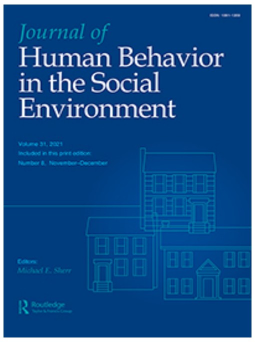

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Suffering yet surviving: narratives of women living with obstetric fistula in the Northern Region of Ghana

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ABSTRACT
Drawing on the insights of Bronfenbrenner's ecological systems and Lazarus' coping theories, this article highlights the challenges and coping strategies of women living with obstetric fistula in the Northern Region of Ghana. Employing the convenience sampling technique, 55 women were purposively recruited to participate in the study. Focus group discussions (FGDs) and in-depth interviews (IDIs) were conducted to collect data. With the permission of participants, the FGDs and IDIs were audio-recorded and transcribed. The data were analyzed to identify emerging themes that addressed the objectives of the study. The findings indicated that participants encountered varied challenges (physiological issues; abandonment and divorce; psychological problems; financial constraints; and difficulty accessing healthcare). Furthermore, it was found that the women included in this study adopted both problem-focused and emotion-focused coping strategies. Evidence showed that the problem-focused strategies were begging for assistance and seeking support from the Fistula Kpandai support group. Maintaining personal hygiene and optimistic motivation were the emotion-focused strategies employed by the participants. Based on the findings of the study, implications are discussed.

KEYWORDS
Challenges; coping; Ghana; obstetric fistula; qualitative research; women

Introduction

Obstetric fistula is a global public-health problem that is devastating for women, especially women in developing countries. It is a preventable maternal medical condition that involves an abnormal opening between the (a) bladder and the vagina (vesicovaginal fistula), (b) rectum and vagina (rectovaginal fistula), or both, which results in uncontrolled leakage of urine and/or feces caused by prolonged, obstructed labor, in the absence of timely, high-quality medical treatment (Bashah et al., 2018; Capes et al., 2011). The prolonged, constant pressure of the fetal head in the birth canal cuts off the blood supply to the soft tissues surrounding the woman's bladder, rectum, and vagina (Mohamed et al., 2018). It could cause life-long disabilities and poor quality of life among affected women (Bashah et al., 2018; Kalembo & Zgambo, 2012). Usually, when labor is obstructed, the babies do not survive (Cowgill et al., 2015).

While obstetric fistula is among the prevalent causes of maternal morbidity in developing countries (Browning & Patel, 2004; Wall et al., 2005), it is very sporadic and faded away

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100 years ago following improved obstetric care in developed countries (Bashah et al., 2018; Langkilde et al., 1999). Some scholars have noted that obstetric fistula is uncommon in developed countries, following universal access to safe delivery and emergency obstetric care, which rendered its preventability undisputable (S. Ahmed & Tunçalp, 2015; Changole et al., 2017). Thus, for women living in penurious countries like Ghana where health care is limited or unavailable and the rates of infectious disease and malnutrition are prevalent, the risk of developing obstetric fistula increases (Bangser et al., 2011; Pope et al., 2011; Sullivan et al., 2016). The care of women living with obstetric fistula (WLOF) is three-pronged and consists of (a) awareness that the condition is preventable and treatable, (b) treatment through surgery, and (c) family and community reintegration (Jarvis et al., 2017).

It is estimated that each year between 50,000 and 100,000 women worldwide are affected by obstetric fistula and two million young women live with untreated obstetric fistula in Asia and sub-Saharan Africa (World Health Organization, 2020). For instance, a report on the assessment of obstetric fistula in Ghana indicated that between 2011 and 2014, 1538 cases were recorded and only 40% of the cases were repaired, with between 711 and 1352 new cases developing each year (Ghana Health Service, 2015). Also, the report stated that Northern Ghana reported the highest number of cases. Furthermore, high maternal morbidity rates (approximately 1.8 per 1000 births) that are recorded in Ghana, includes obstetric fistula (United Nations Population Fund, 2012). Given that many women conceal their condition from society's view, it is possible that the numbers do not depict the full extent of the morbidity (Bangser et al., 2011; Sullivan et al., 2016). Higher rates of obstetric fistula in many developing countries are not only influenced by poverty, but cultural practices, such as giving women lots of water to drink during labor (Ghana Health Service, 2015). However, a full bladder has a higher tendency to cause fistula during the delivery of babies (Cook et al., 2004).

Even though it is difficult to indicate the actual number of WLOF in Ghana, the condition could adversely affect the lives of women, their families and communities in diverse ways. Most often, they encounter physical, psychological, sexual health, social and economic challenges (Kabayambi et al., 2014; Pacagnella et al., 2014). In addition, they experience neglect and isolation by family and community members as a result of the uncontrollable leakage of urine and / or feces, as well as the related smell (Mselle & Kohi, 2015). Some affected women are abandoned by their husbands, have poor living standards, and have little or no means of employment (Gebresilase, 2014; Khisa et al., 2017; Mantey et al., 2020). Without financial support from their spouses, WLOF often experience difficulties securing their basic needs as many of them are unable to work, especially if they have to handle food (Sullivan et al., 2016). Moreover, many women diagnosed with the condition experience challenges accessing treatment due to poverty, long distances from health facilities and stigma, leading to the women remaining invisible to the formal health-care system (Bashah et al., 2018; Engender Health, 2004; Mwini-Nyaledzigbor et al., 2013).

Additionally, the death of a baby, inability to carry a live child, and the humiliation that is associated with obstetric fistula result in negative psychosocial and emotional challenges (World Health Organization, 2020). Also, in some communities, the disease is perceived as sexually transmitted and/or as a spiritual punishment (Okoye et al., 2014). Thus, women with the condition may be prevented from seeking medical care by their in-laws in order to avoid stigma and discrimination against their families due to the belief that the condition ought to be kept a secret (Ghana Health Service, 2015). The stigma experienced by affected women could be extended to their caregivers (Jarvis et al., 2017; Kabayambi et al., 2014), and this could result in neglect and lack of support from family and non-family members. Social isolation could lead to psychological ill health that could lead to severe depression and suicidal thoughts (Khisa et al., 2017; Muleta et al., 2008). Even after successful fistula repair, some women find it difficult to reintegrating into their communities (Khisa et al., 2017; Lavender et al., 2016). Furthermore, surgical repair lags behind the disease load due to lack of skilled surgeons (Fistula Foundation, 2016). In this regard, affected women would have no choice than find ways and means to cope with their situation.

Some coping strategies adopted by WLOF are eating and drinking only when it is needed, bathing regularly, using perfume and powder, putting calamine lotion on the sores around the genitals and thighs, and the use of old pieces of cloth as pads (Ghana Health Service, 2015). As women diagnosed with fistula live in diverse social environments and have different experiences regarding loss of newborns, family relationships, and livelihoods, it is important to explore their challenges and means of coping. In this article, we aim to highlight the challenges and coping strategies of women living with obstetric fistula in the Northern Region of Ghana. Such information is useful because although some initiatives have been implemented to support women with fistula in Ghana (Diallo, 2009; Donnelly et al., 2015; Lavender et al., 2016; Watt et al., 2015), many affected women, especially in Northern Ghana still encounter diverse challenges that they are compelled to cope with. Accordingly, identifying and gaining a better and deeper understanding of the plight of women is crucial in developing effective policies and strategies that would enhance the health and well-being of WLOF, their families and communities.

Theoretical underpinnings

In view of the fact that obstetric fistula is a complex issue, Bronfenbrenner's (1977, 1979) ecological systems and Lazarus (1993) coping theories underpinned this study. These theories were utilized because they provided valuable explanations regarding the challenges and coping strategies adopted by WLOF. Bronfenbrenner (1979) opined that human development is a consequence of an individual's personal attributes and the environment in which the individual lives. The theory suggests that people are in constant interaction with their environment and are enclosed within five nested systems (i.e., microsystem, mesosystem, exosystem, macrosystem, and chronosystem) that could influence them both positively and negatively. Each of these systems exert influence on the development of people, such as women living with obstetric fistula. The microsystem is the closest environment of an individual and consists of the family, peers and neighborhood that the individual has direct contact (Bronfenbrenner, 1979).

As the most influential level, the microsystem consists of roles, activities, and interpersonal relationships experienced by people in their settings. It includes other people with distinct characteristics of personality, temperament, and systems of beliefs (Bronfenbrenner, 1995). Relating this to the study, WLOF's microsystem includes their families, religious groups, and peers who could provide support for WLOF, and thereby reduce the extent to which they would be scorned by people who become aware of their condition. Most often, WLOF experience stigma, including gossip, verbal abuse and social exclusion (El Ayadi et al., 2020; Changole et al., 2017; Mohamed et al., 2018). The mesosystem is the linkages and processes that transpire between two or more settings that contain the person (Bronfenbrenner, 1979).

Thus, the mesosystem could consist of the relationship between the families and religious groups of WLOF. The exosystem involves relationships between two separate systems of which the person is in direct contact with one (Bronfenbrenner, 1977; Pittenger et al., 2016).

At the exosystem level, lack of or limited social support due to family members' relationship with community members could negatively affect the wellbeing of WLOF. Family support is crucial, especially in times of ill health when people are at risk of being stigmatized and discriminated against. Victims of stigma and discrimination are at a higher risk of experiencing mental health challenges, especially depression (Dako-Gyeke, 2018; Dako-Gyeke et al., 2019; Mwini-Nyaledzigbor et al., 2013). Some WLOF are neglected by their family members due to fear of the entire family being shunned as one of its members has the condition (Changole et al., 2017; Women's Dignity Project and Engender Health, 2006). The exosystem includes environmental elements that have influence on an individual's development, although that individual is not directly involved with the elements (Bronfenbrenner, 1989). Applying this to the study, there are instances that WLOF may face challenges due to family members' or friends' beliefs or lack of understanding of the condition.

The macro system entails the micro-, meso-, and exo-systems that exist, or could exist within the subculture or the culture as a whole, as well as any belief system or ideology (Bronfenbrenner, 1977). It includes government policies, laws and customs, social class, ideologies, values and beliefs that influence societal perceptions. For instance, peoples' beliefs about the condition could impact WLOF's functioning in their respective communities. The chronosystem comprises changes over time not only in the characteristics of the individual, but also the environment in which that individual lives, such as historical changes (Bronfenbrenner, 1977). In this study, the chronosystem could involve unfavorable life experiences like isolation from spouses which could lead to divorce. As WLOF experience challenges at different levels, they generally find ways to cope. In his coping theory, Lazarus (1993) noted that people in stressful situations adopt coping strategies to handle adverse effects of their problems.

Coping is defined as ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resource of a person (Berjot & Gillet, 2011; Lazarus, 1993). The theory proposes that coping relate to skills and abilities that permit people to manage and face challenges in order to prevent and minimize stress. In addition, individual coping mechanisms change in stressful situations like living with obstetric fistula. The theory emphasizes that there are at least two key forms of coping: problem-focused coping and emotion-focused coping (Berjot & Gillet, 2011; Folkman & Lazarus, 1980; Stanisławski, 2019). Problem-focused coping involves changes in the troubled person-environment relationship by acting on the environment or oneself (Folkman & Lazarus, 1985; Ouch & Moradi, 2019). It is an adaptive mode of coping that involves actively planning, instrumental support or engaging in a specific behavior to overcome the problem that is causing distress (Folkman & Lazarus, 1985).

Most often, women with obstetric fistula live in a state of distress and fear of their future as the condition has a distressing impact on them and their families (Bashah et al., 2018). In order therefore to reduce the stress associated with their condition, WLOF may rely on support from family members, friends or through active planning. Emotion-focused coping on the other hand, refers to the change in meaning of a stressful situation that alleviates the stress although the actual condition has not changed (Lazarus, 1993). Emotion-focused coping is divided into two sub categories; active and avoidant emotion focused coping. Active coping (e.g., positive reframing) is an adaptive emotion regulation strategy while avoidant coping (e.g., self-distraction) aims at avoiding the stressor (Folkman & Lazarus, 1985; Holahan & Moos, 1987).

In view of the fact that WLOF may experience challenges such as lack of support and family care, physical or financial incapability to access care, and lack of information or knowledge about fistula care and treatment (Bashah et al., 2018; Nsemo, 2014), which could make life stressful, they are likely to develop a positive attitude or reframe their situation in order to survive. The ecological systems and coping theories were appropriate for this study as these enabled the researchers to have a comprehensive understanding of the experiences of WLOF with regard to their challenges and how they were surviving. Given that obstetric fistula is a problem that is distressing for women (Mwini-Nyaledzigbor et al., 2013) the need to consider the various systems WLOF interact with and cope within cannot be over emphasized.

Data and methods

Research design

A qualitative descriptive approach was adopted to explore the challenges and coping strategies adopted by women living with obstetric fistula. The approach enabled the researchers to gain in-depth knowledge of participants' experiences by staying close to the data and describing it accordingly (Creswell & Creswell, 2017; Sandelowski, 2000a). Also, the approach allows researchers to investigate sensitive and complex issues in order to understand phenomena from the perspectives of an individual, as well as the wider social contexts of participants (Dako-Gyeke & Donkor, 2018; Rahman, 2017). In addition, the qualitative research design enabled the researchers to engage a small number of participants extensively in order to develop patterns and connections of meaning with the aim of gaining individual values rather than generalized findings (Hammersley, 2013). Thus, the qualitative research approach provided the researchers opportunity to obtain information about the experiences of WLOF regarding their challenges and coping strategies.

Study site and participants

The study was conducted in the Kpandai District in the Northern Region of Ghana. Compared to the coastal South, the Northern Region is less developed in terms infrastructure and the healthcare system reflects the difference. Access to healthcare is limited as many health facilities are located far away from rural villages or community settlements (Danso et al., 2007; Mwini-Nyaledzigbor et al., 2013). Shortage of skilled birth attendants and lack of proximity to health facilities adversely affect pregnant women and as a result, many Ghanaian women (about 70%) who are diagnosed with obstetric fistula reside in the three northern regions of Ghana (Sullivan et al., 2016). The Kpandai District was selected for this study due to the existence of a support group for WLOF known as Fistula Kapadia. Many members of the support group accessed health-care services at the Buya Health Center in the Northern Region. The support group identifies women with the condition in villages in the Kpandai District and provides social and emotional support for them.

Furthermore, the group trains women with obstetric fistula in varied trades such as soap making. Members of the support group meet once every month either in Nkanchina or Buya (villages in the Kpandai District).

An initial contact was established by the researchers with the leaders of the support group and the researchers were assured of the cooperation of group members. Meetings of the support group are held in either Nkanchina or Buya. Some members resided in these two villages and others traveled from other villages (Tali, Prang, Wuyaye, Chokori, Nkanchina and Wayai), which were far away from the meeting sites. To be included in this study, participants must have been (a) 18 years and above, (b) members of Fistula Kpandai Support Group and (c) diagnosed and lived with the condition for at least 2 years. Women living with obstetric fistula who were not members of the support group were excluded from the study. In addition, women living with obstetric fistula who did not reside in the Kpandai District were not included in the study. A total of 55 members of the support group were purposively recruited to participate in the study. Purposive sampling helps researchers to select a sample on the basis of their knowledge of the population, its elements, and the purpose of the study (Maxfield & Babbie, 2011). Recruitment continued until the point of saturation when interviews and discussions yielded no new information (Bowen, 2008; Saunders et al., 2018).

Data collection procedures

Ethical approval for the study was obtained from the Ethics Committee for the Humanities (ECH) at the University of Ghana. Semi-structured interviews were employed to collect data through Focus-Group Discussions (FGDs, n = 40, four FGDs with 10 participants in each group) and individual In-depth Interviews (IDIs, n = 15) with the aid of an interview guide developed by the researchers. This data collection approach is consistent with the methodology proposed by Bradshaw et al. (2017) as it offers a vehicle for the voices of those experiencing a phenomenon to be heard. It also provides a straight description of the data (Sandelowski, 2000b). Combining FGDs and IDIs improves data richness (Lambert & Loiselle, 2008). Focus group discussions were used because it enabled the researchers to understand relevant issues of agreement and disagreement, as well as provided them an opportunity to observe participants as issues unfolded during discussions (Creswell, 2012).

Furthermore, FGDs help to unearth features of a phenomenon that would be difficult to obtain through individual interviews (Carey & Asbury, 2016). The FGDs were structured in a way that sharing information and experiences were therapeutic for the members. The IDIs were conducted with participants who preferred to be interviewed privately. It permitted participants to freely express themselves and enabled the researchers to probe for more information (Morris, 2015). The FGDs and IDIs were conducted on the meeting days of the support group so that group members who were willing to participate in the study did not have an additional burden of meeting again for the purpose of this study. The FGDs and IDIs were conducted in three Ghanaian languages (Twi, Nawuri and Basare, spoken by both the participants and researchers) based on the language participants understood and could freely express themselves. This approach was useful because in Northern Ghana, there is a diverse multi-lingual population with distinct ethnic backgrounds (Government of Ghana, 2013).

Also, the approach is valuable as it sets the paper apart from other research studies that data are collected through translators who may not engage in the process and could omit some linguistic nuances. The approach aimed to decrease loss of linguistic nuances and permitted participants to choose the interview language (Dako-Gyeke & Kodom, 2017). The interview guide was developed in English and translated into Twi, Nawuri and Basare. Each FGD session lasted between 90 and 120 minutes, while IDIs lasted between 40 and 60 minutes. Permission was sought from the participants for the FGDs and IDIs to be audio recorded for later transcription. Each researcher kept a field diary for notes taking during the sessions. Participants were given the option of individual interview or focus group discussion. The purpose of the study was explained to each participant before the data collection began, and they were informed of their right to withdraw their participation at any point of the study.

Both verbal and written informed consents were obtained from all participants. Participation in the study was voluntary and confidentiality was ensured by concealing the identity of participants. Participants completed a short pre-interview demographic questionnaire. Open-ended questions were used to explore challenges and coping strategies adopted by participants of the study. Key questions asked included, what are the challenges you encounter as a result of living with obstetric fistula? and how are you coping since you were diagnosed with obstetric fistula? Follow-up probes were utilized to elicit fistula-related challenges and coping strategies. After the FGDs and IDIs, participants were given snacks, money for lunch and reimbursement for travel. Each participant received an average amount of GHC 30 (Ghana Cedi) for travel reimbursement and payment for lunch. These items were approved and recommended by the Ethics Committee for the Humanities at the University of Ghana.

Analysis of data

After the data collection, the audio recorders were replayed many times in order to transcribe the data. The interviews conducted in Ghanaian languages were translated into English and some of the quotations were edited grammatically, ensuring that the contents were preserved. All identifying information on participants were concealed and the transcripts were saved with no personal identifiers. The data were analyzed thematically using three major stages. At the first stage, two researchers carefully and independently read and re-read the interview transcripts and applied descriptive codes (Lincoln & Guba, 1985; Miles & Huberman, 1994). Employing this process, the researchers were able to reflect on the main content of the data and its meaning (Creswell, 2015; Miles et al., 2014).

At the second stage, the researchers grouped similar codes into conceptual categories and each category had similar characteristics (Miles & Huberman, 1994; Sargeant, 2012). The third stage was a higher-level of categorization where the researchers identified and summarized what they had learned using interpretive themes. The sets of codes, categories and themes independently developed were discussed and modifications were made through an iterative process until the researchers were in agreement. To ensure credibility of the findings, the transcriptions were augmented with field notes taken by research assistants during data collection. Moreover, themes that were developed independently were interpreted and consensus reached through discussions with academic colleagues who had professional and/or academic knowledge in the field (Lincoln & Guba, 1985).

Results

Demographic characteristics of participants

The sample consisted of fifty-five women aged between 20 and 70 years. Table 1 describes the socio-demographic characteristics of women who participated in this study. The next section is organized under the following themes: (a) challenges encountered by women living with obstetric fistula (b) coping strategies adopted by women living with obstetrics fistula (Table 2).

Table 1. Socio-demographic characteristics of participants.

Characteristics	Population
	n = 55
Gender	
Female	55
Age (years)	
20–30	7
31–40	16
41–50	18
51–60	10
61–70	4
Highest Educational Level	
Primary	6
JHS	1
No Formal Education	48
Occupation	
Farming	40
Trading	6
Dressmaking	2
Unemployed	7
Religion	
Christians	30
Muslims	14
Traditionalists	11
Marital Status	
Married	39
Divorced	6
Others	10
Place of Residence	
Buya	20
Tali	4
Prang	4
Wuyaye	4
Chokori	4
Nkanchina	10
Wayai	5
Kakraka	4
Number of Children	
None	2
1–5	34
6–10	18
11–15	1
Number of years lived with the disease	
1–5	21
6–10	23
11–15	4
16–20	3
21–25	2
26–30	1
31–35	1

Table 2. Themes and sub-themes.

Themes	Areas of Focus
Challenges faced	Physiological issues Abandonment and divorce Psychological problems Financial constraints Difficulty accessing health care
Coping strategies	Begging for assistance Maintaining personal hygiene Seeking support from Fistula Kapadia Optimistic motivation

Challenges faced by women living with fistula

The participants included in this study faced diverse challenges and these were: physiological issues; abandonment and divorce; psychological problems; financial constraints; and difficulty accessing healthcare. These challenges according to the participants, had adverse effects on their lives and that of their family members.

Physiological issues

Many of the participants indicated that the physical aspects of obstetric fistula are very painful with continual leakage, smell and soreness in the genital space. These adversely affected their health, as well as their relationship with family and community members. A participant recounted her ordeal after undergoing two surgeries:

> *I am always in pain after undergoing two surgeries. I had one agonizing surgery and after that I had a second one, but still my condition has not improved because the doctors discovered more than two openings. Currently, I experience a lot of pain so I have to take anti-pain medications all the time. Life is difficult living with this condition as most often, I do not have the strength to do anything, and even carrying water to the bathroom for my bath is a problem.* (30 years, Nkanchina).

Adding her voice, this participant revealed how the condition has restricted her movement:

> *This is the worse sickness ever in my life. It has affected me so much that I cannot go anywhere. If I walk around I get wet and if I do not clean myself often, I develop sores at my private part. The doctors asked me to change my diapers many times in a day because I have multiple openings. The diapers are expensive so I use them only when I go out. Once you have this condition, you really suffer, especially if you are left alone without support from your family* (52 years, Buya).

According to this participant, her deteriorating health condition has affected her family:

> *I have lived with this condition for many years. I have taken different medications, both orthodox and herbal, but none worked for me. I have become a burden on my family, especially my husband and children since I depend on them for everything. Sometimes they complain, and that is understandable. I do not go anywhere, if I need to buy something nearby, I am unable to do so. I would have to wait for the return of my children or husband from farm to be assisted. I develop blisters between my thighs when I am wet and when I walk.* (60 years, Wayai).

Abandonment and divorce

The participants reported how fistula had adversely affected their relationship with their husbands or partners. While some of them were abandoned by their spouses, others indicated that they were divorced by their husbands. This participant explained how she was abandoned by her husband few years after she was diagnosed with obstetric fistula:

> *I lived with my husband in the village, but after I had the condition, his attitude changed. He was always moody and eventually, he left home. I do not know where he resides now. I informed his family about it, but they asked me to take care of my illness and leave him alone. Because of this sickness, I find it difficult doing things on my own as I cannot sit down for long. My husband would have been of good help in these difficult times, however, he is nowhere to be found.* (40 years, Tali).

This woman indicated that she was divorced by her husband:

> *I lived with my husband and children, but he divorced me after I was diagnosed with the condition. He has married another woman and I feel very sad. We used to work on his farm together to support our family. He gave me a small piece of land to farm after the divorce. I do not have the strength to work on the farm and because my children are young, they cannot help either. He has deserted us and neither support us nor care for us. My children are now living with my brother in the next town.* (35 years, Chokori).

A participant who was contemplating divorcing her husband, had this to say:

> *I am still living together with my husband and our children. He treats me badly and makes me feel worthless. He verbally abuses me and has disclosed my condition to his family members and friends although we both decided to keep it a secret. He does not give me money and does not care about my wellbeing. If I divorce him, I would have my peace of mind since I get empathy and support from a lot of people. Although this is my wish, it is difficult to undertake it because I do not have my own accommodation, so I have to be quite and suffer.* (43 years, Kakraka).

Psychological problems

The participants expressed their views regarding how obstetric fistula had affected their psychological wellbeing and social interactions. They reported of experiencing anger, hatred, sadness, suicidal thoughts, as well as stigma and discrimination. This participant narrated how her husband was responsible for her condition:

> *I am annoyed with my husband because he caused this problem and since then, has left the village and now living with another woman. This was my third pregnancy so I knew when I was in labor, my husband insisted that I should not rush to the hospital. I waited until the next day when I could not bear the pains any longer, before I was sent to the hospital. I had complications and when my baby was delivered, he did not cry. After few days, I did not have the urge to pass urine by myself. That was how it started.* (37 years, Buya).

This participant described how she had developed hatred for her child and husband due to the condition:

> *I was diagnosed with fistula after the birth of my fourth child. I had a prolonged labor for about three days. Since then, I have developed hatred towards my child and my husband. Compared to my other children, I do not like him. I hope to be patient with him so I do not hurt him. I know my attitude towards my son is not good, but I think it is normal for me to feel that way. I have asked my mother to live with my son because his presence reminds me of my pains and that is not good for my emotional wellbeing.* (35 years, Nkanchina).

According to this participant, the thought of the condition makes her feel sad:

> *I have five children and I was diagnosed with this condition after the birth of my last child. Since then, I have never been happy. I would say sadness is the hallmark of this disease, especially those of us who*

> *have multiple openings, and do not have financial and social support. I am always sad because my husband complains that he has spent all his savings on me. Most often, I wonder if I did something wrong during my last pregnancy and I was cursed by someone or an evil spirit.* (56 years, Tali).

Some WLOF indicated that they had suicidal thoughts because people were often rude and cynical toward them:

> *Sometimes, I wonder what I am doing here in this world. There are times that thoughts of suicide flash through my mind due to rude and cynical attitude of others towards me. What makes it worse is the fact that some family members and friends relate to me as if I am less of a human being. I have even had thoughts of poisoning myself, but when I think about my children, I stop. Life is not pleasant without family and friends as their support is needed, especially during times of illness.* (46 years, Buya).

This participant opined that she was tired of living with the condition:

> *Most often, I wonder if I could continue living with the illness. I am always in my room, I cry a lot and wish life was over. I marvel what life is all about if I cannot be a part of the world. I feel very excluded from my family and friends. I consider myself a burden on my family who are sometimes scorned because of me. Many people in my community are aware of my condition and this gives me the urge to migrate to another town. I hardly know where to go and I am wondering how I would survive in another town.* (44 years, Kakraka).

All of the women reported being stigmatized and discriminated against:

> *Living with this condition is difficult because people mistreat you. Even some of my family members see me as a worthless person. I am treated like a child because of this sickness. It is sad that sometimes when I cook, my own children refuse to eat the food. They all shun my company so I am always by myself. When I got married, I was very close to my in-laws, especially my mother in-law, but now they all gossip about me and insult me by reference to my condition so I keep to myself.* (48 years, Prang).

Often, the stigma is extended to family members of the WLOF as a result of their condition:

> *My children and I have stopped attending social gatherings like weddings and funerals because people ridicule us. Friends and extended family members have stopped visiting us, the rejection is intolerable. It is unfortunate that people in my community behave as if fistula is infectious. Attending church service has even become a challenge because some congregants do not want to sit close or talk to us. My children and I do not have friends. Our life is restricted to our home since the humiliation is unbearable.* (56 years, Buya).

Financial constraints

Many of the WLOF encountered financial difficulties that made it challenging for them to cater for themselves and their families, especially their children. According to this participant, she is unable to engage in any economic activity due to the illness:

> *My business was flourishing but now because of the sickness, I have used all my capital to cater for myself and everything is gone. I do not have funds to start a new business. Currently, I am not working and life has not been easy after going jobless for many years. My mother is now taking care of my children, she is old and may soon be unable to work. I feel bad about it because I should rather be taking care of my mother.* (38 years, Nkanchina).

This woman explained that undergoing surgeries for her condition, worsened her financial situation:

> *At the moment, I do not have any job that I do for a living. Before I developed the condition, I used to sell 'pito' (local beverage) but as a result of this sickness, people do not buy from me so I stopped. I started farming and had to quit because anytime I weed, my urine flows. It was difficult walking to and from the farm. I am not a lazy person, but because of this sickness, I cannot work. I have become poor and unable to take care of my children. I miss hospital appointments as I cannot afford transportation and hospital charges. I use herbal medicines, which are much cheaper.* (50 years, Prang).

Although some of the women indicated that they engaged in some form of economic activities, especially trading, they still faced financial challenges as they spent much of their earnings on detergents and other sanitary items:

> *I have a small shop that I sell petty household items. I use all my profit to buy soap and other detergents to ensure that I do not smell bad at the shop. I am unable to replenish the stock in the shop so now the shop is empty. I am afraid I would have to close down soon. I am married to a man who has another wife who has a good job to support him. Due to my condition, he considers me a worthless person. My business is dwindling and money is a very big problem for me.* (37 years, Wuyaye).

This participant described how she had to switch trades, but people still patronize her business as a last resort:

> *I operated a local restaurant and I was able to take care of my family. When customers became aware of my condition, they stopped patronizing my business. Now, I sell firewood and charcoal and my goods are bought only when my competitors run out of stock, although my stuffs are always cheaper. The little profit I make; I spend all on detergents. I bathe and wash my clothes often due to the stench. I also spend money on medicines I buy from the pharmacy shop since I cannot afford hospital bills. My children and I depend on the benevolence of others to survive.* (46 years, Buya).

Difficulty accessing health care

Many of the participants indicated that they were unable to access health care due to financial challenges, particularly inability to afford the cost of surgery to repair their condition since they had multiple openings. For others, they were unable to meet scheduled hospital appointments because of the high transportation cost to the city where the health facility is located. A participant expressed how her family cannot afford to pay for the cost of her surgery:

> *The doctors and nurses have assured me that my condition could be repaired, but I cannot afford it. Even if I sell my family's property, it will not be enough to cover the cost so I rely on herbal medicines and buy non- prescription medicines from pharmacy shops. Since I do not have a job, money to buy food and detergents is a challenge. People have directed me to places I could seek for financial assistance, but my efforts were not successful. Even if I receive support for the surgery, I cannot afford to buy the required medicines.* (60 years, Nkanchina).

In addition, this participant expressed how difficult it was to travel from her village to the health facility:

> *I cannot afford to go to the hospital because I do not have money for transportation. My village is far from the town where the hospital is located. Since I have multiple openings, sitting in a vehicle for many hours on bad roads is not helpful. I have the National Health Insurance card but it will expire soon. I do not have money to renew it. Living with fistula is difficult for people who live in*

> *villages without health facilities as we are forced to use herbal concoctions. Life would have been better if I could visit the hospital for assistance.* (44 years, Kakraka).

A participant who was not enrolled on the National Health Insurance Scheme, noted:

> *I am sick, but I do not have health insurance to go to the hospital. I do not have money to buy even paracetamol (pain medicine) so I use herbal medicines since that is not expensive. I know my condition could be repaired through surgery, but that is not an option for me because I cannot afford it. On occasions that I went to the hospital, the doctors and nurses were very nice and took care of me well. I was given some medicines, I took all as prescribed, but I continue to leak.* (28 years, Buya).

Coping strategies adopted by women living with fistula

The women living with fistula described diverse ways they coped with the challenges they encountered. Among these were begging for assistance, seeking support from Fistula Kpandai, maintaining personal hygiene, and optimistic motivation. Since many of them did not have jobs nor received assistance from their family members, they were compelled to seek financial help and food stuffs from friends and other community members in order to survive:

> *For me, I am not able to do any work, so if I see people returning from their farms, I approach them and plead with them for food hand-outs. Normally, they give me tubers of yam and some vegetables and if they have firewood, they offer me that, as well. They know my condition so they give me enough yams and firewood. Sometimes, I go out to ask for alms and also I sell some of the gifts to enable me purchase soap for bathing and washing of my clothes. I also use some of the money to purchase pain medicines.* (50 years, Buya).

A participant who asked for alms on market days had this to say:

> *On every market day, I go there to ask for alms as many people come to the market. My children live with my mother in another town so I use the money I receive to take care of myself. Sometimes, I get considerable amount of money, but other times, I get just a little and that makes life difficult. On days that I do not receive enough, I receive help from a cooked food seller nearby. Before the onset of the condition, life was good; I sold alcoholic beverages and engaged in farming. Now, because of my condition, I am unable to work.* (45 years, Nkanchina).

Furthermore, according to some participants, they managed the condition through financial assistance from Fistula Kpandai:

> *Money is a huge problem since I do not have a job, but most often when we attend the support group meetings, some philanthropists come around to give us money. Although it is not enough, it is better than nothing as I am able to manage it. I use the money to buy some food items, soap and diapers. I do not know how I would have survived without that help since I look forward to the money every time I attend meetings. I reside in Buya so I walk to the venue of the meeting, I do not have to pay for transportation.* (60 years, Buya).

This participant was appreciative of the emotional support she received from the support group:

> *I do not know what I would have done without the Fistula Kpandai support group. Members of the group have become my family since my family has neglected me because of my condition. We respect and empathize with each other. Every time I attend meetings, I feel like I am a human*

> *being as we comfort ourselves and discuss our dilemmas. Our leaders encourage us to be patient and believe that one day we may be supported by doctors who will do the surgery for us free of charge. I cannot wait to see that day.* (40 years, Pramg).

> Another strategy that was utilized by the women to deal with their challenges was maintenance of personal hygiene. This was important for all the WLOF included in the study because a major problem that is associated with fistula is urinary incontinence. This makes acceptance into social events and other communal activities very challenging. Accordingly, a participant noted:

> *I always keep myself clean because of the condition. Initially, I did not know about personal hygiene but now I know how to maintain personal hygiene to avoid bad odor and embarrassing situations. I bath very often and wash my clothes regularly to reduce the odor that attracts insults and isolation. I always use perfume before I go out and most often, I do not smell bad for the entire period I would be out. I feel uncomfortable when I smell bad, especially in public so I try to change myself often.* (35 years, Wayai).

A participant who compared fistula with other stigmatizing health conditions, narrated:

> *Fistula is different from other illnesses like leprosy or HIV because it requires a lot of personal hygiene in order to avoid or reduce bad smell. I manage the condition well by always maintaining personal hygiene because that is the only way people would respect me. In my community, women are disrespected if they do not keep themselves clean so living with this condition is a huge task. Anytime I ran out of adult diapers and I do not have money, I use a clean washable cloth to contain the leakage.* (40 years, Buya).

Moreover, many of the participants indicated that they handled the condition by being optimistic and trusting God as a participant asserted:

> *I have gone through many challenges because of this condition. I am still alive because of the I hope I have in God to continue taking care of me. If I rely on human beings, even my family members, they would disappoint me. When I listen to the stories of other people, then I stop grieving because I know there is hope. I believe that God will take care of me and at the right time, I will receive assistance for the surgery and life would be better. I cannot wait to return to normal life, which I always look forward to.* (65 years, Tali).

A participant who indicated that she had been neglected by her close associates shared her experience:

> *If all your family and friends neglect you, what else can you do? My hope is in God who takes care of me. I am trusting God that I would get financial assistance to undergo the surgery to repair my condition. All I have to do is to have hope and wait on God. People will fail you, but God will not. Most often, I encourage myself that things will get better soon. I do not know how I would have survived without God. I have lived with this condition for a long time. Although I am suffering, I am alive and optimistic about my future.* (55 years, Nkanchina).

Discussion of findings

This study explored the challenges and coping strategies of women living with obstetric fistula in the Northern Region of Ghana. The participants were between ages 20 – 70 years and resided in different villages in the Kpandai District. As a maternal medical condition, the disease is caused by prolonged, obstructed labor and usually affects poor women without access to timely, high-quality medical treatment (Bashah et al., 2018; Capes et al., 2011; Mohamed et al., 2018). Many of the women included in this study lived in rural areas in the Northern Region of Ghana where there are no health-care facilities. The risk of developing obstetric fistula is high for women living in many impecunious countries such as Ghana where health care is limited or unavailable due to poverty (Bangser et al., 2011; Pope et al., 2011; Sullivan et al., 2016). In addition, the findings showed that WLOF experienced diverse challenges within their environment (e.g., physical health; abandonment and divorce; psychological issues; financial constraints; and difficulty accessing healthcare). These challenges could be linked to women's personal attributes and the nested systems in their environments (Bronfenbrenner, 1979).

Many of the WLOF reported experiencing frequent pains and leakage of urine and/or feces due to the condition. Obstetric fistula could cause life-long disabilities and poor quality of life among affected women (Bashah et al., 2018; Capes et al., 2011; Kalembo & Zgambo, 2012). Furthermore, evidence showed that many of the WLOF were abandoned and divorced by their spouses. Extant studies (e.g., Gebresilase, 2014; Khisa et al., 2017; Mantey et al., 2020) have reported that many WLOF were divorced, abandoned and lacked social and financial support. The few women who lived with their spouses received no support from them. As opined by Mohamed et al. (2018) women with fistula who were still living with their spouses had limited relationships. This could result in psychosocial issues including blame, hatred, sadness, suicidal thoughts, as well stigma and discrimination as experienced by some women included in this study. Social isolation could lead to psychological ill-health like depression and suicidal thoughts (Khisa et al., 2017; Muleta et al., 2008).

Most often, WLOF is abandoned by their family members, religious groups, and peers due to stigma that is associated with the condition. As explained by the ecological systems theory, the various systems influence the development and actions of individuals such as WLOF, which could impact either positively or negatively on their well-being. In many African rural communities including those in Ghana, the family is considered a safe refuge for family members, particularly in times of sickness (Dako-Gyeke et al., 2015). In the Ghanaian culture (macro system), the health of an individual is linked to the health of the entire clan, which therefore takes on the responsibility of ensuring that a sick family member is healed or recovers from the illness (Awusabo-Asare, 1995). However, WLOF are often abandoned by their close contacts including family members due to stigma and traditional beliefs associated with the illness. Complicating the situation is the fact that the stigma and discriminatory practices are rooted in superstition and supernatural beliefs, which are part of the Ghanaian culture (Dako-Gyeke et al., 2015).

Also, some WLOF were neglected by their close associates due to fear of the stigma being extended to them (Dako-Gyeke, 2018; Jarvis et al., 2017; Kabayambi et al., 2014). The negative behaviors and attitudes toward WLOF usually stem from the fact that many people in Ghanaian rural communities do not have much knowledge about the cause of obstetric fistula and as a result, are unwilling to offer support to affected women. The shame linked with the disease, as well as other factors like financial constraints could serve as barriers to WLOF accessing treatment until their condition deteriorates. Without financial support, WLOF included in this study had difficulty securing their basic needs. Generally, the WLOF were poor as they had little or no means of employment due to stigma and/or ill-health. They are unable to work, especially if they have to handle food (Sullivan et al., 2016). Some of them therefore engaged in activities that were less stigmatizing, such as farming and selling of firewood. Even in such situations, WLOF engaged in these activities on irregular basis due to their condition.

The financial challenges of WLOF were exacerbated as they had to spend a lot of money on detergents to keep themselves clean, purchase drugs to manage their pains, as well as seek medical treatment. In view of the fact that almost all of the participants did not earn income and the National Health Insurance did not cover the cost of surgery, they were compelled to live with the condition. The participants complained about (a) transportation cost and distance to health facilities, (b) their inability to renew their national health insurance cards that would allow them to access basic medical services, and (c) the high cost of and other challenges associated with the repair surgery. Sullivan et al. (2016) noted that fistula repair was available at unpredictable times and only for few days every 1 or 2 months. The challenges associated with accessing health care, compelled many WLOF to resort to herbal and non-prescription medications, which unquestionably could have harmful consequences on their health.

Additionally, WLOF adopted problem focused (asking for alms and seeking support from Fistula Kpandai) and emotion focused (maintaining personal hygiene and optimistic motivation) coping strategies within their social environment to deal with their condition. Since many of the participants did not earn income, they resorted to begging and sought assistance from their support group. Gbola (2007) asserted that WLOF devised ways of preventing embarrassment and humiliation by begging for alms and forming associations with other patients in the spirit of self-support. These are adaptive modes of coping that involve planning, support or engaging in behaviors to overcome the problem that is causing distress (Folkman & Lazarus, 1985). Maintenance of personal hygiene and optimistic motivation were emotion-focused coping mechanisms adopted by WLOF. Personal hygiene was upheld in order to reduce odor as a result of the continuous flow of urine and/or feces. As explained by Mantey et al. (2020), living with fistula means maintaining personal hygiene in order to avoid embarrassment.

For the WLOF who had difficulties buying sanitary pads, they resorted to the use of cloth, which they had to wash with detergents very often. Similarly, the Ghana Health Service (2015) reported that women with fistula used old pieces of cloth as pads, perfume and powder to manage fistula-related odor. To cope with the physical signs of incontinence, many women used homemade absorbent pads (Mselle & Kohi, 2015; Mwini-Nyaledzigbor et al., 2013). Cleanliness is very important for WLOF because the smell of urine and leaking are discrediting and stigmatizing for women as they are sources of shame, low self-esteem, anxiety, embarrassment and humiliation (Mwini-Nyaledzigbor et al., 2013). In addition, as many WLOF were neglected by their families, had difficulty accessing health care, and lacked knowledge about fistula treatment (Bashah et al., 2018; Nsemo, 2014), which could make life stressful, they developed positive attitudes or reframed their situation in order to survive. The coping theory proposes that when nothing useful could be done to change an individual's relationship with the environment or when problem-solving efforts fail, emotion-focused efforts become an option (Lazarus, 1993).

Usually, people tend to change the way they feel about a situation if they realize that it cannot be changed. While some of the WLOF had a positive attitude toward their future, others were sad and some even contemplated suicide. As a way of coping with the situation, some of the women included in this study had optimistic motivation by relying on hope and faith in God. The findings of the study are limited as purposive sampling was conducted with participants from selected communities. Thus, the findings cannot be generalized to all rural communities in the Northern Region of Ghana. Moreover, participants included WLOF who were members of a support group and as a result, WLOF who were not members of the support group and also those who resided in other Regions of the country were excluded. Additional studies that draw on WLOF in other Regions in Ghana are needed to fully understand the phenomenon. The limitations notwithstanding, the findings could be applied to a comparable context (Lincoln & Guba, 1985) as the findings offer evidence regarding the challenges and coping strategies of WLOF in a Ghanaian rural context.

Conclusions and Implications

In conclusion, the findings of this study demonstrate that WLOF included in this study faced diverse challenges (physiological issues, abandonment and divorce, psychological problems, financial constraints and difficulty accessing health care), which had implications for their wellbeing. Undeniably, uncontrolled leakage of urine and/or feces underpinned the challenges experienced by WLOF and this was worsened by the myths associated with the disease. Thus, the need for surgeries to repair the condition of WLOF should be taken more seriously and made available by the government and relevant stakeholders. It is therefore important to prioritize and make resources available to improve the quality and coverage of treatment of obstetric fistula and women's wellbeing in general. Furthermore, many of the women experienced social isolation and in consequence, were confined to their homes with little or no opportunity to engage in income generation activities and social participation outside of their homes. This suggests the need for financial assistance and psychosocial counseling for WLOF warrants.

Additionally, it would be useful to educate the general public, especially spouses and family members about obstetric fistula, through awareness-raising campaigns that are contextualized and aimed at behavioral change. Furthermore, evidence indicated that WLOF who participated in this study employed both problem-focused and emotion-focused coping strategies to deal with their condition. The coping strategies included asking for alms, seeking support from Fistula Kpandai, maintaining personal hygiene, and optimistic motivation. These were reported by other scholars (e.g., Gbola, 2007; Mantey et al., 2020; Mselle & Kohi, 2015; Mwini-Nyaledzigbor et al., 2013). The strategies utilized by participants in the current study provides an opportunity for researchers and helping professionals, particularly social workers to understand how WLOF cope with their challenges. This is crucial because the systems within the social environment of WLOF could serve as sources, as well as solutions to their problems.

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