying to find out my family life and I realized that the only thing that I did that

my body kept signaling me that I didn't head to was stress. High levels of stress. Otherwise, my eating level is not bad, my marriage is not bad, my children are grown and it is not like I had little children giving me pressure at home. In fact I realized that it was more work-based. Because at a point in time, I was always having breakdowns. For about 3 years, my white blood cells were not functioning properly so I was on immune boosters and all manner of supplements" (P11).

Another participant also reported physiological basis as the perceived cause of her breast cancer she indicated that her inability to breastfeed her child after delivery might have led to her breast cancer.

"....my belief is that because I did not give my girl (her daughter) the breast milk and I was forcing it to come... They have an extractor that you put at your nipple and it would extract the milk. I used it but it did not work for me. This right breast of mine, I really worked on it. I really forced it. I feel it is caused by the milk that was supposed to come out but did not come. If I had gotten any old lady to tell me. They have a way of doing it, if you don't breastfeed your child, they'll give you some medicine, you'll rub it on your breast and by the time you realise, it will come out by itself. As at that time, I didn't know anything like that and by the time I realised, the thing was hardened" (P3).

#### Duration/curability of breast cancer

From the analysis, it was not possible to separate illness duration from curability as most of the participants linked duration to curability. A substantial number of the participants were of the view

that their breast cancer can be completely cured with the medical treatments and help of God. However some of the participants were not sure of the curability of the disease. The participants went further to provide reasons for their perceived duration/curability of their breast cancer as illustrated below.

"Nothing is too hard for the Lord. God can do a lot of miracles. God also uses doctors to perform his miracles. That is why I always run to doctors when I am sick...as for me...with the treatment I am currently going through...I know of someone who started with it since the year 2000 and the person is still alive and kicking. Nothing has happened to her....So I know that God will also have favour on me so that I can be healed completely" (P10).

"Aww....according to people....For instance, my siblings showed me one woman who has been treated of breast cancer for about 18 years now. A lot of people...even in my church....there are people I know have been cured of the disease....almost about 4 people. They all confessed to have gotten some but now, they have been cured. What I have realized to be the most difficult aspect is the chemotherapy...if i am try my best and go through the process, I know I will be fine. There was one woman who also testified that she had this disease when she was 71 just like me and now she is 82...she is very strong. She told me that if I am able to go through all the processes, I will become stronger than how I am now. However, I don't really know how long my sickness will last" (P8).

However, a participant was of the opinion that she is uncertain about the duration/curability of her sickness since the causes are not even known in the first place.

"I don't really know because like we are saying...I don't know the root cause. Sometimes, they say it is from your diet...sometimes but I don't really know. I can't tell because we haven't found the real cause of the disease...so to say it can be done away completely....I am not sure...I believe with the mastectomy and radiation, it will go away very soon...because of the treatment and my faith in God" (P9).

Another participant had mixed perceptions about the duration/curability of her breast cancer and stated that it all depends on the stage of the disease.

"...yes, I think at times. I may say yes or no. And seeing that the thing is now common, I think when you report early, it can help. And I may say that, even the doctors...I mean...those medicines, some are very strong so they have to add some local herbs. I think some herbs can help a lot...than even these orthodox medicine" (P6).

#### Coping with breast cancer

This theme describes ways in which persons living with chronic medical conditions such as breast adjust to their life circumstances. In their adjustment process, they employ several coping strategies that may influence both their short and long-term health outcomes. Three key coping strategies emerged from the interviews: the use of spirituality/religious coping, social support and seeking diversion. It is, however, to note that the participants in the study did not rely on only one form of coping but a myriad of strategies all aimed at helping to adjust to the disease and improve their quality of life.

#### Spirituality/religious coping

Almost all the participants mentioned that breast cancer and its treatment has drawn them closer to God/Allah. That is, they were of the view that living with breast cancer and undergoing the difficult medical treatments have strengthened their faith in God/Allah and helped them in in dealing with the challenges associated with living with breast cancer. Some of the participants engaged in several religious activities such as daily prayers and rituals to help them cope with their condition i.e. in building of hope, financial provision, healing and acceptance of their health condition as reflected in the quotations below:

".....It has rather strengthened my faith because...you know....when something happens to you, as a Christian, you trust God that, He is your healer, so it has strengthen my faith in God that He will heal me...even though the doctors are working on it. He is the ultimate Healer" (P9).

"...so you see...so if you don't have faith that God will provide for the treatment...I mean what do you do? You just lose hope. But with God...you trust that help will come. So our faith in God should rather strengthen us in this times (of living with breast cancer)" (P4).

Apart from religiosity and spirituality providing hope and healing to the participants, reliance on God served to provide companionship to some participants. This helps women to make meaning of their social role limitations and viewed God as their hope and source of comfort:

"... I think it (breast cancer and its treatment) has even made me much stronger because at a point in time, I didn't have anybody apart from God. So it has rather drawn me closer to God...just that some roles that I was playing in church, because I am now not too regular in church, I am not able to play those roles because of the sickness but I am very close to God than before" (P11).

On the other hand, the use of spirituality as a coping mechanism is influenced by the participants' belief that their disease is a test from God which they must pass and therefore, will not give up.

"I think it is just a test from God...hmm because one cannot live His life just like that, if you say you believe in God He will never leave you like that. He tests you to see whether it is true you believe in Him and whether you will divert your faith somewhere. This is what my faith tells me. He has brought it and shown me a way out of it" (P2).

These quotes from the participants indicate that God or a supreme being plays an important part in the breast cancer journeys of these women and thus, may subsequently influence their perception of the illness and overall health outcomes through acceptance, hope, companionship and meaning making.

## Social support

From the narratives, social support in the forms of emotional, financial and instrumental support emerged as key coping strategies. Social support plays significant role in the overall coping with the disease. One thing that run through all the narratives was social support from immediate family most especially, children, spouses and siblings. Below are some direct quotes from participants regarding the value of social support in coping.

"Everything is normal now because my husband is matured and I am also old. I am 50 years. My husband is a matured person and this is not what will make him say 'I don't love you again'. So things are quite normal in my home. He is very supportive. The children too are grown. It is not like little kids that you have to do so much for them. They are also cooperative so I don't really have any serious challenge at home" (P11).

"They (family) are crying for me. I'm here with my dad, he takes care of me so he sees me. If there's any help, he assists me. Those abroad, especially my mum, she calls me every day. She calls to check up on me and find out how I am doing, because she's not here. She should be here but she also has a problem. She has to have a surgery on her spine. My brothers too support me with money" (P3).

## Diversion coping

A substantial number of the participants in the study also reported the use of diversion coping strategies which include listening to music, or religious sermons and/or watching movies to take their minds off their breast cancer.

For participants who use songs and inspirational messages, one woman reported that;

"I love songs ...so I have a lot of songs on my phone which I listen to. Sometimes on the television too...Mostly, gospel songs. A few friends who are also aware of the situation do send me inspirational messages. When I read them, it encourages me. You are a Christian but sometimes, you get down as a human being. You need to encourage yourself so I like reading them" (P11).

Other participants use either television alone or both as illustrated by the following direct quotes from the participants;

"...oh I watch movies if I am at home, you see once a while you will laugh err if it's emotional too you say aww and I watch movies, I like watching movies not any movie at all but movies that encourage and inspire me or make me laugh... local, foreign. You see some movies... you learn from them, you learn from them maybe like somebody has done something and you see it you would not want to do it because of the end results "ahaa" so I like watching movies, movies that will educate you. You see, not any movie at all, will educate you, encourage you or teach you lesson. I also like music, I listen to music a lot especially, gospel, even these local music like the ones by Ampofo Adjei (a Ghanaian musician) and co if you listen to the words and lyrics in the song you can see that they inspire you" (P4).

These quotes from the participants suggest that radio and television may play significant roles in their breast cancer journey as it may serve to help them cope and as a potential source of life lessons that might be meaningful to them.

#### **DISCUSSION**

This study explored illness perception and coping among women with breast cancer in Ghana. In this study, we found that participants cognitive and emotional representations of their illness was influenced by three main factors namely their knowledge about breast cancer, perceived causes of breast cancer and duration/curability of breast cancer. The majority of women living with breast cancer lacked factual information about breast cancer is all about and its potential causes. This lack of inadequate knowledge about breast cancer has consequences for patients' illness perception and treatment outcomes [21-23]. This is because perceptions of the causes of breast cancer could influence patients' ability to adhere to medical treatments as erroneous beliefs may lead to seeking alternative healthcare from unapproved sources. There are inadequate qualitative studies exploring cognitive and emotional representations of breast cancer as most of the studies were either cross-sectional or longitudinal examining the impact on health outcomes[6]. However, evidence abounds in other chronic disease conditions like diabetes especially in Ghana which found that chronic diease patients make several causal attributions rooted in the supernatural [24].

For example, a participant recounted that she seems to be moving in circle with no apparent difference in her circumstances. That is, her focus was on the short-term outcomes such as the side effects of the medical treatment procedures and not the long-term health outcomes of the treatment. However, most of the participants believed that their illness can be completely cured and that they believe their illness will not last long so far as they have God and go through the medical treatments. This perception of the curability and duration of the illness is rooted in the personal faith of the participants as reference to God run through all the responses of the participants.

The subjective perceptions of women living with breast cancer influenced their coping strategies. Participants used three main resource for coping with their illness namely spiritual/religious coping, social support and diversional strategies such as listening to music and watching of movies. Spirituality plays a significant role in the life of the African and for that matter Ghanaians and therefore, served as a major resource for them in coping with the challenges of living with breast cancer [25, 26]. This finding is consistent with previous studies which found deferring responsibility to God and personal faith as important resource for coping with breast cancer [13, 14]. Participants reliance on their personal spirituality as a coping strategy could be attributed to their lack of inadequate knowledge about the disease and its causes as well as the uncertainties surrounding the outcomes of the medical treatment. It was observed that reliance on God and spirituality has led to disease acceptance among the participants which serves to protect them against the experience of negative emotional states. Acceptance of a disease has been reported by other studies among women with different cancer types [16, 17].

We also found that social support from family members and friends served as a key coping resource for women living with breast cancer. Evidence in the psycho-oncology literature revealed that social support plays a pivotal role in the treatment of breast cancer and its aftermath [12-14]. Social support from family, friends and significant others have been linked to decreased mental health problems such as depression, anxiety and suicidal behaviours and improved quality of life among women living with breast cancer [27-30]. This finding underscores the need for improved social networks and support systems for women living with breast cancer to cushion them against the negative consequences of the medical treatment and living with breast cancer.

Interestingly, we found that participants use music and films to divert attention from the breast cancer. Radios and televisions served as the main sources of these music and films which help women avoid thinking about their predicament. The use of this coping strategy may relate to a component of cancer-specific coping strategies called cognitive avoidance which has been linked to decreased depression and anxiety but improved quality of life among women living with breast cancer [31, 32]. On the other hand, a few of the participants indicated that they rely on self-care practices in the form of adherence to their medical treatments and dietary habits as coping strategies. Although not mentioned frequently by the participants, adherence to medical treatments and other prescribed self-care practices could have significant impact on disease outcome of the women. Evidence in the cancer literature suggests the use of self-care practices as coping strategies employed by patients living with breast cancer [16, 33-35].

The findings from this study imply that there is the need for oncology healthcare workers to understand how breast cancer is cognitively and emotionally represented by their clients and factor these perceptions into their health communication and treatment strategies. The use of varied coping strategies suggests that oncology healthcare workers need to provide support and encourage patients to participate in activities geared towards recovery as well increased social networks. The study is however limited to only patients receiving care at the chosen health facility which may not necessarily represent the views of all women living with breast cancer in Ghana. Despite this shortcoming, the information provided may serve as the basis for future studies which would examined illness perceptions and their influence on the short and long-term health outcomes of women living with breast cancer.

#### Conclusion

There is a general lack of factual knowledge about breast cancer which manifested in most participants reporting no knowledge or belief of what might have caused their disease. However, most participants believed that their disease can be completely cured and this belief was rooted in their faith in God and on the medical treatments which suggests the importance of incorporating some positive religious activities into the overall treatment regimen of the women living with breast cancer. In terms of the coping strategies, religious faith and spirituality were prominent but other coping resources such as social support from family and friends proved to be significant in adjusting to living with breast cancer and the negative effects of the medical treatment. Diversion coping and the use of self-care practices were also reported by the participants. It is heart-warming that the participants did not report the use of a lot of maladaptive coping strategies. a loc

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**Data sharing statement:** Due to the nature of the data (audio recordings and transcripts), we are not able to share the raw data. We are able to share upon request the deidentified transcripts to researchers for the purposes of further analysis and comparison or research translation.

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Based on the SRQR guidelines.

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		Reporting Item	Page Number
Title			
	<u>#1</u>	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract	<u>#2</u>	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2-3
Introduction			
Problem formulation	<u>#3</u>	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4-5
Purpose or research question	<u>#4</u>	Purpose of the study and specific objectives or questions	5

#### **Methods**

Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	6
Researcher characteristics and reflexivity	<u>#6</u>	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	N/A
Context	<u>#7</u>	Setting / site and salient contextual factors; rationale	6
Sampling strategy	<u>#8</u>	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	6
Ethical issues pertaining to human subjects	<u>#9</u>	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7 & 22
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	7

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## An exploratory study of illness perception and coping among women with breast cancer in Ghana

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#### **Abstract**

**Objective:** Illness perception has been shown to have significant influence on the wellbeing and coping strategies of persons living with chronic medical conditions. Understanding of how women living with breast cancer cognitively and emotionally represent their illness and coping strategies utilized is likely to help in designing focused psychosocial interventions aimed at improving their health and wellbeing. This study explored the illness perceptions and coping strategies among women receiving care for breast cancer.

**Design:** A qualitative study-phenomenology (using semi-structured in-depth interviews)

**Setting:** Oncology department of a tertiary hospital in Ghana

**Participants:** Eleven (11) women receiving breast cancer treatment were purposively sampled and in-depth individual interviews were conducted with questions based on previous illness perception and coping literature.

**Results:** In terms of illness perceptions, it emerged that most of the participants lacked adequate factual knowledge about breast cancer and perceived causes but believed in the curability of their illness through the medical treatments and the help of God. Spirituality, social support, diversion coping and self-care practices were the key resources for coping among the participants.

Conclusion: Breast cancer patients lacked adequate factual knowledge of breast cancer and their perception about the causes of breast cancer is rooted in biopsycho-spiritual model of illness. The reliance on spirituality and social support as the main coping strategies suggests the need for psychosocial interventions tailored to the spiritual and psychosocial needs of the patients.

### Strengths and limitations of this study:

- This study is the first of its kind which comprehensively explored illness perceptions and coping strategies among breast cancer patients.
- Findings from this study have laid the foundation for more psycho-oncology research focused on understanding bio-psychosocial issues associated with living with breast cancer to inform evidence-based interventions.
- The sample included only breast cancer patients receiving oncology care at only one referral hospital and findings may not represent the views of patients located at other parts of Ghana.

**Keywords**: Illness perception, coping strategies, breast cancer, Ghana

#### INTRODUCTION

Living with breast cancer presents women with significant challenges that they must deal with as the illness interferes with their physical, social, psychological, economic and spiritual lives [1, 2]. These challenges have been found to be the major contributing factors to decreased health-related quality of life among women living with breast cancer [3-5]. Evidence suggests that women diagnosed with breast cancer differ in their reaction to the illness and that these reactions in turn influence their coping strategies and disease management [6].

Breast cancer patients' cognitive and emotional representations of their illness becomes a critical aspect of the healthcare delivery process which cannot be overlooked. This is because patient-centered care requires health professionals to take the needs and views of patients into consideration to ensure satisfaction and thus, improved health outcomes [7]. Illness perceptions among breast cancer patients have been linked to several health outcomes including depression, anxiety, physical and mental quality of life [8-10].

However, the specific socio-cultural and economic contexts may influence patients' perception and understanding of their illness which are inextricably linked with their lived experiences. The interrelationships among the entire experiences of the women suggest that the socio-economic and cultural factors may impact on how patients make meaning of their illness and these illness representations may influence the lived experiences of the patients. Thus, the relationships among these factors are multidimensional and may sometimes revolves in a cycle as the lived experiences may also influence the socio-economic status and illness perception of the patients. These represent significant challenges confronting women living with breast cancer.

In dealing with the multitude of challenges, various coping strategies are employed. It has been argued that coping plays a major role in the lives of persons diagnosed with chronic medical conditions including breast cancer [11]. As noted earlier, the illness representations of the women are likely to influence the type of coping strategies they adopt in trying to adjust with the burden of the medical treatment and living with the disease. Evidence suggests that spirituality, social support, acceptance, cognitive restricting and avoidance are common coping strategies among women living with breast cancer [12-14]. These coping strategies among breast cancer patients significantly influence their health outcomes [15].

However, contextual and cultural differences may influence the illness representation and coping strategies that are employed by women living with breast cancer in a low-resourced healthcare setting like Ghana. Studies among Ghanaian women diagnosed with various cancer types have showed that surrendering to God, illness acceptance, the will to live and self-care practices as key coping strategies [16, 17]. These studies did not consider the cognitive and emotional representations of breast cancer and how these perceptions may influence coping strategies. There is paucity in the literature regarding illness repression and coping strategies utilized by women living with breast cancer and the current study explored the illness perception and coping strategies used by women living with breast cancer in Ghana. It is believed that this information would provide practitioners and researchers with the roadmap to improving the health and wellbeing of women living with breast cancer as their illness perceptions are most likely to inform treatment choice and overall health seeking behaviours.

#### **METHODS**

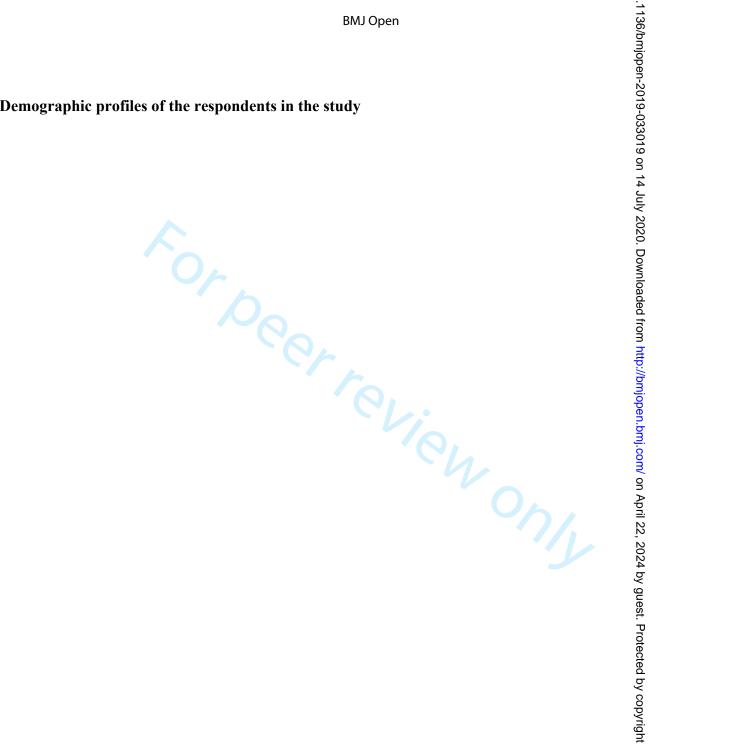
# Research design and research setting

A qualitative research design (phenomenology rooted in the interpretivist paradigm) was employed to understand the lived experiences of breast cancer patients regarding their illness representation and the coping strategies they adopt in their breast cancer journey. The population for this study consisted of all women diagnosed with breast cancer and receiving treatment at the Radiotherapy and Nuclear Medicine Department of the Korle-Bu Teaching Hospital (KBTH) in Ghana, West Africa. The Korle-Bu Teaching Hospital is one of the Tertiary Hospitals and the oldest in terms of healthcare provision in Ghana. Patients who access healthcare at the KBTH are usually referred from the smaller health facilities. This hospital caters for all patient groups regardless of socioeconomic status. The National Health Insurance Scheme covers part of the cancer treatment but patients still bear some of the cost not covered by the scheme.

#### Participants and sampling

A total of eleven (11) women receiving treatment for breast cancer were purposively sampled after they were initially recruited for a quantitative study [4, 5, 11]. In terms of the demographic characteristics of the sample, it was observed that most of the participants were younger than 60 years and all of the participants except one reported to be a Christian. The details of the distributions in terms of marital status, years of marriage, number of children, employment status, educational level, duration of illness and the types of treatment received are summarized in Table 1.

Table 1: Demographic profiles of the respondents in the study



#### Patient and public involvement

There was no patient or public involvement in setting the research agenda.

# **Data collection procedure**

Ethical approvals for this study were obtained from the Humanities and Social Sciences Ethical Committee (HSS/1428/016D) of the University of KwaZulu-Natal, South Africa and Scientific and Technical Committee as well as Institutional Review Board of the Korle-Bu Teaching Hospital in Ghana (KBTH-IRB/00035/2016). An interview guide (See Appendix 1) was used to conduct in-depth individual interviews with the women living with breast cancer to explore their illness perception and coping strategies within the Ghanaian context as culture influences the perceptions causal attributions and experience of illness [18]. All the participants were visited in their homes and their informed consents were sought after the purpose of the study was explained to their understanding. Permission was also sought to record the interviews using an audio recorder. An interview guide was used and it focused on two key topics: illness perception and coping strategies. The responses from the participants were used to generate further probing questions for clarifications as the interview guide allowed for flexibility. The data collection lasted between September, 2017 and January, 2018. The individual interviews lasted between 30 and 60minutes.

#### Data analysis

Verbatim transcription of the audio recording was done. This was to ensure that the views expressed by the participants are not distorted. Most of the participants could speak English and thus, all the interviews were conducted in English with few local language interjections to emphasize their views. These interjections were appropriately translated as the researchers understand the predominant Ghanaian language which is Twi. The Interpretative

Phenomenological Approach (IPA) which involves exploration of participants' own subjective real-life experiences with no attempts at measuring the objectiveness of the experiences of the women living with breast cancer were used [19]. The analysis utilized the four principles and guidelines (gaining an understanding of the transcribed interview by reading and re-reading of the data and identifying points of interest, linking identified and harmonized quotes together to form themes, making connections with identified themes, and summarizing main themes together with their sub-themes with their appropriate quotations) recommended by Storey [20]. In following the guidelines stated above, the researchers read and re-read the transcribed data which allowed for an in-depth understanding of the views of the participants. The researchers proceeded to make meaning of the data and developed themes to encapsulate the views expressed by the participants. Sub-themes were developed to elaborate on the dimensions of the major themes that emerged from the data. The sub-themes were supported with direct quotes from the narratives of the participants for emphasis.

#### **RESULTS**

#### Illness representation

This main them describes participants' cognitive and emotional representations of their illness. Participants understanding and meanings of breast cancer are likely to influence their lived experiences. Under this theme, three main sub-themes were found which are breast cancer knowledge, perceived causes of breast and duration/curability of breast cancer.

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#### Knowledge of breast cancer

Factual and accurate knowledge about breast cancer is likely to help patients in their adjustment to their illness as it may minimize the uncertainties surrounding breast cancer. Two key dimensions of what participants think breast cancer emerged. That is, those who have no factual

knowledge and those who have some factual knowledge about breast cancer. The majority of the participants do not have any factual knowledge about breast cancer as illustrated by a narrative from one of the participants:

"as a matter of fact, if you ask me, I wouldn't know even before the thing (breast cancer) happened, I had not heard of the name before and in my family, I had not heard that anyone has had that disease before" (P6).

Contrary to the above, some of the participants had some factual knowledge about what breast cancer is with emphasis on the biological changes cells of the breast as illustrated below:

"It starts with the lump. I think when you go (to the hospital) earlier, they can just take the lump out for you. When you don't see it and it spreads, that's when it becomes cancerous...Like I told you, at the initial stages, I thought it was meant for old ladies who'd given birth already, sixty years upwards. That was what was in my mind. That was how I knew breast cancer to be. Nowadays in your thirties and forties, if you're not careful, you'll get it" (P4).

#### Perceived causes of breast cancer

Participants in the study had varied views about their perceived causes of breast cancer. Whereas a substantial number of the women stated that they did not know how their breast cancer came about or they have no ideas as to what might have caused their disease, others mentioned supernatural forces, physiological and stress as the possible causes of their illness.

"I do not know my child (referring to interviewer). As for me...hmmm...I do not know. Sometimes, they say it is a family sickness or runs through the family but my mother did not experience this, neither did any member from my father's

family experience this....hmmm...so my child (interviewer)....I don't know ooo" (P8).

Some of the participants perceived their illness to have some underlying supernatural causes and these perceived causes were influenced by what they have heard from people and their own beliefs.

"Ah...as for me... I do not know if I was shot spiritually or the sickness came on its own. As for me, in all things, I just give it to God. I also told you earlier that I had a dream that I was being shot. Where I had the gunshot in the dream is the same place that I experienced the cancer in the breast" (P7).

Another participant emphatically stated that she is convinced that extreme stress from her work might have caused her breast cancer.

"...as for mine (breast cancer), I suspect stress...high level of stress... I am not someone who lives a careless life. By nature, I am the prudent type in all aspects of life...eating...whatever. I have never even taken alcohol before in my whole life. I do not even know how it tastes...and I am not someone who leads reckless life. You see...they said this disease is a lifestyle related problem. My psychologist sat with me trying to find out my family life and I realized that the only thing that I did that my body kept signaling me that I didn't head to was stress. High levels of stress. Otherwise, my eating level is not bad, my marriage is not bad, my children are grown and it is not like I had little children giving me pressure at home. In fact I realized that it was more work-based. Because at a point in time, I was always having breakdowns. For about 3 years, my white

blood cells were not functioning properly so I was on immune boosters and all manner of supplements" (P11).

Another participant also reported physiological basis as the perceived cause of her breast cancer she indicated that her inability to breastfeed her child after delivery might have led to her breast cancer.

"....my belief is that because I did not give my girl (her daughter) the breast milk and I was forcing it to come ... They have an extractor that you put at your nipple and it would extract the milk. I used it but it did not work for me. This right breast of mine, I really worked on it. I really forced it. I feel it is caused by the milk that was supposed to come out but did not come. If I had gotten any old lady to tell me. They have a way of doing it, if you don't breastfeed your child, they'll give you some medicine, you'll rub it on your breast and by the time you realise, it will come out by itself. As at that time, I didn't know anything like that and by the time I realised, the thing was hardened" (P3).

### Duration/curability of breast cancer

From the analysis, it was not possible to separate illness duration from curability as most of the participants linked duration to curability. A substantial number of the participants were of the view that their breast cancer can be completely cured with the medical treatments and help of God. However some of the participants were not sure of the curability of the disease. The participants went further to provide reasons for their perceived duration/curability of their breast cancer as illustrated below.

"Nothing is too hard for the Lord. God can do a lot of miracles. God also uses doctors to perform his miracles. That is why I always run to doctors when I am

sick...as for me...with the treatment I am currently going through...I know of someone who started with it since the year 2000 and the person is still alive and kicking. Nothing has happened to her....So I know that God will also have favour on me so that I can be healed completely" (P10).

"Aww....according to people....For instance, my siblings showed me one woman who has been treated of breast cancer for about 18 years now. A lot of people...even in my church....there are people I know have been cured of the disease....almost about 4 people. They all confessed to have gotten some but now, they have been cured. What I have realized to be the most difficult aspect is the chemotherapy...if i am try my best and go through the process, I know I will be fine. There was one woman who also testified that she had this disease when she was 71 just like me and now she is 82...she is very strong. She told me that if I am able to go through all the processes, I will become stronger than how I am now. However, I don't really know how long my sickness will last" (P8).

However, a participant was of the opinion that she is uncertain about the duration/curability of her sickness since the causes are not even known in the first place.

"I don't really know because like we are saying...I don't know the root cause. Sometimes, they say it is from your diet...sometimes but I don't really know. I can't tell because we haven't found the real cause of the disease...so to say it can be done away completely....I am not sure...I believe with the mastectomy and radiation, it will go away very soon...because of the treatment and my faith in God" (P9).

Another participant had mixed perceptions about the duration/curability of her breast cancer and stated that it all depends on the stage of the disease.

"...yes, I think at times. I may say yes or no. And seeing that the thing is now common, I think when you report early, it can help..." (P6).

# Coping with breast cancer

This theme describes ways in which persons living with chronic medical conditions such as breast adjust to their life circumstances. In their adjustment process, they employ several coping strategies that may influence both their short and long-term health outcomes. Three key coping strategies emerged from the interviews: the use of spirituality/religious coping, social support and seeking diversion. It is, however, to note that the participants in the study did not rely on only one form of coping but a myriad of strategies all aimed at helping to adjust to the disease and improve their quality of life.

### Spirituality/religious coping

Almost all the participants mentioned that breast cancer and its treatment has drawn them closer to God/Allah. That is, they were of the view that living with breast cancer and undergoing the difficult medical treatments have strengthened their faith in God/Allah and helped them in in dealing with the challenges associated with living with breast cancer. Some of the participants engaged in several religious activities such as daily prayers and rituals to help them cope with their condition i.e. in building of hope, financial provision, healing and acceptance of their health condition as reflected in the quotations below:

".....It has rather strengthened my faith because...you know....when something happens to you, as a Christian, you trust God that, He is your healer, so it has

strengthened my faith in God that He will heal me...even though the doctors are working on it. He is the ultimate Healer" (P9).

"...so you see...so if you don't have faith that God will provide for the treatment...I mean what do you do? You just lose hope. But with God...you trust that help will come. So our faith in God should rather strengthen us in this times (of living with breast cancer)" (P4).

Apart from religiosity and spirituality providing hope and healing to the participants, reliance on God served to provide companionship to some participants. This helps women to make meaning of their social role limitations and viewed God as their hope and source of comfort:

"... I think it (breast cancer and its treatment) has even made me much stronger because at a point in time, I didn't have anybody apart from God. So it has rather drawn me closer to God...just that some roles that I was playing in church, because I am now not too regular in church, I am not able to play those roles because of the sickness but I am very close to God than before" (P11).

On the other hand, the use of spirituality as a coping mechanism is influenced by the participants' belief that their disease is a test from God which they must pass and therefore, will not give up.

"I think it is just a test from God...hmm because one cannot live His life just like that, if you say you believe in God He will never leave you like that. He tests you to see whether it is true you believe in Him and whether you will divert your faith somewhere. This is what my faith tells me. He has brought it and shown me a way out of it" (P2).

These quotes from the participants indicate that God or a supreme being plays an important part in the breast cancer journeys of these women and thus, may subsequently influence their perception of the illness and overall health outcomes through acceptance, hope, companionship and meaning making.

#### Social support

From the narratives, social support in the forms of emotional, financial and instrumental support emerged as key coping strategies. Social support plays significant role in the overall coping with the disease. One thing that run through all the narratives was social support from immediate family most especially, children, spouses and siblings. Below are some direct quotes from participants regarding the value of social support in coping.

"I think I have my family with me...they understand and give me the necessary support so I am okay....I am ok....apart from the few side effects here and there...the family is always there as they used to" (P9).

"...they (family) have been very supportive. All my children support me. I also have friends who have been very supportive. When I was on admission, there was this friend who was always visiting me"(P7).

"... I'm here with my dad, he takes care of me so he sees me. If there's any help, he assists me. Those abroad, especially my mum, she calls me every day. She calls to check up on me and find out how I am doing, because she's not here (in Ghana)... My brothers too support me with money" (P3).

#### Diversion coping

A substantial number of the participants in the study also reported the use of diversion coping strategies which include listening to music, or religious sermons and/or watching movies to take their minds off their breast cancer.

For participants who use songs and inspirational messages, one woman reported that;

"I love songs ...so I have a lot of songs on my phone which I listen to. Sometimes on the television too ...Mostly, gospel songs. A few friends who are also aware of the situation do send me inspirational messages. When I read them, it encourages me. You are a Christian but sometimes, you get down as a human being. You need to encourage yourself so I like reading them" (P11).

Other participants use either television alone or both as illustrated by the following direct quotes from the participants;

"...oh I watch movies if I am at home, you see once a while you will laugh err if it's emotional too you say aww and I watch movies, I like watching movies not any movie at all but movies that encourage and inspire me or make me laugh... local, foreign. You see some movies... you learn from them, you learn from them maybe like somebody has done something and you see it you would not want to do it because of the end results "ahaa" so I like watching movies, movies that will educate you. You see, not any movie at all, will educate you, encourage you or teach you lesson. I also like music, I listen to music a lot especially, gospel, even these local music like the ones by Ampofo Adjei (a Ghanaian musician) and co if you listen to the words and lyrics in the song you can see that they inspire you" (P4).

These quotes from the participants suggest that radio and television may play significant roles in their breast cancer journey as it may serve to help them cope and as a potential source of life lessons that might be meaningful to them.

#### **DISCUSSION**

This study explored illness perception and coping among women with breast cancer in Ghana. In this study, we found that participants cognitive and emotional representations of their illness was influenced by three main factors namely their knowledge about breast cancer, perceived causes of breast cancer and duration/curability of breast cancer. The majority of women living with breast cancer lacked factual information about breast cancer and its potential causes. This lack of adequate knowledge about breast cancer has consequences for patients' illness perception and treatment outcomes [21-23]. This is because perceptions of the causes of breast cancer could influence patients' ability to adhere to medical treatments as erroneous beliefs may lead to seeking alternative healthcare from unapproved sources. There are inadequate qualitative studies exploring cognitive and emotional representations of breast cancer as most of the studies were either cross-sectional or longitudinal examining the impact on health outcomes[6]. However, evidence abounds in other chronic disease conditions like diabetes especially in Ghana which found that chronic disease patients make several causal attributions rooted in the supernatural [24].

In terms of patients' perception of the curability and duration of their illness, varied opinions were expressed. For example, most of the participants believed that their illness can be completely cured and that they believe their illness will not last long so far as they have God and go through the medical treatments. This perception of the curability and duration of the

illness is rooted in the personal faith of the participants as reference to God ran through all the responses of the participants. This findings imply the need for a multidisciplinary approach which involves faith-based practitioners and healthcare professionals who will work by utilizing their strengths for the benefit of the patients.

The perceptions of women about breast cancer was found to have influenced the coping strategies adopted by the women in dealing with their illness. Three main coping strategies were identified and these include; spiritual/religious coping, social support and diversional strategies such as listening to music and watching of movies. Spirituality plays a significant role in the life of the African and for that matter Ghanaians and therefore, served as a major resource for the women in coping with the challenges associated with living with breast cancer [25, 26]. This finding is consistent with previous studies which found deferring responsibility to God and personal faith as important resources for coping with breast cancer [13, 14]. Participants' reliance on their personal spirituality as a coping strategy could be attributed to their lack of inadequate knowledge about the disease and its causes as well as the uncertainties surrounding the outcomes of the medical treatment. It was observed that reliance on God and spirituality has led to disease acceptance among the participants which serves to protect them against the experience of negative emotional states. Acceptance of a disease has been reported by other studies among women with different cancer types [16, 17].

We also found that social support from family members and friends served as a key coping resource for women living with breast cancer. Evidence in the psycho-oncology literature revealed that social support plays a pivotal role in the treatment of breast cancer and its aftermath [12-14]. Social support from family, friends and significant others have been linked to decreased mental health problems such as depression, anxiety and suicidal behaviours and improved quality of life among women living with breast cancer [27-30]. This finding

underscores the need for improved social networks and support systems for women living with breast cancer to cushion them against the negative consequences of the medical treatment and the numerous challenges associated with living with breast cancer.

Interestingly, we found that participants use music and films to divert attention from the breast cancer. Radios and televisions served as the main sources of these music and films which help women avoid thinking about their predicaments. The use of this coping strategy may relate to a component of cancer-specific coping strategies called cognitive avoidance which has been linked to decreased depression and anxiety but improved quality of life among women living with breast cancer [31, 32]. Thus, availability and accessibility of television sets for these women living with breast cancer could serve as avenue to lessen their emotional burdens associated with their illness. However, there is the need for the contents of the television and radio programmes to be monitored by national authorities to streamline the contents to promote their health and wellbeing.

The findings from this study imply that there is the need for oncology healthcare workers to understand how breast cancer is cognitively and emotionally represented by their clients and factor these perceptions into their health communication and treatment strategies. The use of varied coping strategies suggests that oncology healthcare workers need to provide support and encourage patients to participate in activities geared towards recovery as well as increased social networks. The study is however limited to only patients receiving care at the chosen health facility which may not necessarily represent the views of all women living with breast cancer in Ghana. Despite this shortcoming, the information provided may serve as the basis for future studies which would examine illness perceptions and their influence on the short and long-term health outcomes of women living with breast cancer.

#### Conclusion

There is a general lack of factual knowledge about breast cancer which manifested in most participants reporting no knowledge or belief of what might have caused their disease. However, most participants believed that their disease can be completely cured and this belief was rooted in their faith in God and on the medical treatments which suggests the importance of incorporating some positive religious activities into the overall treatment regimen of the women living with breast cancer. In terms of the coping strategies, religious faith and spirituality were prominent but other coping resources such as social support from family and friends proved to be significant in adjusting to living with breast cancer and the negative effects of the medical treatment. Diversion coping and the use of self-care practices were also reported by the participants. It is heart-warming that the participants did not report the use of a lot of maladaptive coping strategies.

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**Provenance and peer review:** Not commissioned; externally peer reviewed

**Data sharing statement:** Due to the nature of the data (audio recordings and transcripts), we are not able to share the raw data. We are able to share upon request the deidentified transcripts to researchers for the purposes of further analysis and comparison or research translation.

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#### **APPENDIX: INTERVIEW GUIDE**

#### A. Demographics

A1: How old are you?

A2: Are you currently married? If yes, for how long?

A3: Do you have children? If Yes, how many?

A4: Are you currently working?

A5: What is your highest level of education?

A6: What is your religion?

#### B. Perceptions about Breast Cancer and coping strategies

B1: What do you think is breast cancer?

B2: What do you believe to have caused your breast cancer?

(Probe: Why?)

B3: How did you arrive at this information?

B4: Do you believe breast cancer can be completely cured?

(Probe: Why?)

B5: How long do you believe your breast cancer will last?

(Probe: Why?)

B6: How do you feel talking about your illness to others?

(Probe: why?).

B7: How do you cope with your condition?

(Probe: why this coping strategy)

B8: What role does religion play in your coping with breast cancer?

B9:What role does your family and friends play in your coping with breast cancer?

# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

# **Instructions to authors**

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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		Reporting Item	Page Number
Title			
Abstract	<u>#1</u>	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract	<u>#2</u>	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2-3
Introduction			
Problem formulation	<u>#3</u>	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4-5
Purpose or research question	<u>#4</u>	Purpose of the study and specific objectives or questions	5

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Methods

## Qualitative approach and #5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory research paradigm if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together. Researcher characteristics #6 Researchers' characteristics that may influence the research, N/A and reflexivity including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability Context #7 Setting / site and salient contextual factors; rationale 6 Sampling strategy #8 How and why research participants, documents, or events 6 were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale 7 & 22 Ethical issues pertaining to #9 Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; human subjects other confidentiality and data security issues Data collection methods #10 Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale Data collection instruments 7 #11 Description of instruments (e.g. interview guides, and technologies questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study

Units of study	<u>#12</u>	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	7
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	7-8
Techniques to enhance trustworthiness	<u>#15</u>	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	7-8
Results/findings			
Syntheses and interpretation	<u>#16</u>	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8-17
Links to empirical data	<u>#17</u>	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	8-17
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	18-20
Limitations	<u>#19</u>	Trustworthiness and limitations of findings	20
Other			
Conflicts of interest	<u>#20</u>	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	22
Funding	<u>#21</u>	Sources of funding and other support; role of funders in data collection, interpretation and reporting	22

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# **BMJ Open**

# Illness perception and coping among women living with breast cancer in Ghana: an exploratory qualitative study

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# Illness perception and coping among women living with breast cancer in Ghana: an exploratory qualitative study

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#### **Abstract**

**Objective:** Illness perception has been shown to have significant influence on the wellbeing and coping strategies of persons living with chronic medical conditions. Understanding of how women living with breast cancer cognitively and emotionally represent their illness and coping strategies utilized is likely to help in designing focused psychosocial interventions aimed at improving their health and wellbeing. This study explored the illness perceptions and coping strategies among women receiving care for breast cancer.

**Design:** A qualitative study-phenomenology (using semi-structured in-depth interviews)

Setting: Oncology department of a tertiary hospital in Ghana

**Participants:** Eleven (11) women receiving breast cancer treatment were purposively sampled and in-depth individual interviews were conducted with questions based on illness perception and coping literature.

**Results:** In terms of illness perceptions, it emerged that most of the participants lacked adequate factual knowledge about breast cancer and perceived causes but believed in the curability of their illness through the medical treatments and the help of God. Spirituality, social support and diversion coping were the key resources for coping among the participants.

**Conclusion**: Breast cancer patients lacked adequate factual knowledge of breast cancer and their perception about the causes of breast cancer is rooted in biopsycho-spiritual model of illness. The reliance on spirituality and social support as the main coping strategies suggests the need for psychosocial interventions tailored to the spiritual and psychosocial needs of the patients.

#### Strengths and limitations of this study:

- This study is the first of its kind which comprehensively explored illness perceptions and coping strategies among breast cancer patients.
- Findings from this study have laid the foundation for more psycho-oncology research focused on understanding bio-psychosocial issues associated with living with breast cancer to inform evidence-based interventions.
- The sample included only breast cancer patients receiving oncology care at only one referral hospital and findings may not represent the views of patients located at other parts of Ghana.

Keywords: Illness perception, coping strategies, breast cancer, Ghana

# INTRODUCTION

Living with breast cancer presents women with significant challenges that they must deal with as the illness interferes with their physical, social, psychological, economic and spiritual lives [1, 2]. These challenges have been found to be the major contributing factors to decreased health-related quality of life among women living with breast cancer [3-5]. Evidence suggests that women diagnosed with breast cancer differ in their reaction to the illness and that these reactions in turn influence their coping strategies and disease management [6].

Breast cancer patients' cognitive and emotional representations of their illness becomes a critical aspect of the healthcare delivery process which cannot be overlooked. This is because patient-centered care requires health professionals to take the needs and views of patients into consideration to ensure satisfaction and thus, improved health outcomes [7]. Illness perceptions among breast cancer patients have been linked to several health outcomes including depression, anxiety, physical and mental quality of life [8-10].

However, the specific socio-cultural and economic contexts may influence patients' perception and understanding of their illness which are inextricably linked with their lived experiences. The interrelationships among the entire experiences of the women living with cancer suggest that the socio-economic and cultural factors may impact on how patients make meaning of their illness and these illness representations may influence the lived experiences of the patients [11]. Thus, the relationships among these factors are multidimensional and may sometimes revolves in a cycle as the lived experiences may also influence the socio-economic status and illness perception of the patients. These represent significant challenges confronting women living with breast cancer.

In dealing with the multitude of challenges, various coping strategies are employed [12-15]. It has been argued that coping plays a major role in the lives of persons diagnosed with chronic medical conditions including breast cancer [16]. As noted earlier, the illness representations of

the women living with cancer are likely to influence the type of coping strategies they adopt in trying to adjust with the burden of the medical treatment and living with the disease [17]. Evidence suggests that spirituality, social support, acceptance, cognitive restricting and avoidance are common coping strategies used by women living with breast cancer [12, 15, 18]. These coping strategies among breast cancer patients significantly influence their health outcomes [19].

However, contextual and cultural differences may influence the illness representation and coping strategies that are employed by women living with breast cancer in a low-resourced healthcare setting like Ghana [20]. Studies conducted in Ghana among women diagnosed with various cancer types have showed that surrendering to God, illness acceptance, the will to live and self-care practices were key coping strategies used [20, 21]. These studies, however did not consider examine both cognitive and emotional representations of breast cancer and how these perceptions may influence coping strategies. Additionally, there are inadequate qualitative studies exploring cognitive and emotional representations of breast cancer as most of the studies were either cross-sectional or longitudinal examining the impact on health outcomes [6]. There is paucity in the literature regarding illness representation and coping strategies utilized by women living with breast cancer in Ghana. This study was therefore conducted to explore illness perception and coping strategies used by women living with breast cancer in Ghana. It is believed that this information would provide practitioners and researchers with the roadmap to improving the health and wellbeing of women living with breast cancer as their illness perceptions are most likely to inform treatment choice and overall health seeking behaviours.

#### **METHODS**

#### Research design and research setting

A qualitative research design (phenomenology rooted in the interpretivist paradigm) was employed to understand the lived experiences of breast cancer patients regarding their illness representation and the coping strategies they adopt in their breast cancer journey. The population for this study consisted of all women diagnosed with breast cancer and receiving treatment at the Radiotherapy and Nuclear Medicine Department of the Korle-Bu Teaching Hospital (KBTH) in Ghana, West Africa. The Korle-Bu Teaching Hospital is one of the Tertiary Hospitals and the oldest in terms of healthcare provision in Ghana. Patients who access healthcare at the KBTH are usually referred from the smaller health facilities. This hospital caters for all patient groups regardless of socio-economic status. The National Health Insurance Scheme covers part of the cancer treatment, but patients still bear some of the cost not covered by the scheme[22].

#### Participants and sampling

A total of eleven (11) women receiving treatment for breast cancer were purposively sampled after they were initially recruited for a quantitative study [4, 5, 16]. This sampling approach was adequate for the study as it allowed the researchers to select participants who would be able to provide critical and in-depth information necessary to achieve the objectives of the study. Participants included in the study were between the ages of 46 to 71 years. The majority of the participants were between the ages of 40-49 years with an average age of 56.5 years). All of the participants except one reported to be a Christian. The majority of the participants were married (n= 6) and had secondary level education (n=5). Specific demographics of the participants are presented in Table 1 below.

# Patient and public involvement

There was no patient or public involvement in setting the research agenda.

Table 1: Demographic profiles of the respondents in the study

	·
Variables	Frequency
Age range	
40-49	6
50-59	2
60-69	2
70 years and over	1
Marital status	
Single	2
Married	6
Widowed	2
Re-married	1
Level of education	
Basic/primary education	4
Secondary education	5
Fourth year	2
<b>Employment status</b>	
Self-employed	3
Employed	2
Retired	3
Unemployed	3
Religion	
Christian	10
Muslim	1
Years lived with illness	
Less than 1 year	1
1-5 years	7
6-10 years	1
11 years and above	2

### **Data collection procedure**

Ethical approvals for this study were obtained from the Humanities and Social Sciences Ethical Committee (HSS/1428/016D) of the University of KwaZulu-Natal, South Africa and Scientific and Technical Committee as well as Institutional Review Board of the Korle-Bu Teaching Hospital in Ghana (KBTH-IRB/00035/2016). An interview guide (Appendix 1) was used to

conduct in-depth individual interviews with participants living with breast cancer to explore their illness perception and coping strategies within the Ghanaian context as culture influences the perceptions causal attributions and experience of illness [23]. Participants were visited in their homes and their informed consents were obtained after the purpose of the study was explained to them. Permission to record the interview sought and granted by the participants. The semi-structured interview that guided the interview process focused on two main areas: illness perception and coping strategies. The responses from the participants were used to generate further probing questions for clarifications as the interview guide allowed for flexibility. The data collection lasted between September, 2017 and January, 2018. The individual interviews lasted between 30 and 60 minutes.

#### Data analysis

Verbatim transcription of the audio recording was done. This was to ensure that the views expressed by the participants are not distorted. Most of the participants could speak English and thus, all the interviews were conducted in English with few local language interjections to emphasize their views. These interjections were appropriately translated as the researchers understand the predominant Ghanaian language (i.e. Twi). The Interpretative Phenomenological Approach (IPA) which involves exploration of participants' own subjective real-life experiences with no attempts at measuring the objectiveness of the experiences of the women living with breast cancer were used [24]. The analysis utilized the four principles and guidelines (gaining an understanding of the transcribed interview by reading and re-reading of the data and identifying points of interest, linking identified and harmonized quotes together to form themes, making connections with identified themes, and summarizing main themes together with their sub-themes with their appropriate quotations) recommended by Storey [25]. In following the guidelines stated above, the researchers read and re-read the transcribed data

which allowed for an in-depth understanding of the views of the participants. The researchers proceeded to make meaning of the data and developed themes to encapsulate the views expressed by the participants. Sub-themes were developed to elaborate on the dimensions of the major themes that emerged from the data. The sub-themes were supported with direct quotes from the narratives of the participants for emphasis.

#### **RESULTS**

# **Illness representation**

This main them describes participants' cognitive and emotional representations of their illness. Participants understanding and meanings of breast cancer are likely to influence their lived experiences. Three sub-themes were identified under this theme namely breast cancer knowledge, perceived causes of breast and duration/curability of breast cancer.

# Knowledge of breast cancer

Factual and accurate knowledge about breast cancer is likely to help patients in their adjustment to their illness as it may minimize the uncertainties surrounding breast cancer. Two key dimensions of what participants think breast cancer emerged. That is, those who have no factual knowledge and those who have some factual knowledge about breast cancer. The majority of the participants do not have any factual knowledge about breast cancer as illustrated by a narrative from one of the participants:

"as a matter of fact, if you ask me, I wouldn't know even before the thing (breast cancer) happened, I had not heard of the name before and in my family, I had not heard that anyone has had that disease before" (P6).

Contrary to the above, some of the participants had some factual knowledge about what breast cancer is with emphasis on the biological changes cells of the breast as illustrated below:

"It starts with the lump. I think when you go (to the hospital) earlier, they can just take the lump out for you. When you don't see it and it spreads, that's when it becomes cancerous...Like I told you, at the initial stages, I thought it was meant for old ladies who'd given birth already, sixty years upwards. That was what was in my mind. That was how I knew breast cancer to be. Nowadays in your thirties and forties, if you're not careful, you'll get it" (P4).

# Perceived causes of breast cancer

Participants in the study had varied views about their perceived causes of breast cancer. Whereas a substantial number of the women stated that they did not know what causes breast cancer, others also narrated came about or they have no ideas as to what might have caused their disease, others mentioned supernatural forces, physiological and stress as the possible causes of their illness. The narrative illustrates the ambivalence on the cause of breast cancer from a participant

"I do not know my child (referring to interviewer). As for me...hmmm...I do not know. Sometimes, they say it is a family sickness or runs through the family, but my mother did not experience this, neither did any member from my father's family experience this.....hmmm...so my child (interviewer)....I don't know ooo" (P8).

For some of the participants, perceived their illness to have some underlying supernatural causes and these perceived causes were influenced by what they have heard from people and their own beliefs. This is illustrated in the narrative below:

"Ah...as for me... I do not know if I was shot spiritually or the sickness came on its own. As for me, in all things, I just give it to God. I also told you earlier that I had a dream that I was being shot. Where I had the gunshot in the dream is the same place that I experienced the cancer in the breast" (P7).

Another participant emphatically stated that she is convinced that extreme stress from her work might have caused her breast cancer.

"...as for mine (breast cancer), I suspect stress...high level of stress... I am not someone who lives a careless life. By nature, I am the prudent type in all aspects of life...eating...whatever. I have never even taken alcohol before in my whole life. I do not even know how it tastes...and I am not someone who leads reckless life. You see...they said this disease is a lifestyle related problem. My psychologist sat with me trying to find out my family life and I realized that the only thing that I did that my body kept signaling me that I didn't head to was stress. High levels of stress. Otherwise, my eating level is not bad, my marriage is not bad, my children are grown, and it is not like I had little children giving me pressure at home. In fact, I realized that it was more work-based. Because at a point in time, I was always having breakdowns. For about 3 years, my white blood cells were not functioning properly, so I was on immune boosters and all manner of supplements" (P11).

### Duration/curability of breast cancer

From the analysis, it was not possible to separate illness duration from curability as most of the participants linked duration to curability. A substantial number of the participants were of the view that their breast cancer can be completely cured with the medical treatments and help of

God. However, some of the participants were not sure of the curability of the disease. The participants went further to provide reasons for their perceived duration/curability of their breast cancer as illustrated below.

"Nothing is too hard for the Lord. God can do a lot of miracles. God also uses doctors to perform his miracles. That is why I always run to doctors when I am sick...as for me...with the treatment I am currently going through....I know of someone who started with it since the year 2000 and the person is still alive and kicking. Nothing has happened to her....So I know that God will also have favour on me so that I can be healed completely" (P10).

"Aww....according to people....For instance, my siblings showed me one woman who has been treated of breast cancer for about 18 years now. A lot of people...even in my church....there are people I know have been cured of the disease....almost about 4 people. They all confessed to have gotten some but now, they have been cured. What I have realized to be the most difficult aspect is the chemotherapy...if I try my best and go through the process, I know I will be fine. There was one woman who also testified that she had this disease when she was 71 just like me and now she is 82...she is very strong. She told me that if I am able to go through all the processes, I will become stronger than how I am now. However, I don't really know how long my sickness will last" (P8).

However, a participant was of the opinion that she is uncertain about the duration/curability of her sickness since the causes are not even known in the first place.

"I don't really know because like we are saying...I don't know the root cause. Sometimes, they say it is from your diet...sometimes but I don't really know. I can't tell because we haven't found the real cause of the disease...so to say it can be done away completely....I am not sure...I believe with the mastectomy and radiation, it will go away very soon...because of the treatment and my faith in God" (P9).

### Coping with breast cancer

This theme describes ways in which persons living with chronic medical conditions such as breast adjust to their life circumstances. In their adjustment process, they employ several coping strategies that may influence both their short and long-term health outcomes. Three key coping strategies emerged from the interviews: the use of spirituality/religious coping, social support and seeking diversion. It is, however, to note that the participants in the study did not rely on only one form of coping but a myriad of strategies all aimed at helping to adjust to the disease and improve their quality of life.

# Spirituality/religious coping

Almost all the participants mentioned that breast cancer and its treatment has drawn them closer to God/Allah. That is, they were of the view that living with breast cancer and undergoing the difficult medical treatments have strengthened their faith in God/Allah and helped them in in dealing with the challenges associated with living with breast cancer. Some of the participants engaged in several religious activities such as daily prayers and rituals to help them cope with their condition i.e. in building of hope, financial provision, healing and acceptance of their health condition as reflected in the quotations below:

".....It has rather strengthened my faith because...you know....when something happens to you, as a Christian, you trust God that, He is your healer, so it has

strengthened my faith in God that He will heal me...even though the doctors are working on it. He is the ultimate Healer" (P9).

Apart from religiosity and spirituality providing hope and healing to the participants, reliance on God served to provide companionship to some participants. This helps women to make meaning of their social role limitations and viewed God as their hope and source of comfort:

"... I think it (breast cancer and its treatment) has even made me much stronger because at a point in time, I didn't have anybody apart from God. So, it has rather drawn me closer to God...just that some roles that I was playing in church, because I am now not too regular in church, I am not able to play those roles because of the sickness but I am very close to God than before" (P11).

On the other hand, the use of spirituality as a coping mechanism is influenced by the participants' belief that their disease is a test from God which they must pass and therefore, will not give up.

"I think it is just a test from God...hmm because one cannot live His life just like that, if you say you believe in God He will never leave you like that. He tests you to see whether it is true you believe in Him and whether you will divert your faith somewhere. This is what my faith tells me. He has brought it and shown me a way out of it" (P2).

These quotes from the participants indicate that God or a supreme being plays an important part in the breast cancer journeys of these women and thus, may subsequently influence their perception of the illness and overall health outcomes through acceptance, hope, companionship and meaning making.

## Social support

From the narratives, social support in the forms of emotional, financial and instrumental support emerged as key coping strategies. Social support plays significant role in the overall coping with the disease. One thing that run through all the narratives was social support from immediate family. Below are some direct quotes from participants regarding the value of social support in coping.

"I think I have my family with me...they understand and give me the necessary support, so I am okay....I am ok....apart from the few side effects here and there...the family is always there as they used to" (P9).

"... I'm here with my dad, he takes care of me, so he sees me. If there's any help, he assists me. Those abroad, especially my mum, she calls me every day. She calls to check up on me and find out how I am doing, because she's not here (in Ghana)... My brothers too support me with money" (P3).

### Diversion coping

A substantial number of the participants in the study also reported the use of diversion coping strategies which include listening to music, or religious sermons and/or watching movies to take their minds off their breast cancer. For participants who use songs and inspirational messages, one woman reported that:

"I love songs ...so I have a lot of songs on my phone which I listen to. Sometimes on the television too ...Mostly, gospel songs. A few friends who are also aware of the situation do send me inspirational messages. When I read them, it

encourages me. You are a Christian but sometimes, you get down as a human being. You need to encourage yourself, so I like reading them" (P11).

Other participants use either television alone or both as illustrated by the following direct quotes from the participants;

"...oh I watch movies if I am at home, you see once a while you will laugh err if it's emotional too you say aww and I watch movies, I like watching movies not any movie at all but movies that encourage and inspire me or make me laugh... local, foreign. You see some movies... you learn from them, you learn from them maybe like somebody has done something and you see it you would not want to do it because of the end results "ahaa" so I like watching movies, movies that will educate you. You see, not any movie at all, will educate you, encourage you or teach you lesson. I also like music, I listen to music a lot especially, gospel, even these local music like the ones by Ampofo Adjei (a Ghanaian musician) and co if you listen to the words and lyrics in the song you can see that they inspire you" (P4).

These quotes from the participants suggest that radio and television may play significant roles in their breast cancer journey as it may serve to help them cope and as a potential source of life lessons that might be meaningful to them.

#### **DISCUSSION**

This study explored illness perception and coping among women living with breast cancer in Ghana. This study filled an important gap in scientific literature as few studies within the Ghanaian context have explored illness representation and coping strategies utilized by women living with breast cancer. We found out that participants cognitive and emotional

representations of their illness was influenced by three main factors namely their knowledge about breast cancer, perceived causes of breast cancer and duration/curability of breast cancer. It was also found that participants used three (3) key coping strategies: spirituality/religious coping, social support and seeking diversion as resources for survival against the emotional and psychosocial challenges for patients living with breast cancer.

The lack of adequate factual knowledge about breast cancer as found in this study has consequences for patients' illness perception and treatment outcomes [26-28]. This is because perceptions of the causes of breast cancer could influence patients' ability to adhere to medical treatments as erroneous beliefs may lead to seeking alternative healthcare from unapproved sources [29]. In terms of patients' perception of the curability and duration of their illness, we found that the majority of the participants believed that their illness can be completely cured; and that they believe their can live long with their illness as long as they had faith in God and adhere to medical treatments. This perception of the curability and duration of the illness is rooted in the personal faith of the participants as reference to God ran through all the responses of the participants [30]. Evidence abounds in other chronic disease conditions like diabetes especially in Ghana which found that chronic disease patients make several causal attributions rooted in the supernatural [30]. These findings underscore the for a multidisciplinary approach which involves faith-based practitioners and healthcare professionals who will work by utilizing their strengths for the benefit of the patients.

In this study it was also found that participants used three (3) key coping strategies: spirituality/religious coping, social support and seeking diversion. Spirituality plays a significant role in the life of the African and for that matter Ghanaians [31] and therefore, served as a major resource for the women in coping with the challenges associated with living with breast cancer [31, 32]. This finding is consistent with previous studies which found

deferring responsibility to God and personal faith as important resources for coping with breast cancer [15, 18]. Ghanaians have been described to be religious [33], and it is possible that their reliance on a supreme being may be helpful for them to accept their illnesses. Thus, their spirituality creates some form of protection from the negative emotional states that have been shown to be associated with breast cancer [1, 21]. Acceptance of a disease has been reported by other studies among women with different cancer types [20, 21].

We also found that social support from family members and friends served as a key coping resource for women living with breast cancer. Evidence in the psycho-oncology literature revealed that social support plays a pivotal role in the treatment of breast cancer and its aftermath [12, 15, 18]. Social support from family, friends and significant others have been linked to decreased mental health problems such as depression, anxiety and suicidal behaviours and improved quality of life among women living with breast cancer [34-37]. This finding underscores the need for improved social networks and support systems for women living with breast cancer to cushion them against the negative consequences of the medical treatment and the numerous challenges associated with living with breast cancer.

Interestingly, we found that participants use music and films to divert attention from the breast cancer. Radios and televisions served as the main sources of these music and films which help women avoid thinking about their predicaments. The use of this coping strategy may relate to a component of cancer-specific coping strategies called cognitive avoidance [14] which has been linked to decreased depression and anxiety but improved quality of life among women living with breast cancer [38, 39]. Thus, availability and accessibility of television sets for these women living with breast cancer could serve as avenue to lessen their emotional burdens associated with their illness. However, there is the need for the contents of the television and radio programmes to be monitored by national authorities to streamline the contents to promote

their health and wellbeing. This is particular important in Ghana as previous study has shown that the television and radio were the main sources of information for women living with breast cancer[4].

The findings from this study imply that there is the need for oncology healthcare workers to understand how breast cancer is cognitively and emotionally represented by their clients and factor these perceptions into their health communication and treatment strategies. The use of varied coping strategies suggests that oncology healthcare workers need to provide support and encourage patients to participate in activities geared towards recovery as well as increased social networks. The study is however limited to only patients receiving care at the chosen health facility which may not necessarily represent the views of all women living with breast cancer in Ghana. Despite this shortcoming, the information provided may serve as the basis for future studies which would examine illness perceptions and their influence on the short and long-term health outcomes of women living with breast cancer.

#### Conclusion

This study was conducted to explore illness perception and coping among women with breast cancer in Ghana. We found that there was a general lack of factual knowledge about breast cancer which manifested in participants low knowledge or belief of the causes of breast cancer. We however, found that the majority of our participants believed that their disease can be completely cured, and this belief was rooted in their faith in God and on the medical treatments which suggests the importance of incorporating some positive religious activities into the overall treatment regimen of the women living with breast cancer. Participants relied predominantly on, religious faith and spirituality as key coping strategies in addition to social support from family and friends. Maladaptive coping approaches to living with breast cancer was minimal in our study. However, diversion coping, and the use of self-care practices were

also reported by the participants. These findings underscore the need for oncology healthcare workers to provide support and encourage patients to participate in activities that are geared towards recovery. Healthcare workers understanding of how breast cancer is cognitively and emotionally represented by patients may influence how they perceive health communication and recommended treatment strategies.

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**Data sharing statement:** Due to the nature of the data (audio recordings and transcripts), we are not able to share the raw data. We are able to share upon request the deidentified transcripts to researchers for the purposes of further analysis and comparison or research translation.

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# **APPENDIX: INTERVIEW GUIDE**

#### A. Demographics

A1: How old are you?

A2: Are you currently married? If yes, for how long?

A3: Do you have children? If Yes, how many?

A4: Are you currently working?

A5: What is your highest level of education?

A6: What is your religion?

# B. Perceptions about Breast Cancer and coping strategies

B1: What do you think is breast cancer?

B2: What do you believe to have caused your breast cancer?

(Probe: Why?)

B3: How did you arrive at this information?

B4: Do you believe breast cancer can be completely cured?

(Probe: Why?)

B5: How long do you believe your breast cancer will last?

(Probe: Why?)

B6: How do you feel talking about your illness to others?

(Probe: why?).

B7: How do you cope with your condition?

(Probe: why this coping strategy)

B8: What role does religion play in your coping with breast cancer?

B9:What role does your family and friends play in your coping with breast cancer?