


Reintegration of Women Post Obstetric Fistula Repair: Experience of Family Caregivers

Global Qualitative Nursing Research
Volume 4: 1–9
© The Author(s) 2017
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/2333393617714927
journals.sagepub.com/home/gqn


Kimberly Jarvis¹, Solina Richter¹, Helen Vallianatos¹,
and Lois Thornton²

Abstract

In northern Ghana, families traditionally function as the main provider of care. The role of family, however, is becoming increasingly challenged with the social shifts in Ghanaian culture moving from extended kinship to nuclear households. This has implications for the care of women post obstetric fistula (OF) repair and their family members who assist them to integrate back into their lives prior to developing the condition. This research is part of a larger critical ethnographic study which explores a culture of reintegration. For this article, we draw attention to the findings related to the experience of family caregivers who care for women post OF repair in northern Ghana. It is suggested that although family caregivers are pleased to have their family member return home, there are many unanticipated physical, emotional, and economic challenges. Findings lead to recommendations for enhancing the reintegration process and the need for adequate caregiving support.

Keywords

Africa, sub-Saharan, critical methods, ethnography, families, caregiving, gender, health care, culture of health, health policy/policy analysis, social support, women's health

Received October 30, 2016; revised April 24, 2017; accepted May 1, 2017

An obstetric fistula (OF) is a serious condition most often associated with prolonged obstructed labor (Semere & Nour, 2008) where emergency obstetrical care is frequently unavailable. It is estimated that two to three million women live with OF worldwide, with most cases occurring in sub-Saharan Africa (World Health Organization, 2014). A total of 1,538 women were reported to be assessed for OF in Ghana between 2011 and 2014 with the highest number of consultations occurring in the Northern region (Ghana Health Service, 2015). Although OF can be surgically corrected (Avevor, 2013; EngenderHealth, 2004), life beyond the repair can have intense emotional, social, and economic ramifications for women and their families (Yeakey, Chipeta, Rijken, Taulo, & Tsui, 2011) and often includes the loss of an unborn child (Cowgill, Bishop, Norgaard, Rubens, & Gravett, 2015).

Much of the research pertaining to reintegration post OF has been conducted in East Africa with no studies identified in Ghana (Donnelly, Oliveras, Tilahun, Belachew, & Asnake, 2015; Gebresilase, 2014; Khisa & Nyamongo, 2012; Mselle, Evjen-Olsen, Moland, Mvungi, & Kohi, 2012). The majority of these studies were qualitative and limited to the experiences of women who had an OF repair. Frequently, the experiences of women were recalled soon after surgery and commonly highlighted the negative aspects of reintegration.

Women, for example, indicated not being allowed to cook or serve guests in the home despite being cured of their illness because it was believed the condition was dirty, sinful, and could spread through food preparation (Khisa & Nyamongo, 2012). In addition, needing to avoid the past trauma of stigma and discrimination was often seen as a barrier to women integrating back into their communities (Gebresilase, 2014; Khisa & Nyamongo, 2012).

Family support is essential to assist women in reintegrating to the life they had prior to the development of OF (Donnelly et al., 2015). This is particularly true in Ghana where family is a fundamental and highly valued institution and where the extended family functions as a support group responsible for and obligated to assist each other (Gyekye, 2003; Tettey, Pupilampu, & Berman, 2003). It is, therefore, important to understand how family caregivers are affected by a woman's return after OF repair because their physical

¹University of Alberta, Edmonton, Alberta, Canada

²Leslie Groves Hospital, Dunedin, New Zealand

Corresponding Author:

Kimberly Jarvis, Edmonton Clinic Health Academy, University of Alberta,
11405 87 Avenue, Edmonton, Alberta, Canada T6G 1C9.
Email: kdjarvis@ualberta.ca



and emotional health can influence a woman's health, welfare, and successful reintegration (Bowen, 2006). Understanding a husband's perception and the level of support he can provide is particularly important because culturally Ghanaian men play a key role in decision-making about health and health care (Ganle & Dery, 2015). Few studies address the experiences of family caregivers and how they manage the reintegration process (Pope, Bangser, & Requejo, 2011; Yeakey et al., 2011).

This research is part of a larger critical ethnographic study which explores a culture of reintegration. For this article, we draw attention to the findings related to the experience of family caregivers who care for women post OF repair in northern Ghana. Testimony about the roles and responsibilities of family caregivers can inform decision makers, opinion leaders, health care providers and the general public about the significant role family members play in supporting women to reintegrate home after OF repair. The findings give rise to recommendations for improved formal supports and family-based initiatives which ensure men's participation and women's empowerment.

Method

Design

A critical ethnographic design was utilized to "engage in [a] cultural critique by examining larger political, social, and economic issues that focus on oppression, conflict, struggle, power and praxis" (Schwandt, 1997, p. 22). A critical ethnographic design helps to engage with a potentially disenfranchised group (Madison, 2011; Thomas, 1993) like family members caring for women reintegrating after their OF repair and supporting them in advocating for their needs. The design exposes the taken for granted perceptions about the world in which these women and their families live and how caregivers and/or communities think about reintegration. The theoretical underpinnings of the approach are situated in the critical social theory, thus moving the discourse from describing "what is" to the realization of "what could be" (Calhoun, 1995; Madison, 2011). Through exploring the experiences, values, beliefs, and practices of family caregivers, it is believed that new insights will emerge to inform a culture of reintegration post OF repair.

Ethics approval was received through the Human Research Ethics Review Board at the University of Alberta, Canada, and through the Navrongo Health Research Center, Institutional Review Board, Ghana. Participants were informed that their participation was voluntary both in English and in their local language by means of a translator when necessary. Participants gave consent using their signature or thumbprint.

Setting and Culture

The research spans across two time intervals from March to June 2014, and April to May 2015. The study setting is in

northern Ghana, recognized to be multilingual and ethnically diverse (Government of Ghana, 2016). Northern Ghana is exceedingly underdeveloped in terms of infrastructure in comparison with its southern counterpart, and this is reflected in the delivery of health care services (Tsikata & Seini, 2004). The largest ethnic group in northern Ghana is the Mole-Dagbon tribe. Northern Ghanaian society is known to be hierarchical and patrilineal where people are respected because of their age, experience, and status. With respect comes responsibility and people expect the senior most man to make decisions that are in the best interest of the family. Ghanaians pride themselves in their communal way of life though family obligations. These obligations take priority above most things except for their faith in God or Allah, where the dominant religion in northern Ghana is Islam (Government of Ghana, 2016; Gyekye, 2003).

The institution of marriage is culturally significant, joining two or more families together. Polygamous marriages are common in northern Ghana and are permitted under customary law (Ardayfio-Schandorf, 2006). The purpose of marriage is procreation. Children are customarily very important, and the possibility of a woman being unable to bear children is socially viewed as a great calamity and burden on the family (Gyekye, 2003).

Recruitment and Sample

Participants were recruited using convenience, purposive, and snowball sampling. The main recruitment sites were a fistula treatment center in the northern region, along with 24 northern communities known to have women reintegrating post OF. To be eligible, the participant should be:

- A woman who had experienced an OF repair a minimum of 3 months prior to being interviewed.
- A family caregiver, either primary or secondary, of a woman who had received an OF repair. A primary caregiver is defined as an individual who has the sole responsibility for the care and well-being of others in the family, whereas a secondary caregiver provides assistance to the primary caregiver (Goodhead & McDonald, 2007). Only family members of women interviewed were eligible.
- A health care provider, community and/or stakeholder who was directly or indirectly involved in OF care or reintegration post repair.

In this article, we report on qualitative findings based on interviews with family members ($n = 24$) from a larger study ($N = 99$) aimed at exploring a culture of reintegration post OF repair.

Data Collection

Although observation and a review of government, and non-governmental documents related to OF care were used in

data collection, semistructured interviews were the main tool utilized. Semistructured interviews allowed for a dialogical approach that facilitated in examining the dominant beliefs shaping the reality of the participants (Sullivan, 2012). Questions asked focused on changes in family roles, responsibilities, and relationships once a woman returned home to her community after OF repair, the impact of living with and caring for these women and the needs and resources required for families to support them. Access to participants was negotiated through a Ghanaian nurse-midwife who had a strong connection to northern Ghanaian communities, community stakeholders, and staff from the OF treatment clinic.

Interviews were conducted in seven different languages with the support of translators. Interviews were audio recorded and lasted 30 to 90 minutes. Extensive field notes were written or audio recorded after each interview. Field notes provided both descriptive and reflective evidence about the meaning and understanding of a culture of reintegration. Data collection continued until no new information emerged which could inform the inquiry. Data were stored in the Health Research Data Repository (HRDR), a secure and confidential virtual research environment, at the University of Alberta, Canada.

Data Analysis

Interviews were transcribed verbatim, and a subset of the interviews was translated forward and backward to ensure accuracy in the meaning of the original language. Data were analyzed using Hammersley and Atkinson's (2007) approach to ethnographic analysis. The data subset was read line by line and keywords and phrases were highlighted. These concepts were organized into 10 categories to create a coding framework which was tested using randomly selected interviews from the main data set. After the coding frame was deemed appropriate for critical analysis, it was then applied to the remaining data. Nvivo 10.0 software was used for data management.

Trustworthiness was maintained in several ways, for example, the use of multiple and different data collection methods, the extended time in the field to ensure that analysis and interpretations were based on long-term knowledge and not conjecture, the use of a stepwise replication procedure where the first and second author independently coded and compared a subset of the data to ensure accuracy and consistency in interpretation, and reflexivity where the first author kept a field journal to record personal feelings, thoughts, and beliefs about the research process and experienced happenings.

Findings

Family Caregiver: Roles and Characteristics

Twenty-four ($n = 24$) participants identified themselves as family members providing care for women who had received OF repair and were reintegrating to their family, community,

social, and work life. Family members were affiliated by consanguinity or affinity and consisted of husbands, mothers, fathers, children, brothers, sisters, paternal aunts, and second wives. Of the 24 family members interviewed, 20 men and two women identified themselves as primary caregivers. The rest were women who identified themselves as secondary caregivers. In many Ghanaian societies, the senior most man of the household is responsible for overseeing family needs and the distribution of family resources (Gyekye, 2003). One man identified his role as family head as follows:

In this compound [family home] I'm like a wooden bar. You know when they build these round huts usually in the middle . . . there is a bar that will hold the other pieces together. That is my role in this compound. I am that wooden bar and the other members of this house are resting on me.

All participating family members lived in northern Ghana, most in small rural communities with inadequate infrastructure in comparison with larger northern communities or metropolis areas. Most families were polygamous, consisting of a husband with two wives and their children. These families commonly lived together with a husband's patrilineal clan. Household tasks were shared between family members but differed according to gender. A male family member stated,

Here in this compound [family home] the women are responsible for cooking, collecting firewood, fetching water from the pipe. The women go to the farm to help with planting and harvesting and they sell some small things to get food stuff . . . Women are social creatures . . . seen in the community helping . . . they care for small children. But us men, we work hard in the fields.

Twenty-two of the family members who participated stated they were working outside the home, primarily in farm activities.

Experiences of Family Caregivers: Beyond OF Repair

Relieved from the burden of fistula. Many family members expressed a sense of relief and joy once a woman with OF was successfully treated and the woman returned home to her family and community. As this husband stated, "it was all happiness and joy when she returned home. People shared that joy with us in this community . . . I [husband] am happy now that we can mingle among people again."

It is assumed that a family member's needs might change when a woman progresses through the reintegration process. A husband stated,

After the operation, we thought it was all over but she still needs assistance [nine months post OF repair]. It's hard on me. Then she said a small amount of urine was coming. Doctor said its okay . . . but how, when she is like a small child needing care . . . even after the operation the sickness is still keeping us down . . .

The reintegration period is a subjective experience, and its duration is determined by the person who is reintegrating and the family's ability to adapt (Creech, Hadley, & Borsari, 2014). All participants reported challenges related to caring for a family member with an OF, and the physical, emotional, and economic consequences for the family.

Physical impact on family. A woman recovering from an OF repair and reintegrating might be exempt from her family and social responsibilities, thus displacing her duties on other family members. A female family member commented,

... we [family] do not allow her to be doing anything that will take her back to her former days [with OF]. We see her as a sick person. Her duty is to come and pick her food and eat and be sitting down and getting well. Sweeping, no we do not allow her any work.

Family members discussed how they tried to accommodate a woman returning home after her OF repair. Most women lived with an extended or polygamous family in a communal environment where the burden of care was shared. This husband stated,

In this compound [family home], we do everything communally. So when [my wife] came home we discussed all the things she shouldn't do so all the women were aware. The things the men can help with, we did but if it's something related to women's work then the other women would help with that.

In some cases, men had to carry out "women's work," which in Ghana traditionally includes "spending a great deal of time not only working in the family enterprise but in the nurture and rearing of children and in important household tasks such as cooking and fetching water and firewood" (Tengey, n.d., p. 143). When this occurred, men were frequently ridiculed by the community for participating in the care of their family member. A husband stated,

The biggest challenge is the household chores so when I come from the farm I go and collect firewood. People here in this community will be making fun saying look at the man who has turned into a woman carrying firewood. They ask me are you a man or a woman?

Although most family members described caring for a woman's physical needs post OF as being undemanding, some expressed frustration and resentment with their role as caregiver. This was especially shared by secondary caregivers, and for women who were second wives caring for their husband's other wife post OF. A female participant notes the comments from a second wife, "why should I have to be carrying her [woman with OF repair] things and for her to be lying down like that doing nothing."

Emotional impact on family. The psychological distress for family members who provide care and support for persons recovering from OF can be overwhelming. During the reintegration period, many emotions surfaced for family members, some of which were rooted in prior experiences of coping with OF. When families were asked about the emotional burden of caring for a woman after OF repair, many reflected with sadness and concern. A husband commented,

When [my wife] came home it was all happiness . . . but now that some time has passed it is all worry. Causing me sickness and big headaches. I don't sleep and my food gets stuck in a lump, I can't force it down. It's all [a] big worry for me . . .

Many women in this study had experienced prior failed surgical repairs. It was common for families to express feelings of uncertainty, believing that a reoccurrence of OF was likely. Some family members believed they needed to appear strong within the family and suppress their uncertainties about the possibility of reoccurrence. A husband noted:

It was hard for me [husband] to believe that it [OF] was finally cured . . . I too was expecting it to come back but as the years went by, I knew that she was finally cured. [Initially] I was afraid saying something would spoil it, perhaps make it come back. There were ups and downs and some days when she would be just sitting there like that doing nothing I would get a big lump [point to stomach]. As the man of this house, how can I be telling my family I'm worrying like that . . . a man must have a strong body and a strong mind . . .

Many families grieved the loss of their unborn child and the potential loss of family hopes and future dreams of having more children, a frequent result of OF. This was another sentiment identified by family members that carried a heavy emotional burden during the reintegration period. The consequences of OF can cause physical or biological changes that affect family relationships and plans for future children. Although having an OF does not necessarily imply that a woman is infertile, some women require a hysterectomy during OF repair. A husband stated,

I wanted my wife to have a child with me but the doctors say her womb is not fine and she will not be able to give birth. This is a very bad thing to hear . . . your wife not birthing a child. We are disappointed but that is how it is.

Some husbands also felt emotionally detached from their wives because they were unable to have sexual intercourse with them for 3 to 6 months after surgery. Husbands noted that their lack of understanding about abstinence led to misunderstandings during the reintegration process.

My wife told me no sex for some time. That is what she was told at the clinic . . . I thought she was telling lies, causing a whole lot of confusion in our marriage until the nurse told me she was being sincere.

Alternatively, a small number of husbands revealed they feared intimacy for months after their wife's OF repair. A husband stated, "once bitten twice shy."

Impact of stigmatization on the family. Women who experience OF are often highly stigmatized and marginalized. This stigma can continue post OF repair because culturally OF is not viewed as a medical condition that can be treated and cured but as a divine punishment or a curse for ill-mannered behavior. Though most of the stigma is directed toward women with OF, stigmatization can be directed toward family members because of their relative's condition. A husband recalls an experience he had with a community member after his wife returned home post OF repair:

... because the borehole is in front of our house we [the family] are in charge of repairing it . . . Usually, I go around the village to collect money. When I went out . . . one woman told me proverbially, to look for a calabash [bowl], to go and block my wife's leaking anus and not to come and stand here collecting money.

Family members spoke of how being stigmatized affected them and how they often dissociated themselves from their family members during the illnesses. This behavior later created feelings of shame and regret during the reintegration period especially when the source of the stigma originated from within the family. Several husbands stated they had thought about leaving or had shielded themselves from the stigma of the illness by temporarily leaving their wives when they were experiencing OF. A husband asserted,

You know it was all difficult times. My family was angry and said I should leave her. I would be telling lies if I said I did not think about it. I'm telling you if you have ten women who are affected with this condition . . . only one or two men will be able to stand behind their wives and endure the embarrassment. When I look at her now, I regret those thoughts I had somewhere down the line.

In addition, a son noted the regret he had for disrespecting his mother when she was experiencing an OF. His words illustrate how opinions and attitudes can change with time, maturity, and increased knowledge about the illness.

I was a young boy when my mother had the sickness but that is no excuse. My fellow colleagues [friends] would say "look at the woman smelling of urine and walking like that" . . . I didn't like my mother growing up because of the sickness. A son is supposed to honour [his] mother but the sickness, it brought shame. I am now grown and I have deep pain for how I treated her.

Some families spoke of the need to shield their relatives from any potential stigma post OF repair and acted to facilitate in the healing process. A husband commented:

I am over joyed that my wife is well . . . but it still hurts to recollect what we went through. After the surgery, I could not go

back to the village, so we stayed here in this town. . . I could not take her back where people had stigmatized her.

Economic impact on family. Economic hardship and financial strain occur when a woman is reintegrating to her family and community because the physical restrictions needed for recovery and the subsequent limitations in contributing to family life and resources. A husband stated:

You know I was worried about my wife returning home because she was coming with regulations about what she could do and not do. No hard work on the farm, no carrying firewood, no lifting heavy objects . . . I am a farmer and if she can't come to the farm and work it creates a big money problem.

Families believed that any source of financial support provided by nongovernmental organizations (NGOs) to women following OF repair should benefit the whole family. A husband commented, "I think families should be given some small capital, not just the women. We the husbands have suffered too but no one sees." Financial support is needed for the family's basic necessities and when money is not available because of the loss of an income, decisions must be made about how to prioritize needs. This might mean that commodities like a child's schooling are not possible either because the family cannot afford the school fees or uniforms, or because the children are needed for income earners in place of their mother. A household head stated:

You know if a woman can't work and care for herself to buy soap, cloths, and small food stuff then I have to buy it since I have sole responsibility for her care. That means little money to buy other important things. Our children have not been schooling, there is no money . . . I need them [the children] to take her place in the farm.

Discussion

The experiences of family caregivers living in northern Ghana were highlighted. Common emerging themes focused on the physical, emotional, and economic burden of care related to the process of reintegration in rural Ghana. Family members who identified themselves as primary caregivers were predominately men. Through exploring the experiences, values, beliefs, and practices of family caregivers, insights gained lead to recommendations.

Although family members described their joy in having their relatives return home after their surgical repair, they admitted that the high degree of caregiving support needed was more than they had anticipated. Similar results have been reported in other studies when women post OF repair were unable to return home and take up their traditional family roles (Donnelly et al., 2015; Gebresilase, 2014; Yeakey et al., 2011). A family member's account of their experiences caring for a woman post OF is subjective and is dependent on the physical, emotional, and socioeconomic well-being of

the individual reintegrating and the family's ability to adapt to the current situation (Creech et al., 2014). Little is known about caregivers of women experiencing OF, but Dempster et al. (2011) and Elmore (2014) suggested that it is common for caregivers of cancer survivors to experience health outcomes like depression, anxiety, and physical ailments. Family relationships can become strained during reintegration. This is most noticeable 4 to 9 months after an individual returns home (Marek et al., 2014). This might be the time when family support and education are most needed to minimize family difficulties.

Traditionally in Ghana, women in the north are obliged to spend time working in the farm, raising children, and tending to household chores (Tengey, n.d.). During the OF healing and reintegration period, a woman requires rehabilitation, which seriously affects the family because of her inability to do strenuous tasks. Women returning home post OF are often viewed by their families as ill and in need of substantial care. Crossley (1998) notes, "sickness and the experience of being ill is not just a physical/biological phenomenon but a socio-cultural one insofar as it locates people within social roles incorporating certain institutionalized expectations" (p. 509). Primary caregivers suggested they had a considerable amount of physical support because they lived in polygamous homes or with extended kin who provided support as secondary caregivers. The institution of family sustained through a series of kinship networks, is acknowledged as the bedrock of all Ghanaian social life (Gyekye, 2003). Ghanaian families customarily function as the main provider of care and offer support to their members, but it was noted that physical support (i.e., fetching water, cooking) was not always given readily. Some family members, particularly secondary caregivers or second wives in polygamous relationships, felt frustrated and resentful when expected to be "caregiver" to their husband's other wife. In a polygamous marriage, relationships between a man and his wives, or between wives who share a common husband are complex. First wives frequently have a higher status whereas junior wives enjoy preferential status (Slonim-Nevo & Al-Krenawi, 2006). Even though most polygamous families interviewed were supportive of each other, feelings of resentment are not unusual when the caregiving role is imposed on an individual. The role might be increasingly resented in some polygamous families where unequal distribution of household duties can lead to jealousy, competition, and disruption of family resources (Slonim-Nevo & Al-Krenawi, 2006).

Family caregivers reported feelings of sadness, uncertainty, shame, remorse and grief. Many of these emotions were embedded in a family member's prior experiences of dealing with the condition. Many family members were uncertain that the OF had been successfully repaired. Family members expressed fear of reoccurrence, but family members who were men often indicated that they were unable to express their fears. The norms for emotional expression are culturally determined (Kuo, 2011). Many men believed they

were expected to be emotionally strong. This is depicted in a common Ghanaian expression *Barima nsu*, translated as "a man does not weep" (Boakye, 2010, The zoo keeper, para. 3). Ghanaian men choose to withhold their feelings or to speak metaphorically, creating vagueness and ambiguity in what is being communicated so to preserve harmony within the family (Obeng, 2003).

Family members expressed feelings of shame and remorse during reintegration. Many family caregivers along with the women they cared for post OF repair were transitioning from dealing with a chronic condition to a phase of rehabilitation and reintegration. This caused some emotional upheaval, because family members recalled a previous time when they had dishonored their family member for having OF. It was important for caregivers to be aware of and to validate these feelings because the role of caregiving is laden with challenges that task both the caregiver and the care recipient. Self-forgiveness is an important part of emotional healing for family caregivers of women post OF repair. It is suggested that to move beyond deep hurt, you must "be able to name one's pain in order to sever the pain nerve linking the soul to the injury . . . to free oneself from a cluster of old thoughts . . ." (Owusu-Ansah, 2015, Forgiveness, para. 1).

Grief was commonly conveyed by family caregivers. Families grieved the loss of a child, a frequent consequence of obstructed labor that results in OF, and sometimes the loss of future children. In Ghana, the main purpose of marriage is procreation, and families will pray for many children because "there is no wealth where there are no children" (Gyekye, 2003, p. 84). When a woman fails to bear children in Ghanaian society, she often experiences humiliation (Gyekye, 2003).

In addition, family caregivers who were husbands or partners commented that they felt emotionally disconnected from their wives because health care providers advised couples to abstain from sexual intercourse for 3 to 6 months after OF repair. Some husbands mentioned that the fear of a reoccurring OF was so great that they abstained from sexual intercourse with their wives for an extended period of time. These remarks emphasize that families, particularly husbands or partners, need to be involved in post OF education. Intimacy and sexuality are an important aspect of one's health and well-being. Couples who have experienced an OF repair need comprehensive and timely information about their sexual and reproductive health. Providing support for couples to discuss and explore their sexual needs and how to provide pleasure to one another without vaginal intercourse is necessary. Sexuality is a sensitive and value-laden topic in Ghana but health care providers must be prepared to support families in this vital aspect of OF care.

Stigma by association is a well documented phenomenon (Östman & Kjellin, 2002; van der Sanden, Bos, Stutterheim, Pryor, & Kok, 2013). It is the result of a lack of understanding of the stigmatized condition by family members and society. Many family members in this study were stigmatized and ridiculed even after successful fistula repair. For that reason,

some families opted to relocate and start life anew to avoid being denounced by the community. The negative opinion of community members toward families who cared for women post OF illustrated the need for greater community awareness about the cause of the illness and its treatment. It has been shown that stigma and labeling can affect the course of healing and prevent successful reintegration (Tawiah, Adongo, & Aikins, 2015). Furthermore, it has been shown that stigma leaves individuals in a state of grief that prevents them from seeking support and provokes feelings of powerlessness (Tawiah et al., 2015).

Finally, the economic challenges for families caring for relatives post OF repair were articulated and have been well documented (Kimani, Ogutu, & Kibe, 2014; Women's Dignity Project & EngenderHealth, 2006). Many families post OF are increasingly impoverished because of the cost incurred in seeking treatment, and the loss of an income earner within the family. The loss of income and productivity might continue for some time while a woman is recovering, placing an increased economic strain on the entire family and forcing them to assess their financial priorities. The United Nations Population Fund (UNFPA)-Ghana and the Ministry of Gender, Children, and Social Protection provide a 2-week training program for women post OF repair, with the aim of helping them to acquire income generating skills, but this program has been met with mixed reviews. Many family members vehemently believe that financial support should directly benefit the family in addition to the individual woman who experienced the OF repair.

Recommendations

Recommendations to help support family members who care for women post OF repair in Ghana should be directed toward encouraging women and families to set realistic reintegration goals and expectations, and to be engaged in discharge planning prior to returning home post OF repair. Discharge planning from an OF clinic is essential in providing an opportunity to review an affected woman's visit, provide educational instructions, and answer remaining concerns. Education about post OF care should be conducted with family members present. Family caregivers need to know and understand the care their family member requires and how best to give support while maintaining a reasonable quality of life for themselves. Husbands or household heads need to be included in post OF teaching because they are viewed as the family's decision maker and carry significant authority. Family education needs to be timely, comprehensive, accurate, and appropriate to the family's current circumstances. To accomplish this, health care providers must be able to assess the home environment and the availability and accessibility of support systems for both the woman and her family. Health care providers have to be knowledgeable about resources and be comfortable approaching a range of sensitive topics (i.e., sexual health). Health institutions and professional health associations have a

role to play in ensuring that health care providers are competent in their role as family health educators and OF care advocates. Professional continuing educational courses and mentorship programs regulated through professional associations might be one method of achieving these competencies. Families also need to be given a safe and reassuring environment to ask questions and to help them express their concerns and feelings (i.e., fear, uncertainty, guilt, frustration) throughout the reintegration period.

Improvements in a formal health referral system and community follow-up should be implemented between the fistula clinic and health clinics within the districts. Community health nurses need to be formally made aware of and responsible for families in their district who are caring for women post OF. Technical strategies like the Mobile Technology for Community Health (MOTEC) have been successfully implemented in Ghana since 2010 for improving maternal health care. Similarly, mobile phones could be utilized to provide support (health information, counseling) to families by way of text messaging (Grameen Foundation, 2011).

Greater community awareness and understanding about the causes of and treatments for OF are needed to assist families to be better supported within their communities. A campaign to create OF awareness in northern Ghana is currently underway by a nonprofit organization, Net Organization for Youth Empowerment and Development (NOYED)-Ghana (2016). This program utilizes community volunteers to disseminate health information about how to prevent and treat OF. There are many nonprofit organizations in Ghana with similar goals of creating OF awareness that work independently of each other. These programs need to collaborate and coordinate their awareness initiatives, combining resources and expanding their initiatives to include community awareness about how to support families and women returning home post OF repair. This might be initiated through the Fistula Task Force, established in 2014, consisting of a group of government and community stakeholders interested in OF care. Men in the community, particularly those in leadership positions, need to be strong advocates for families during the reintegration period post OF. Family members also need to be encouraged to share their experiences so to support other families and to validate the need for formal family supports.

Economic difficulties continue to be an issue. UNFPA-Ghana and the Ministry of Gender, Children, and Social Protection skills training program has been successful in meeting some of the financial challenges experienced by families. Additional skills training options should be explored in partnership with families to ensure that training is appropriate in supporting family needs.

Finally, Ghanaian family caregivers need to be supported by the community, government, and NGOs to develop or enhance effective support systems that identify with their worldview "to maintain a sense of harmony and balance within the physical, metaphysical, collective/communal, and the spiritual/psychological realms of existence" (Utsey, Adams, & Bolden, 2000, p.

197). Family members who care for women post OF can be invited to participate in formal and informal discussions about OF care. Family members can provide valuable firsthand knowledge and insight into the issues of OF that are important to women and families during all stages of OF care. Family input is particularly important during the reintegration period because many family members are the primary caregivers and the decisions made about OF impacts their well-being and that of the women they care for.

Conclusion

Family members who care for women post OF repair in northern Ghana have a myriad of intertwining physical, emotional, and economic challenges. Ghana's kinship system prescribes the roles, duties, responsibilities, and obligations of family members in all aspects of social life. The nuclear and extended families have traditionally played an important role in caregiving, and an additional strain is potentially placed on families when illness or adversity arises. The findings reported here aim to shed light on the burden families face when they care for a woman post OF repair. The recommendations highlight the areas requiring government, nongovernmental, and community attention concerning the need for improved formal supports as identified by family caregivers.

Acknowledgment

The first author wishes to acknowledge her participants, the Health Research Data Repository at the University of Alberta for their assistance, the staff at the fistula treatment center in northern Ghana, and Ms. Priscilla Naa Boakye for her support in data collection.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Association of Registered Nurses of Newfoundland and Labrador who provided research funding to offset the cost of transcription.

References

- Ardayfio-Schandorf, E. (2006). The family in Ghana: Past and present perspectives. In Y. Oheneba-Sakyi & B. K. Takyi (Eds.), *African families at the turn of the 21st century* (pp.129-152). Westport, CT: Praeger.
- Avevor, D. (2013, August 23). Obstetric fistula, the enemy of women in Ghana. *Modern Ghana*. Retrieved from www.modernghana.com/news/484317/1/obstetric-fistula-the-enemy-of-women-in-ghana.html
- Boakye, J. (2010, February 1). What you must know about Ghanaian men. *Modern Ghana*. Retrieved from <https://www.modernghana.com/lifestyle/1287/what-you-must-know-about-ghanaian-men.html>
- Bowen, M. (2006). Alcoholism as viewed through family systems theory and family psychotherapy. *Annals of the New York Academy of Sciences*, 233, 115–122. doi:10.1111/j.1749-6632.1974.tb40288.x
- Calhoun, C. (1995). *Critical social theory*. Oxford, UK: Blackwell Publishers.
- Cowgill, K. D., Bishop, J., Norgaard, A. K., Rubens, C. E., & Gravett, M. G. (2015). Obstetric fistula in low-resources countries: An under-valued and under-studied problem-systematic review of its incidence, prevalence, and association with still-birth. *BMC Pregnancy and Childbirth*, 15(193). doi:10.1186/s12884-015-0592-2
- Creech, S., Hadley, W., & Borsari, B. (2014). The impact of military deployment and reintegration on children and parenting: A systemic review. *Professional Psychology: Research and Practice*, 45, 452–464. doi:10.1037/a0035055
- Crossley, M. (1998). Sick role or empowerment? The ambiguities of life with an HIV positive diagnosis. *Sociology of Health & Illness*, 20, 507–531. doi:10.1111/1467-9566.00113
- Dempster, M., McCorry, N. K., Brennan, E., Donnelly, M., Murray, L. J., & Johnston, B. T. (2011). Psychological distress among family carers of oesophageal cancer survivors: The role of illness cognitions and coping. *Psycho-Oncology*, 20, 698–705. doi:10.1002/pon.1760
- Donnelly, K., Oliveras, E., Tilahun, Y., Belachew, M., & Asnake, M. (2015). Quality of life of Ethiopian women after fistula repair: Implications on rehabilitation and social reintegration policy and programming. *Culture, Health & Sexuality*, 17, 150–164. doi:10.1080/13691058.2014.964320
- Elmore, D. L. (2014). The impact of caregiving on physical and mental health: Implications for research, practice, education, and policy. In R. C. Talley, G. L. Fricchione, & B. G. Druss (Eds.), *The challenges of mental health caregiving* (pp. 15–31). New York, NY: Springer.
- EngenderHealth. (2004). *Obstetric fistula: A needs assessment in Ghana and Rwanda: Expanding our knowledge*. New York, NY: EngenderHealth. Retrieved from www.engenderhealth.org/pubs/maternal/fistula.php
- Ganle, J. K., & Dery, I. (2015). “What men don’t know can hurt women’s health”: A qualitative study of the barriers to and opportunities for men’s involvement in maternal healthcare in Ghana. *Reproductive Health*, 12(93). doi:10.1186/s12978-015-0083-y
- Gebresilase, Y. T. (2014). A qualitative study of the experience of obstetric fistula survivors in Addis Ababa, Ethiopia. *International Journal of Women’s Health*, 6, 1033–1043. doi:10.2147/IJWH.S68382
- Ghana Health Service. (2015). *Report on the assessment of obstetric fistula in Ghana*. Retrieved from http://ghana.unfpa.org/sites/default/files/pub-pdf/Report%20on%20Fistula%20Report%20Burden%20in%20Ghana_Final_1_1_compressed.pdf
- Goodhead, A., & McDonald, J. (2007). *Informal caregivers literature review* (A report prepared for the National Health Committee). Wellington, Canada: Health Services Centre, Victoria University of Wellington.
- Government of Ghana. (2016). *About Ghana: Northern*. Retrieved from www.ghana.gov.gh/index.php/about-ghana/regions/northern
- Grameen Foundation. (2011). *Mobile technology for community health in Ghana*. Retrieved from <https://courses.cs.washington.edu/courses/cse490d/12sp/docs/MOTECH.pdf>

- Gyekye, K. (2003). *African cultural values: An introduction*. Accra, Ghana: Sankofa Publishing.
- Hammersley, M., & Atkinson, P. (2007). *The process of analysis*. In M. Hammersley & P. Atkinson (Eds.), *Ethnography: Principles in practice* (3rd ed., pp. 158–190). London, UK: Routledge.
- Khisa, A. M., & Nyamongo, I. K. (2012). Still living with fistula: An exploratory study of the experience of women with obstetric fistula following corrective surgery in West Pokot, Kenya. *Reproductive Health Matters*, 20(40), 59–66.
- Kimani, Z. M., Ogotu, O., & Kibe, A. (2014). The prevalence and impact of obstetric on women of Kaptembwa-Nakuru, Kenya. *International Journal of Applied Science & Technology*, 4, 273–287.
- Kuo, B. C. H. (2011). Culture's consequences on coping: Theories, evidences, and dimensionalities. *Journal of Cross-Cultural Psychology*, 42, 1084–1100. doi:10.1177/0022022110381126
- Madison, D. S. (2011). *Critical ethnography: Methods, ethics, and performance* (2nd ed.). Thousand Oaks, CA: Sage.
- Marek, L., O'Rourke, K., Brock, D. J. P., Moore, L., Butler, J., Zhang, J., & Wiles, B. (2014). *Returning home: What we know about the reintegration of deployed service members into their families and communities*. Retrieved from www.ncfr.org/ncfr-report/focus/military-families/returning-home
- Mselle, L., Evjen-Olsen, B., Moland, K., Mvungi, A., & Kohi, T. (2012). Hoping for a normal life again: Reintegration after fistula repair in rural Tanzania. *Journal of Obstetrics and Gynaecology Canada*, 34, 927–938.
- Net Organization for Youth Empowerment and Development–Ghana. (2016). *Campaign for fistula free Northern Ghana*. Retrieved from www.ssg.startsomegood.com/Venture/noyed_ghana/Campaigns/Show/campaign_for_fistula_free_northern_ghana
- Obeng, S. G. (2003). *Language in African social interaction: Indirectness in Akan communication*. Hauppauge, NY: Nova Science.
- Östman, M., & Kjellin, L. (2002). Stigma by association: Psychological factors in relatives of people with mental illness. *The British Journal of Psychiatry: The Journal of Mental Science*, 181, 494–498.
- Owusu-Ansah, F. E. (2015). Sharing in the life of the person with disability: A Ghanaian perspective. *African Journal of Disability*, 4(1). doi:10.4102/ajod.v4i1.185
- Pope, R., Bangser, M., & Requejo, H. (2011). Restoring dignity: Social reintegration after obstetric fistula repair in Ukerewe, Tanzania. *Global Public Health*, 6, 859–873.
- Schwandt, T. A. (1997). *Qualitative inquiry: A dictionary of terms*. Thousand Oaks, CA: Sage.
- Semere, L., & Nour, N. M. (2008). Obstetric fistula: Living with incontinence and shame. *Review of Obstetrics & Gynecology*, 1, 193–197.
- Slonim-Nevo, V., & Al-Krenawi, A. (2006). Success and failure among polygamous families: The experience of wives, husband and children. *Family Process*, 45, 311–330.
- Sullivan, P. (2012). *Qualitative data analysis using a dialogical approach*. Thousand Oaks, CA: Sage.
- Tawiah, P. E., Adongo, P. B., & Aikins, M. (2015). Mental health-related stigma and discrimination in Ghana: Experience of patients and their caregivers. *Ghana Medical Journal*, 49, 30–36. doi:10.4314/gmj.v49i1.6
- Tengey, W. (n.d.). *Gender relations, rural women and land tenure in Ghana: A communication nightmare*. Accra, Ghana: Gender Development Institute. Retrieved from ftp://ftp.fao.org/docrep/fao/011/ak159e/ak159e29.pdf
- Tettey, W. J., Puplampu, K. P., & Berman, B. J. (2003). *Critical perspective on politics and socio-economics development in Ghana*. Boston, MA: Brill Academic.
- Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA: Sage.
- Tsikata, D., & Seini, W. (2004). *Identities, inequalities and conflicts in Ghana*. Center for Research on Inequality, Human Security and Ethnicity, University of Oxford. Retrieved from www3.qeh.ox.ac.uk/pdf/crisewps/workingpaper5.pdf
- Utsey, S. O., Adams, E. P., & Bolden, M. (2000). Development and initial validation of the Africultural Coping Systems Inventory. *Journal of Black Psychology*, 26, 194–215. doi:10.1177/0095798400026002005
- van der Sanden, R. L. M., Bos, A. E. R., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2013). Experiences of stigma by association among family members of people with mental illness. *Rehabilitation Psychology*, 58, 73–80. doi:10.1037/a0031752
- Women's Dignity Project & EngenderHealth. (2006). *Risk and resilience: Obstetric fistula in Tanzania*. Retrieved from www.engenderhealth.org/files/pubs/maternal-health/risk-and-resilience-obstetric-fistula-in-tanzania.pdf
- World Health Organization. (2014). *10 facts on obstetric fistula*. Retrieved from www.who.int/features/factfiles/obstetric_fistula/en/
- Yeakey, M., Chipeta, E., Rijken, Y., Taalo, F., & Tsui, A. (2011). The lived experience of Malawian women with obstetric fistula. *Culture, Health & Sexuality*, 11, 499–513. doi:10.1080/13691050902874777

Author Biographies

Kimberly Jarvis is a Postdoctoral Fellow in the Faculty of Nursing, at the University of Alberta. Her program of research focuses on the culturally entangled practices and gendered roles that have marginalizing consequences for women's maternal and reproductive health.

Solina Richter is a Professor of Nursing and Academic Director of the Global Nursing Office at the University of Alberta. Her research program focuses on the social determinants of health. She conducts both local and global research with vulnerable women populations. She further believes that global collaboration is a fundamental part of scholarly development and necessary to accelerate the scope, rate and importance of international research.

Helen Vallianatos is an Associate Professor of Anthropology at the University of Alberta. Her research and teaching focuses on the topics of food, gender, body and health, with a current emphasis on migration and foodways in immigrant communities. She is also collaborating on projects examining how place shapes health and food behaviours, how food is used to perform identity in different social contexts, and how people's perceptions of food, body and health influence not only their food and health practices but also their uptake of health messages.

Lois Thornton is a Clinical Nurse Specialist in Dunedin, New Zealand. Her research interests and publications focus on caregiver burden, aged care, person centered care, and nursing education.