An Exploration of a Culture of Reintegration with Women Who Have Experienced Obstetrical Fistula Repair in Northern Ghana, West Africa

by
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Abstract

More than two million women in Asia and sub-Saharan Africa live with untreated obstetric fistula (OF). Factors contributing to and affecting the care of OF are embedded in the social determinants of health. A three-pronged approach to OF care has been suggested, including awareness, treatment, and social reintegration; however, women's health organizations have argued that social reintegration is the most important aspect of care next to the surgery itself. The aim of this study was to explore a culture of reintegration for women who experience an OF repair in northern Ghana. A critical ethnography was employed, using a health equity/social justice lens to discern the meaning and point of view of participants about a culture of reintegration post-OF. Ninety-nine participants were recruited from 24 rural communities in northern Ghana using convenience, purposive and snowball sampling. Study participants included:

- Women who had experienced an OF repair a minimum of three months prior to being interviewed.
- Family members of women who had experienced an OF repair and were involved in their care pre- and post-OF repair, or post-OF repair only. Only those identified as family members of women interviewed were considered.
- Health-care providers (HCPs) who cared for women who experienced an OF repair (i.e. nurses, doctors, traditional birth attendants, traditional healers).
- Community stakeholders, those in leadership positions, or who provided service to the community, and were involved in OF care at the community, regional or national level (i.e. government officials, nongovernmental organizations, religious leaders, women leaders).

Observation, field notes, personal reflections, semi-structured interviews, and the assessment of relevant public policy documents were methods utilized. Data was analysed according to Hammersley and Atkinson’s (2007) approach to ethnographic analysis. Nvivo 10.0 software was used for data management. Ethics approval was received from the Human Research Ethics Review Board at the University of Alberta, Canada and at the Navrongo Health Research Center, Institutional Review Board, Ghana. Findings suggest that reintegration does not occur in isolation of the other two components of care; awareness and treatment. Although most families are excited to have their family member return home post-OF, women, families, and communities do express feelings of uncertainty. Women, their families, HCPs, and community stakeholders identify that OF health teaching, skills training, community follow-up, community awareness, family support, and existing health policies are important factors in the success of reintegration. Despite this fact, participants describe the economic, societal, systemic and cultural constraints to a woman’s ability to reintegrate, and offer solutions for change. Additionally, family members describe the impact OF had on them, drawing attention to the need for formal care-giving supports in light of the changing role of the family in Ghanaian society. Research findings provide support for policy development pertaining to improved maternal, reproductive and community health initiatives as it relates to reintegration post-OF repair.

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(Translated: The next time you hear the cock crow, know that it is me, Kimberly, saying God bless you. I so much appreciate what you have done for me).

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List of Acronyms

ASIRT– Association for Safe International Road Travel

BMC– Baptist Medical Center

CA - Capability Approach

CBHIS – Community-based Health Insurance Schemes

CEDAW – Convention on the Elimination of All Forms of Discrimination against Women

CHAG– Christian Health Association Ghana

CHN - Community Health Nurse

CHPS – Community- based Health Planning Services

CIOMS - Council for International Organization of Medical Science

CNA – Canadian Nurses Association

DCE– District Chief Executive

ECOWAS – Economic Community of West African States

EHR – Electronic Health Record

EmOC – Emergency Obstetric Care

ERB– Ethics Review Board

FORWARD – Foundation for Women's Health Research and Development

GHS – Ghanaian Health Service

GNI – Gross National Income

GPS – Global Positioning System

GRNA – Ghana Registered Nurses Association

HCP – Health-care Provider

HDI – Human Development Index

HISP– Health Information System Program

HRDR– Health Research Data Repository

ICN- International Council of Nurses

IFIDA– International Federation of Women Lawyers

LEAP– Livelihood Empowerment Against Poverty

LMIC – Low Middle Income Country

MDG –Millennium Development Goals

MOTECH– Mobile Technology for Community Health

MoH – Ministry of Health

NCWD – National Council on Women and Development

NGO – Nongovernmental Organization

NHIA – National Health Insurance Authority

NHIS – National Health Insurance Scheme

NOYED – Net Organization for Youth Empowerment and Development

OF– Obstetric Fistula

REB - Research Ethics Board

RVR– Recto–vaginal Fistula

SBA – Skilled Birth Attendant

SDG – Sustainable Development Goals

SDOH – Social Determinants of Health

SPRING – Strengthening Partnerships, Results, and Innovations in Nutrition Globally

SSNT - Social Security and National Insurance Trust

SWEGG–Savannah Women’s Empowerment Group Ghana

TBA – Traditional Birth Attendant

TCPS – Tri-Council Policy Statement

TFC – Tamale Fistula Clinic

UDHR -Declaration of Universal Human Rights

UNDP –United Nations Development Program

UNECA – United Nations Economic Commission for Africa

UNESCO – United Nations Educational, Scientific and Cultural Organization

UNFPA – United Nations Population Fund

UNGEI– United Nations Girl Education Initiative

UNICEF – United Nations Children's Fund

USAID – United States Agency for International Development

VRE – Virtual Research Environment

VVF– Vesico–vaginal Fistula

WHO – World Health Organization

WPSN –Women Peace and Security Network

"*In an unequal world, the most unequal of unequals are the women and young girls with obstetric fistula*."

R. F. Zacharin

Chapter 1: Introduction

This thesis explores a culture of reintegration for women who have experienced an obstetrical fistula (OF) repair in northern Ghana, West Africa. The document consists of five stand-alone manuscripts prepared for publication. These manuscripts, chapters two through six are discrete but represent a unified whole. Chapter two focuses on ethical challenges faced while in the field, chapters three through five focus on methodological, philosophical, and analytical appraisal of the study's purpose and objectives and chapter six presents policy and nursing practice recommendations. The manuscripts are preceded by an introductory chapter, which provides a review of the literature and discusses the significance of OF, the purpose, objectives and research question, the conceptual and methodological frameworks and the ethical considerations for the study. The concluding chapter, chapter seven, draws attention to potential study limitations, and recommendations for further research.

Identifying and sharing the cultural understanding and insight of women who have experienced an OF repair and have reintegrated into their communities, can produce valuable nursing knowledge and aid in policy development pertaining to improved maternal, reproductive and community health initiatives as it relates to reintegration post-OF repair. The interest received in this research protocol by Ghanaian stakeholders has already led to consciousness-raising, which in turn may contribute to better and more equitable health care. Since returning to Canada from Ghana, I have been contacted by key stakeholders about the study's preliminary findings and have been informed that a Fistula Task Force has been commissioned by health professionals and community stakeholders to look more closely at the issue of reintegration post-OF repair in Ghana.

Significance of Obstetric Fistula

A fistula is an abnormal opening between two epithelial surfaces or cavities. The two most common are: 1. vesico-vaginal fistula (VVF), which results in an opening between the urinary bladder and vagina and 2. recto-vaginal fistula (RVF) which results in an opening between the rectum and vagina (Arrowsmith, Hamlin, & Wall, 1996). OF is often the result of prolonged or obstructed labour, where a woman does not have adequate obstetric care and/or access to appropriate levels of care that would assist with vaginal birth, or deliver by Caesarean section (Nielsen et al., 2009). When labour becomes obstructed, the soft tissue in the birth canal is wedged between the baby's head and the mother's boney pelvis. Without emergency obstetrical intervention, the compressed tissue can become ischemic and necrotic, creating "a hole" in the soft tissue that enables a continuous and uncontrollable stream of urine and/or feces to leak into the vagina. The persistent leakage of urine and/or feces results in perineal wetness, sores, and an offensive odour, which affects the quality of life for affected women (Danso, 2005). There are other causes of OF, such as injuries related to unsafe abortions, gynecological/surgical trauma (i.e. hysterectomies, colporrhaphies, gynecological cancers) and cultural practices (i.e. Gishiri cut or female genital cutting), but 94.2 % of all OF cases in Ghana are the result of prolonged or obstructed labour (Danso, 2005; Danso, Marley, Wall, & Elkins, 1996; Semere & Nour, 2008).

It is estimated that two to three million women live with untreated OF in Asia and sub-Saharan Africa (Kalembo & Zgambo, 2012; World Health Organization [WHO], 2010). Each year it is reported that between 50,000 and 100,000 new cases of OF are diagnosed (WHO, 2010). The prevalence and incidence of OF in sub-Saharan Africa vary among and within countries. For example, Ethiopia, Malawi, and Nigeria report the prevalence of OF to be 2.2, 1.6 and 1.1 per 1000 deliveries respectively (Ijaiya & Aboyeji, 2004; Kalilani-Phiri, Umar, Lazaro, Lunguzi, & Chilungo, 2010; Muleta, Fantahun, Tafesse, Hamlin, & Kennedy, 2007). In a population-based prospective study conducted in six major West African cities and two rural areas, the incidence of OF is between one to three per 1000 deliveries in urban centers and five to ten per 1000 deliveries in rural areas (Vangeenderhuysen, Prual, & Ould el Joud, 2001). These findings correspond with those for Ghana where the incidence of OF is reported to be one per 1000 deliveries in urban areas but significantly higher in the three rural northern regions of the country (Danso et al., 1996). Approximately 500 to 1000 new cases of OF are diagnosed annually in Ghana (Danso, Opare-Addo, & Turpin, 2007). However, these rates are only estimates since there is rarely any consistent and accurate way in which low to mid-income countries (LMIC) register vital statistics to government departments and international agencies (Danso et al., 2007). Stanton, Holtz, and Ahmed (2007) note the challenges in measuring the incidence and prevalence of OF stating that solid population-based estimates may not exist. A Health Information System Program (HISP) has been implemented in Ghana to collect routine data on maternal health issues, and currently, a new study has been commissioned to explore the incidence of OF within the country (Ghana Heath Services Representative, personal communication, May 12, 2015[1]). Findings from this Ghana Health Service study suggested that between 2011 and 2014, a total of 1538 OF patients were seen in Ghana with the northern region recording the highest numbers of consultations at 527 cases. From the 1538 women with OF, 616 were surgically repaired (Ghana Health Service, 2015; Ghana News Agency, 2015).

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[1] The name of the individual who provided the personal communication is protected in accordance with the confidentiality agreement in conducting this research

The loss of a mother or her newborn during childbirth is a tragedy, and "for every maternal death, another 20 women develop some form of a lifelong morbidity related to pregnancy or childbirth" (D'Ambruoso, Abbey, & Hussein, 2005, p.140). With the elapse of the Millennium Development Goals (MDG) highlighting the world's fifteen year (2000 to 2015) agreement to meet the needs of humanity, discussions now focus on the Sustainable Development Goals (SDG). Improving maternal and reproductive health care was prominently featured in the original MDG and continues to garner global support. This is positive news given the lingering high rates of maternal mortality and morbidity in sub-Saharan Africa. In Ghana, maternal mortality was reported in 2010 to be 350 per 100,000 live births (United Nations Children Fund [UNICEF], 2013). The UN Secretary General, Ban Ki-moon, has embraced maternal, newborn and child health in his "Every Woman Every Child" initiative.

This is an unprecedented initiative to organize national and international action from governments, the private sector, and civil society so to address the health challenges facing women and children around the world (United Nations Foundation, 2016). Additionally, Canada's Prime Minister, Justin Trudeau, has committed government funding to UN agencies tasked with improving global reproductive health (Zilio, 2016). This indicates that the impetus towards reducing global maternal mortality and morbidity is part of a national and international political agenda.

Background

In order to understand the importance of reintegration of women who experience OF repair and treatment, it is necessary to highlight the complexities and the impact of OF for those who experience the condition. An extensive overview is provided outlining the history, contextual factors, implications, and programs designed to assist in the care of OF before conducting a systematized review of the literature on reintegration.

History of Obstetric Fistula Care

The examination of mummified remains of Queen Henhenit, who lived around 2050 BC and was discovered in 1935 in Cairo, Egypt, confirmed the presence of a large OF which likely contributed to her death (Zacharin, 2000). Queen Henhenit is recognized as having the oldest recorded VVF presently known to humankind, but there were also prominent individuals from Europe who experienced OF before operative obstetrical care was available (Zacharin, 2000). One of the best-known reports was Princess Charlotte of England who died during prolonged obstructed labour in 1817 (Holland, 1951).

The early writing about OF appeared on papyrus scrolls from Egypt around 1550 BC making reference to "a prescription for women whose urine is in an irksome place: if the urine keeps coming and she distinguishes it, she will be like this forever" (Hamlin & Little, 2010, p.78). A Persian physician, Avicenna, was the first to record the link between urinary incontinence and obstructed labour. Avicenna documented that women who married early or had "weak" bladders should be instructed in how to prevent pregnancy since it was thought to cause urinary incontinence (Hamlin & Little, 2010). Women who experienced OF prior to the mid-1600's attempted to manage or correct the condition by focusing on techniques to absorb the urine (Zacharin, 1988).

In 1663 physicians began to propose repairing fistulas using needles made of a stiff swan's quill (Zacharin, 1988). It was not until two hundred years later that Johann Fatio, a Swiss physician, would be the first recorded to successfully close a VVF (Zacharin, 1988). The first American physician to successfully close an OF was Dr. John Peter Mettauer in 1838, although many give the acknowledgment to Dr. Marion Sims, known as the father of American gynecology (Zacharin, 1988). Although Sims did not successfully repair the first fistula, he did perfect the surgical technique that is today's surgical standard and is credited for opening the first OF hospital in New York City in 1855 (Zacharin, 1988). This clinic closed its doors, more than one hundred years later, once VVF became an unusual occurrence in North America (Roush, 2009).

In sub-Saharan Africa, there is a shortage of OF facilities and health-care providers (HCPs) who are trained in OF repair and care (Roush, 2009). Australian obstetricians, Catherine and Reginald Hamlin, came to Ethiopia in 1959 to establish a midwifery school. Upon seeing the problems presented with obstructed labour in Ethiopia, they began to focus their efforts on the treatment of women with OF (Hamlin & Little, 2010). The sheer number of obstetric tragedies seen by the Hamlins prompted them to open the world's second OF clinic in Addis Ababa in 1974. This is now the leading medical facility dedicated to repairing approximately 4000 OF per year and serving as a global training center for physicians specializing in OF repair (Hamlin Fistula Foundation, 2009).

Prior to 2010 most of the treatment for OF in Ghana occurred in the large urban centers of Kumasi, Accra and Takoradi. Treatment was expensive ($200.00 US) and focused only on surgical repair. The Baptist Medical Center (BMC) in the northern region was the only facility in the north that performed OF repairs when visiting physicians came from abroad. Fees at the BMC were subsidized ($25 to $40 /surgical repair) since it was a mission hospital and many of the medical staff were volunteers.

In 2002 EngenderHealth, a nongovernmental organization (NGO) working to improve maternal and reproductive health, partnered with the United Nations Population Fund (UNFPA) to assess the resources and effectiveness of OF repair in nine sub-Saharan African countries (EngenderHealth & UNFPA, 2003). This study was later expanded to include additional countries, one of which was Ghana, with the intent of providing a snapshot of OF and OF care in the country (EngenderHealth, 2004). It was identified in the study that the northern and central regions of Ghana were considered the poorest areas where OF remained a “hidden” and neglected condition affecting the most vulnerable members of society i.e. poor, young, and often illiterate girls and women (Avevor, 2013; EngenderHealth & UNFPA, 2003; Kalilani-Phiri et al., 2010). This prompted the UNFPA in 2005 to fund Pathfinder/Ghana to launch an awareness campaign to end fistula by creating awareness about the condition (Pathfinder International, 2009). The sensitization campaign was a large success with many women seeking OF treatment. This influx of women requiring medical assistance put an increased demand on Ghana’s health care system. To better help women, Pathfinder/Ghana connected with *Africa Mercy*, a charity hospital ship to periodically dock in Tema harbour to function as a mobile repair center. Pathfinder/Ghana also sponsored one doctor and two nurses to be trained in a nearby country to start building capacity and expertise in OF repair. The need for highly skilled medical professionals addressed only part of the problem. The recovery period for OF was typically two weeks and, with only a few inpatient beds available, justifying a lengthy hospital stay was difficult. The need for a fistula center was evident.

Since many of the women who came for OF repairs were from the three northern regions, constructing a fistula center in the north was a reasonable strategy. Attaching a fistula clinic to BMC was a rational solution since the facility was already doing OF repairs, but the site was not geographically well suited. Tamale Central Hospital, a regional health care facility, on the other hand, was centrally located in the northern region and accessible by plane thus facilitating foreign surgeons to visit the center. For this reason, the Tamale Central Hospital was deemed an appropriate site for a fistula center. The Northern Regional Health Directorate gave an abandoned building on the hospital grounds and Pathfinder/Ghana and UNFPA refurbished the facility so that it had a gynecological operating theater and a ten-bed inpatient ward. Women would have direct access to the OF care facility, bypassing their local HCPs. UNFPA supported the cost incurred for women who needed to register for a health insurance card so that they would not have to pay for their OF surgery.

Today many of the OF repairs are performed at the Tamale Fistula Clinic (TFC) which officially opened its doors in 2010. Additionally, there are well equipped teaching hospitals to perform OF surgery and several regional hospitals in which a “fistula team”, a group of health professionals trained in OF repair, travel to perform mass operations when needed. There is also a private center founded by the Catholic Archdiocese, Mercy Women’s Hospital, which opened in 2010 in the Central region. Although this facility functions independently it does receive support from the Ghana Ministry of Gender, Children and Social Protection with assistance from the Economic Community of West African States (ECOWAS) Gender Development Centre (Avevor, 2013). The surgical treatment of OF is provided at Mercy Women’s Hospital without cost.

Obstetric Fistula: Contextual Factors

In LMIC a lack of responsiveness towards addressing the social determinants of health (SDOH) may influence the occurrence of OF (Capes, Ascher-Walsh, Abdoulaye, & Brodman, 2011; Mselle, Moland, Evjen-Olsen, Mvungi, & Kohi, 2012b; Pope, Bangser, & Requejo, 2011). The SDOH “are the conditions in which people are born, grow, live, work and age” (WHO, 2016a, para.1). These situations are shaped by the allocation of money, power, and resources at all levels of government and are believed to be responsible for health inequities within and between countries (WHO, 2016a). While there is a relationship between social factors and health, the causal relationship between the two is not clearly understood (Shaw, Dorling, Gordon, & Davey-Smith, 1999). The determinants of good health are not always the same as the determinants of inequities in health (Graham & Kelly, 2004).

The United Nations Economic Commission for Africa (UNECA) in 2014 stated: “Africa is the second most unequal region in the world after Latin America” (p.3). It is evident that good health prior to pregnancy is essential for wellbeing and ill health can contribute to disability or loss of life. Many biological factors that affect health cannot be changed, for example, genetics or age. Factors related to the SDOH, particularly factors related to social disadvantages, must be addressed if health inequities, related to a woman’s maternal and reproductive health, are to be reduced in sub-Saharan Africa. An effort to influence these factors was envisioned in the MDGs and other prior initiatives but were unfortunately sub-optimally delivered, or disorganized (Women & Child Health Research Center, 2015).

Indeed, the historical development of biomedicine and the health care system in Ghana sheds light on existent inequities and inaccessibility in rural Ghana, particularly in the north. Beginning with the establishment of health care, which was described as a medical apartheid from 1471 to 1844, health care was limited to white colonizers and those who had the means and status to acquire it (Senah, 2001). The primary reason for ensuring health care during this time was to protect the colonial masters from infectious diseases.

In 1844 the British and the Ghanaian coastal chiefs in the South signed a peace agreement known as the Bond of 1844 (Senah, 2001). This Bond formally brought the Gold Coast under British rule and enhanced Christian missionary activities (Senah, 2001). These happenings improved the provision of health services for both the colonizers and the local people. The first hospital was built in Cape Coast in 1868 to serve the health needs of Ghanaians, but much discrimination existed in relation to access to hospital services (Senah, 2001). Many Ghanaians continued to access indigenous healers until the new health dispensation banned traditional healing by passing the Native Customs Regulation Ordinance in 1878 (Senah, 2001).

In 1957, during post-colonialism, priorities were established for effective social and welfare services with monies being spent on revamping the health care system (Frimpong, 2013). However, in the late 1960s, the existing government was unable to maintain the quality of care as a result of a prior government's ineffective health care management. This opened the way for the introduction of user fees, which made health care unattainable for most Ghanaians. Health care analysis during colonial and post–colonial times indicated high mortality and morbidity rates nationwide and a dearth of health and infrastructural resources in the north (Senah, 2001).

In the early 1990s, other ways to finance health care in Ghana were explored including NGO initiated community-based health insurance schemes (CBHIS) and the highly unpopular "cash and carry" system (Blanchet, Fink, & Osei-Akoto, 2012). In 2003 the National Health Insurance Scheme (NHIS) was established under Section 31 of Act 650 by the Government of Ghana to provide affordable health care for all Ghanaian residents (Dixon, Tenkorang, & Luginaah, 2013). This plan purports to cover 95% of the diseases afflicting Ghanaians, however, some expensive treatments such as cancer treatments, HIV antiretroviral drugs, organ transplants and dialysis are excluded (Blanchet et al., 2012). All maternal health care services are covered. Enrollment into the NHIS is said to be required for all Ghanaians unless they can show proof of additional health insurance; however, there is no penalty for not registering so enrolment is essentially voluntary. A small registration fee is required and an administration fee is based on an individual’s ability to pay (Blanchet et al., 2012).

Women in some sub-Saharan African countries, Ghana specifically, recognize the barriers facing them in achieving timely and effective maternal health care that can prevent or minimize maternal morbidity/mortality including childbirth injuries. These barriers are formally organized into the Three Delays Model, a WHO initiative, known as: delay in deciding to seek care; delay in reaching care; and delay in receiving adequate health care (Barnes-Josiah, Myntti, & Augustin, 1998; Thaddeus & Maine, 1994). While addressing concerns pertaining to accessing health care, the model by no means encompasses the multilayered factors contributing to maternal deaths and childbirth injuries like OF. For example, there is no explicit focus on poverty, environmental factors, nutrition, health status, education, and status of women or cultural traditions. It is important to recognize these contributing factors within the context of access. The key contextual factors known to increase maternal mortality and morbidity in Ghana must be understood and acknowledged since these factors are linked to prolonging obstructed labour and contributing to the development of OF.

Poverty. The Human Development Index (HDI) is a tool that measures wellbeing on three dimensions: income, education, and health. Ghana’s HDI is 0.579 which gives the country a ranking of 140 out of 187 countries with comparable data (UNDP, 2015). This places Ghana slightly above the regional average for sub-Saharan Africa with a significant and steady annual growth rate from 2011 to 2014 (Index of Economic Freedom, 2015). This economic gain reclassified Ghana from a low income to LMIC in 2011 (Aydin, 2011). Ghana’s economic stability can be contributed in part to the country’s discovery of crude oil in 2007 and profitable oil revenues since 2011(Institute for Fiscal Studies, 2015). Presently with, the low cost of oil per barrel, on the world market the Ghanaian government has demanded economic prudence (Terkper, 2015). This has significantly altered Ghana's ability to meet their development goals of accelerated growth and poverty reduction (Institute for Fiscal Studies, 2015). This change in economic climate occurs at a time when the depth of poverty in the three northern regions is becoming progressively worse (Gadugah, 2015). The gross national income (GNI) per capita for Ghana in 2012 was reported to be $15,50 US with approximately 28.6 % of Ghanaians living below the poverty line, defined as $1.25 US per day (UNICEF, 2013). The poverty rate in the three northern regions is reported to be two to three times the national average and has been associated with the region's geographical location and dry savannah climate (International Fund for Agricultural Development, 2013).

Poverty impacts upon all social determinants including those involving maternal and reproductive health (Capes et al., 2011; Mselle et al., 2012a; Pope, Bangser, & Requejo, 2011). Poor rural women are most affected by maternal and reproductive health issues and, as the majority of Ghana's population live outside the major cities of Accra, Takoradi and Kumasi, the magnitude of the problem is significant (Mwini-Nyaledzigbor, Agana, & Pilkington, 2013). This economic failure, for example, impacts women's access to food, education and health care. As such, it is often too expensive for women living in northern Ghana to deliver their babies at a health facility (Women's Dignity Project & EngenderHealth, 2006). Without a strong commitment to eliminating economic disparities, there is little hope of preventing maternal mortality and morbidity such as OF. Economics is only one reason why Ghanaian women do not deliver in a health facility. Studies suggest a lack of privacy, lack of cultural sensitivity, and lack of professional obstetrical care as supplemental reasons (Ganle, 2015; Mannava, Durrant, Fisher, Chersich, & Luchters, 2015; Mensah, Mogale, & Richter, 2014).

The Minister for Gender, Children and Social Protection, the Honorable Nana Oye Lithur, concedes the Government of Ghana needs to work harder at reducing inequalities within the country. Programs such as the NHIS, Livelihood Empowerment against Poverty (LEAP), and the Labour Intensive Public Works are some of the programs implemented by government to improve the socio-economic status (UNDP, 2014). Excluding this, the Minister was quick to note “it is important we acknowledge the fact that economic growth in itself is meaningless unless it is closely linked to human development” (UNDP, 2014, para.4).

Physical environment, transportation, and access to health care. Motorized transportation in rural Ghana is limited resulting in men and women walking vast distances each day. Women can walk as much as four hours per day while transporting goods on their heads; this can have a negative effect on a woman’s physical and reproductive health reducing a woman’s ability to conceive and carry a healthy newborn to term (Porter et al., 2013). Pregnant rural Ghanaian women may also walk many kilometers to the nearest town to access transportation to the closest medical facility. This is one reason why women do not access health services despite publically funded maternity care (Ministry of Health [MoH], 2004). Although the distance to a medical center may not be far, travel may take much longer because of Ghana’s terrain, weather and road conditions. Major roads in urban areas are generally paved or tarred but secondary and feeder roads are most often unpaved and inadequately maintained. These roads account for approximately 80% of Ghana’s road network and are shared by a mix of motorized vehicles, pedestrians, bicyclists, and free roaming livestock (Association for Safe International Road Travel [ASIRT], 2014). Additionally, roads become flooded during the rainy season making them impassable and inhibiting assess to large urban centers (Awuni, 2014).

HCPs typically use motorcycles (commonly known as a motorbike in Ghana), to access and sometimes transport patients to larger health facilities. The MoH adopted a transport management system in 1993 that provided health clinics with two motorbikes, fuel, and maintenance (Porter, 2002). Bicycles were provided to community volunteers to assist with health messaging. According to a community health nurse (CHN) posted in a rural northern community, motorbikes were received from the MoH, but maintenance was not upheld resulting in inoperable motorbikes (Community Health Nurse, personal communication May, 2014).

Where it exists, emergency transportation in Ghana is unreliable. Dr. Gandow, a physician at the TFC, was quoted as saying, “the Center does not even have a car or an ambulance at its disposal” (Ghana News Agency, 2011, para.14) and called on stakeholders to come to the Center’s aid. Additionally, the aged ambulance in Tamale is used for multiple purposes including a hearse and is frequently not available when emergencies arise (Banchani & Tenkorang, 2014). It should be stated that the ambulance service in Ghana is not covered by the NHIS and patients incur the cost of fueling the ambulance, a cost many cannot afford.

Ghanaian women (n=21) of reproductive age who had given birth within the five years previous to one qualitative study reported that those who manage to reach a larger medical facility often experience abusive treatment (D’Ambruoso et al., 2005). They reported abusive and disrespectful care, including physical abuse, non-supportive care, and neglect. There have also been reports of HCPs judging women who are in obstructed labour as being unfaithful, insisting upon a confession for their immoral behavior instead of managing the health crisis at hand (Amnesty International, 2009). The dissatisfaction felt in these maternal health experiences potentially discourages women from seeking any form of obstetrical care or health advice which could prevent or minimize the effects of OF (D'Ambruoso et al., 2005; Wedderburn & Moore, 1990).

A reason frequently provided for inappropriate obstetrical care is the insufficient number of skilled physicians and/or nurse-midwives in Ghana (Kruk et al., 2010). The doctor and nurse population ratios in northern Ghana are quoted to be the lowest in the country (Singh et al., 2015). Attrition in the number of practicing midwives is a concern, as many midwives are over the age of fifty and are starting to retire (Banchani & Tenkorang, 2014). UNFPA (2014) suggests the number of midwifery schools is increasing, but Banchani and Tenkorang (2014) argue that there remains a low enrolment which compounds the problem not just for today but for years to come (Banchani & Tenkorang, 2014). This places a high workload on a few health professionals in rural areas (Mensah, 2011). Accessing suitably equipped facilities to provide antenatal or comprehensive emergency care is often difficult (Essendi, Mills, & Fotso, 2011). There are reports that a lack of medical supplies plagues both urban and rural hospitals (International Organization for Migration, 2011). Women seeking maternal care are required to provide their own medical supplies (surgical gloves, dressings). Additionally, there are reported cases where blood has not been available for mothers who have suffered intrapartum and/or postpartum hemorrhage (Kuganab-Lem, Dogudugu, & Kanton, 2014).

Health status and nutrition. Good health usually equates to better health outcomes including pregnancy. Anemia "is a marker of socioeconomic disadvantage, with the poorest and least educated being at greatest risk" (Balarajan, Ramakrishnan, Ozaltin, Shankar, & Subramanian, 2011, p. 2124). The prevalence of anemia is higher in LMIC and is associated with nutritional deficiencies and infections such as malaria, HIV/AIDS and hookworm (Tolentino & Friedman, 2007). All of these conditions are found in Ghana, however, Ghana Health Service

(GHS) (2003) reports that inadequate iron intake, malaria, and intestinal worms are the main causes of anemia. In 2011, WHO estimates that 29% of non-pregnant women and 38% of pregnant women worldwide were anemic, with the highest prevalence being in South Asia and West Africa (WHO, 2014). In Ghana in 2008, 59% of women of reproductive age (15 to 49 years), who were assessed, were recorded as being anemic (United States Agency International Development [USAID], 2014). It is well established that anemia or a low hemoglobin level are associated with maternal and neonatal mortality (Kozuki, Lee, & Katz, 2012; Stevens et al., 2013). Additionally, for women who are anemic and experience obstructed labour, the risk of tissue damage (i.e. OF) is greater and the success of OF repair surgery is reduced because of the poor capacity of blood to carry oxygen to the injury site (Wall, 2012).

Nutritional deficiencies, specifically iron deficiency, account for most of the anemia that occurs in LMIC (Tolentino & Friedman, 2007). Ghanaians experience high rates of maternal malnutrition including moderate to severe micronutrient deficiencies. This places Ghana among the 36 countries with the highest burden of malnutrition (Black et al., 2008). A report from Children in Need, an NGO dedicated to understanding children’s issues, suggests that girls and women are often the last to eat in their families, and are reduced to picking leftovers (Mullins, 2013). The resultant malnutrition additionally hampers bone and skeletal development (Wall, 2012). This can be problematic prior to pregnancy as the pelvis can be mis-shaped, immature, and have boney abnormalities restricting the safe passage of the fetus. Weak and underdeveloped bone structure increases the chances of obstructed labour during birth and often results in increased maternal and newborn morbidity and mortality. Similarly, a diet lacking in essential minerals during childhood can lead to stunted growth. There is much research to indicate shorter women, especially those whose growth has been stunted due to nutritional deficiencies, have more difficult labours, higher caesarean section rates, and higher maternal mortality and morbidity rates due to obstructed labour (Adadevoh, Hobbs, & Elkins, 1989; Camilleri, 1981; Everett, 1975; Merchant, Villar, & Kestler, 2001; Ozaltin, Hill, & Subramanian, 2010; Tsu, 1992).

Programs such as Systems for Health and Strengthening Partnerships, Results, and Innovations in Nutrition Globally (SPRING) have been implemented to alleviate under nutrition in Ghana (USAID, 2014). Tailor-made programs have also been implemented in the north where maternal malnutrition is significantly higher and the issues causing malnutrition are unique (USAID, 2014).

Education and health information. In sub-Saharan Africa, a smaller portion of girls traditionally attend school especially if they are from low income families or have brothers since educating boys is culturally seen as a “better” family investment financially. Girls who enroll in primary education often drop out after completing one to two years (Ringheim & Gribble, 2010). Dropout rates steadily increase for girls as they progress into secondary and tertiary education. The high attrition rate for girls is mainly due to school fees (cost of uniforms, books, school supplies and tuition), safety issues especially in conflict areas where girls must walk long distances to school, lack of outdoor toilets for girls, the high demands placed on them to perform domestic duties (cooking, cleaning, caring for children, fetching water), and in some cases child marriage (Ringheim & Gribble, 2010). Young girls, from the age of 9 to 15, living in Bawku District, northern Ghana, are reported to participate in arranged marriages resulting in early pregnancies (Mwini-Nyaledzigbor et al., 2013).

The World Education Forum in Dakar, Senegal put forth a framework to ensure all children, especially girls, have access to good quality primary education by 2015 (United

Nations Educational, Scientific, and Cultural Organization [UNESCO], 2000). Similarly, a goal of MDG II was to ensure that "by 2015, children everywhere, boys and girls alike would have been able to complete a full course of primary schooling" (United Nations, 2010, Target 2A, para.1). These initiatives have greatly improved education in sub-Saharan Africa including Ghana where primary school attendance for boys and girls in 2012 was 72.2% and 73.8% respectively and for secondary education 39.7% and 43.6% consecutively (UNICEF, 2013). These figures reflect a slightly higher proportion for girls. Literacy rates in Ghana for 2012 were 88.3% for boys and 83.2% for girls (UNICEF, 2013). In the northern region literacy rates are significantly lower and vary according to the distance a community is located from an urban center. Literacy rates in the north are recorded to be as low as 12% with a 12% gender gap where boys are most favoured (Government of Ghana, 2016). It is reported that 60% of children in northern Ghana do not attend school because of a shortage of teachers. Student teacher ratios are recorded as high as 1 to 56 in a classroom situated under a tree (Addy, 2013).

While work still needs to be done regarding education in the north, Ghana has made progress towards increasing access to education. This is in part due to the fact that "in 2005, the Ministry of Education abolished school fees nationwide for basic education and introduced a capitation grant for all basic schools" (United Nations Girl Education Initiative, 2012, para.1). This is encouraging since there is global evidence that a positive correlation exists between women's years of formal education and use of maternal health services (Cleland & Van Ginneken, 1998; Addai, 2000; D'Souza, 2003). By increasing the number of years a girl attends school the age at which she marries and becomes pregnant can be delayed. Education also allows women to be aware of and access appropriate nutritional, maternal and reproductive health care with confidence (Addai, 2000; Herz & Speling, 2004; Johannes, 2010). For example, one study conducted in northern Ghana illustrates a positive correlation between secondary education and high attendance at antenatal clinics, a factor associated with a reduction in maternal mortality and morbidity (Addai, 2000). Alternatively, there is evidence to suggest that increased education may not guarantee higher levels of health service utilization since issues of accessing care are complex and multidimensional, and require more than simply focusing on education (Barnes-Josiah et al., 1998; Ganle, Parker, Fitzpatrick, & Otupiri, 2014; Thaddeus & Maine, 1994). This draws attention to the fact that, although education is an important tool in promoting maternal health, it should not be the only consideration.

Accessibility to accurate and timely health information in various formats (newspapers, radio, television, durbars) can be used to inform women about how best to improve their reproductive health. In Ghana media access to health information for women is approximately 85% but again inequalities exist in the north where access is more limited (Ringheim & Gribble, 2010). OF is a preventable and treatable condition, but many Ghanaian women lack sufficient health information about reproductive and maternal care. Community health volunteers have consistently worked with CHNs to deliver health information to rural Ghanaian communities. In 2010 a new initiative, Mobile Technology for Community Health (MOTECH), was launched in the Upper East region of Ghana with the aim of delivering up to three health messages per week to pregnant women and parents via mobile phone (GHS, 2012). Although there are some logistical issues such as poor mobile networks, the program is providing women with relevant, accurate and timely health information related to their pregnancy (i.e. notification for antenatal visits). For example, a Ghana Health Service employee reported MOTECH messages encouraged clients to come on time to the clinic. “A pregnant woman came because she had a text message telling her that she could go into labour at any time” (GHS, 2012, p.8). Research conducted in sub-Saharan Africa supports the view that lower maternal mortality and morbidity rates occur when births take place in a health facility (Chinkhumba, De Allegri, Muula, & Robberstad, 2014; Kruk, Paczkowski, Mbaruku, de Pinho, & Galea, 2009).

Social status of women. In low-income countries, the status of women remains low despite the endorsement of the UN declaration that promotes gender equality and equity (WHO, 2009). The (1992) Constitution of the Republic of Ghana provides protection for all persons. Section 17 prohibits discrimination based on gender, race, color, ethnic origin, religion, creed or social or economic status. There are many government and NGOs, and activist and advocacy groups working to promote women's rights in Ghana. The National Council on Women and Development (NCWD), Women Peace and Security Network (WPSN), Savannah Women's Empowerment Group Ghana (SWEGG), the International Federation of Women Lawyers Ghana (IFIDA), the Ministry of Gender, Children and Social Protection and UNFPA Ghana are agencies and departments working to protect and raise the profile of women in the country. Despite these efforts, Ghanaian women still face discrimination and inequality evident in political, economic, cultural and customary practices where they lag behind their male counterparts in decision-making, and equal rights and opportunities (Sossou, 2006).

Northern Ghana is culturally a patriarchal society (Atuoye & Odame, 2013; Odame, 2013) where land and title are inherited by the male lineage (Adoo-Adeku, 2014). In a theory of sociology, it is reported "patriarchy is the result of sociological constructions passed down from generation to generation and these are most pronounced in societies with traditional cultures and less economic development" (Adoo-Adeku, 2014, p.13). Though various reasons may be advanced for why this occurs, it ultimately illustrates that authoritative or legitimate power is masculine. Consequently, despite the majority of the population consisting of women, women rarely take part in the decision-making process (Yobo, 2012). In the United Nations (2013) Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) it is reported that matters around polygamy, early marriage, illiteracy, harmful traditional practices (e.g. female genital cutting), family planning, widowhood rite, and access to maternal care reinforce the inferior position of women in Ghanaian society. Findings from a qualitative study to explore decision-making about family planning in Tanzania demonstrate the lack of control and decision-making women have regarding their reproductive health and their bodies (Mosha, Ruben, & Kakoko, 2013). In Tanzania men are considered the decision-makers about the number of children their wives will bear and when children are conceived because women are considered possessions which move from their parents to their husbands' homes (Mosha et al., 2013). This would also apply to decisions about health care since many African women cannot seek medical care and advice, including maternal health care, without the permission of their husbands and, in some cases, older women such as mothers-in-law (Gabrysch & Campbell, 2009). Similarly, in a Ghanaian study exploring reproductive decision-making and choice, it was found that only one out of five women can refuse to have intercourse with their partner while one out of four can ask their partner to use a condom (Darteh, Doku, & Esia-Donkoh, 2014). This greatly impacts a woman's ability to make health decisions about her body including family planning and maternity care potentially increasing her risk of OF.

Culture of birthing practices. Motherhood is one of the primary roles of women in Ghana, where women tend to have many children starting at a very early age (Gyekye, 2003). Birth spacing is rarely practiced in Ghana, which has been proven to have a negative impact on both mother and child (Nit et al., 2014). Women who are infertile are viewed by many as "bare", which is a societal tragedy (Gyekye, 2003). In some Ghanaian cultures it is believed that the parents of an infertile girl must have done some terrible deed to cause their child's sterility (Wilkinson & Callister, 2010). Women who are infertile are regarded as "witches" possessed by external "demons". These women are believed by the community to have chewed up their young in their womb and therefore have the power to cast spells upon others (Nurse-midwife, personal communication, May 2014). Witchcraft has been blamed for causing spontaneous abortions and maternal death. Some individuals living in rural Ghana believe pregnant women can be attacked by evil spirits should they venture outside after dark (Nurse-midwife, personal communication, May 2014). This belief inhibits some labouring women from seeking medical assistance should labour start after dusk.

Many women in rural Ghana give birth with the support of a traditional birth attendant (TBA), mother-in-law, or grandmother. TBAs are individuals who are not formally trained in the practice of childbirth care; their skills are acquired through observation of and practice with those before them (Jansen, 2006). TBAs are responsible for addressing a pregnant woman's health concerns during the pregnancy and for two weeks during the post-natal period. Though TBAs educate pregnant women on nutrition, pregnancy-related taboos, and newborn care (Kayombo, 2013) they may be unable to effectively evaluate and intervene should maternal complications occur (Crissman et al., 2013). In many cultures they are revered as wise older women (Crissman et al., 2013). Alternatively, a skilled birth attendant (SBA) is a formally educated and regulated nurse-midwife, physician, nurse, obstetrician, or medical professional who has the appropriate biomedical skills and knowledge in maternal health. Both TBAs and SBAs are able to assess and refer perinatal women with obstetrical problems for more comprehensive or emergency care. What is considered appropriate skills and knowledge, however, can vary among countries and is dependent upon how a country regulates professional practice regarding women's maternal and reproductive health.

Despite the World Health Organization, (n.d) advocating for "skilled care at every birth" (Skilled Birth Attendants, para. 2), approximately 40% of women still give birth at home either alone or with a TBA (Crissman et al., 2013). It is suggested that maternal complications are unpredictable and women in labour and delivery remain safest when a SBA is present during birth with the necessary equipment and medications (Prata et al., 2011). There are reports of multiparous women who labour alone, in a squatting position, a few hundred meters from their village, though this is rarely a custom for first-time mothers unless they are attempting to terminate their pregnancy (Littlejohn, 2013). Birth is considered a natural process and women are expected to deliver at home and to endure the discomforts of labour. Many women will keep their labour a secret to maintain control of their delivery and to deter onlookers who can have a negative spiritual impact (Bazzano, Kirkwood, Tawiah-Agyemang, Owusu-Agyei, & Adongo, 2008). This may contribute to the first delay in seeking obstetric care should women experience obstructed labour.

Typically men are not present for the birth. Their task is to make health decisions and to pay for maternal health care services and supplies (Jansen, 2006). In 2002, Ghana's NHIS exempted all pregnant women from paying maternal health care costs and has helped Ghanaian families (i.e. men) to make better health choices (Mills, Williams, Adjuik, & Hodgson, 2008). There is a small administrative fee when registering with the NHIS. Traditionally home births are deemed more economical but when things go wrong the cost of care is extremely high economically, emotionally, and physically should the end result be the death of a mother or child, or a serious childbirth injury.

There are a number of prenatal clinics in Ghana but woman state the services are inadequate, resulting in a declining attendance over time. It is reported that approximately 80% of women will attend the initial prenatal visit while only 30% attend the fourth visit (Bazzano et al., 2008). This is in part due to improper care, long wait times and provider impatience (Dako-Gyeke, Aikins, Aryeetey, Mccough, & Adongo, 2013). Rather than seek prenatal care, women in rural Ghana often take advice from female elders in the community or consult with herbalists to manage issues such as morning sickness (Farnes, Beckstrand, & Callister, 2011). Geurts (2003) notes how pregnant women in West Africa consume an egg shaped piece of baked clay (eγe), to cope with nausea, vomiting, heartburn, and excess saliva. This alternative approach to prenatal care is frequently challenged by Western medicine; however, the eγe does appear to have some real benefit as a mineral supplement (Geurts, 2003). Although there is secrecy around the potencies of herbs and medicinal plants (Gyekye, 2013) there are reports of women in their last trimester using a herbal concoction containing high levels of oxytocin to quicken birth and ease the process of labour (Adong, 2011; Olowokere & Olajide, 2013). The use of these herbal preparations during pregnancy and childbirth has been linked to complications such as ruptured uterus and hemorrhage, potentially leading to fetal and maternal death (Adong, 2011; Olowokere & Olajide, 2013).

Women are frequently encouraged or expected to labour in quiet. Pain medication is rarely used during labour so women pray or meditate to assist them with the discomfort, calling upon God to protect them and their unborn child during the birth process (Etowa, 2012). Some Ghanaian women believe the pain experienced during labour is the result of disobedience. Individuals of the African Muslim and Christian faiths believe this perspective is rooted in Christian-Islamic teachings about Adam and Eve’s sin (Wilkinson & Callister, 2010). When it is time for a woman to deliver she is taught to conserve her energy and not to cry or yell out in pain (Wilkinson & Callister, 2010).

For many Ghanaians, children are considered to be a gift from God (Dyer, 2007). The birth of a child is an important and celebrated event in the life of the parents and the community at large (Etowa, 2012; Omoaregba, Bawo, Lawani, Morakinyo, & Osasu, 2011). After childbirth, women gain social status and they can begin to provide advice to other women about childbirth based on experience (Jansen, 2006). After the delivery, and depending on the community, a mother is provided with a rest period of up to one week. During this time the TBA will support and teach the new mother how to wash and feed her baby (Jansen, 2006). On the eighth day, mother and baby emerge from the home to participate in the naming ceremony. The naming ceremony or "outdooring" as it is typically called is the first time the newborn is presented to the community and is carried out with much celebration. An animal may be slaughtered as a sacrifice and the animal skin given to the infant as a gift, usually a sleeping mat (Littlejohn, 2013). For women whose babies die in childbirth, the day the baby would have been named can be emotionally difficult not just because she lost a child but because she is viewed as a disappointment in the eyes of her family and her community, especially if she is also afflicted with the unpleasantness of a childbirth injury like OF (Muleta, Hamlin, Fantahun, Kennedy, & Tafesse, 2008).

Implications of Obstetric Fistula

The location and nature of the maternal injury that results from the force of contractions and the duration of obstructed labour, can create numerous physical injuries described as the "obstructed labour injury complex" (Arrowsmith et al., 1996). Although the dominant injury is OF, women experience to varying degrees other sequential injuries that impact their lives and wellbeing. Urologic, gastrointestinal, gynecological, neurological and dermatological injuries have been documented in addition to the psychosocial consequences of OF (Arrowsmith, et al., 1996).

Urologic injuries to the bladder, urethra, ureters, and kidneys are associated with or secondary to OF. One of the most common problems is the ischemic loss of bladder tissue, which renders vesico-vaginal fistulas difficult to repair. When a vesico-vaginal fistula is larger than the amount of surrounding bladder tissue, the only means of repair is to make the size of the bladder remarkably smaller (30-50 ml) leaving it functionless (Glauser, 2008). In some cases the bladder cannot be repaired and specialized bladder surgery must be performed.

Similarly, recto-vaginal fistula is a complete tear of the perineum allowing fecal matter to flow from the rectum and into the vagina. These injuries may also require stoma surgery. For those women who need and can afford to avail themselves to these surgeries, challenges still exist which can negatively impact their self-esteem and wellbeing. The strong stench of human waste is socially offensive and often plays a role in the stigmatization of out-groups (Cottrell & Neuberg, 2005). This can potentially lead to feelings of defilement, shame, and humiliation. Douglas (2001) traced the root cause of defilement to the belief that an individual's wrong doings or impure condition rendered them evil or dirty. This strengthens the cultural belief by some that OF is caused by witchery or a punishment from God for inappropriate behavior (Roush, 2009).

Although the success rate for OF repair is 70% or more, there is no guarantee that normal bladder function can be restored (Rahimi, Capes, & Ascher-Walsh, 2013; Creange, Ahmed, Genadry, & Stanton, 2007; Wall, Arrowsmith, Briggs, & Lassy, 2001). Fibrotic changes are known to occur in the bladder, urethra, and ureters. A proportion of women continue to suffer from urinary incontinence post vaginal fistula repair (Browning & Menber, 2008; Gutman, Dodson, & Mostwin, 2007; Nielsen et al., 2009). For example, scar tissue formed in the urethra may prevent women from urinating at socially acceptable times and in acceptable places (Schleicher, Ojengbede, & Elkin, 1993). Additionally, obstruction in the urinary tract can lead to frequent infections and some are severe enough to cause death (Arrowsmith et al., 1996; Lagundoye, Bell, Gill, & Ogunbode, 1976; Semere & Nour, 2008).

Gynecological injuries to the vagina, cervix, and uterus can also occur in women with OF (Arrowsmith et al., 1996). A small prospective study exploring the effectiveness of ultrasound in detecting urogenital problems in women who experience OF found that 15 out of 22 cases showed signs of vaginal stenosis or minor vaginal fibrosis (Adetiloye & Dare, 2000). Vaginal scarring affects a woman's ability to have pleasurable intercourse with her husband impacting upon the martial relationship (Yeakey, Chipeta, Rijken, Taulo, & Tsui, 2011). Additionally, women who experience OF may show signs of trauma to the cervix and uterus which can lead to amenorrhea and infertility (Adetiloye & Dare, 2000; Wall, et al., 2001). Ghanaian women in some northern communities acquire their identity through marriage especially when they bear children. Women who are unable to bear children may be divorced and returned to their parents in disgrace and shame (Yeakey et al., 2011). In a qualitative study where 100 infertile Nigerian women were interviewed to determine the prevalence of psychological distress, it was found that these women experienced higher emotional anguish than their fertile counterparts (Omoaregba et al., 2011). One of the main reasons for this inconsistency was the fact that infertile women reported experiencing some form of verbal or physical abuse from their spouse (10%), spouse's relatives (14%), and neighbours (15%). These researchers suggest the rates of psychological distress are higher in sub-Saharan African cultures than those in the West. This is because childlessness, which is a private matter in Western cultures, is an issue for open inquiry from relatives, friends, and neighbors in sub-Saharan African where the ability to have children is socially and economically significant.

Another injury associated with OF is foot-drop, a gait abnormality in which the dropping of the forefoot happens due to muscle weakness (Arrowsmith et al., 1996; Miller, Lester, Webster, & Cowan, 2005) caused by damage to the sacral and perineal nerve from prolonged squatting and pushing during labour. This injury prevents dorsal flexion of the foot and, unless repaired, will cause an affected woman to limp or drag her foot behind. Traditionally Ghanaian women work long hours carrying out strenuous household tasks (i.e. fetching water, gathering firewood, cooking), caring for children, and bartering in the marketplace (Mitter & Rowbotham, 1995; Tengey, n.d.). The physical consequences of OF can therefore greatly impact a woman's ability to do traditional "women's work" (Miller et al., 2005).

Finally, the most distressing physical problem for women who experience OF is the constant and unremitting irritation to the skin due to the continuous stream of urine and/or feces over the buttocks, labia, and thighs. These skin irritations can develop into deep ulcerations requiring time and meticulous attention to cleanliness, which is unachievable for most women living in rural sub-Saharan Africa (Polan, Sleemi, Mulu, Lozo, & Morgan, 2015; Wall et al., 2001).

These physical ailments associated with OF take a toll on a woman's psychosocial wellbeing. Harrison (1983) provides a commentary that succinctly describes the devastating plight of these women. Their incontinence becomes confused with venereal disease, and an affected family can feel a deep sense of shame. As a result, these women are hidden away or abandoned, left alone to mourn the loss of their child and dignity. This experience is so traumatic that, even when cured, some women never regain their self-esteem. A qualitative descriptive study which explored the experiences of Ghanaian women who sustained OF during childbirth identified abandonment, defilement, economic disparity and physical suffering as the main challenges of living with OF (Mwini-Nyaledzigbor et al., 2013). In some cases women who experience OF contemplate suicide as a solution to their physical and emotional problems (Tebeu, Rochat, Kasia, & Delvaux, 2010).

Awareness, Treatment, and Reintegration

A ground-breaking study conducted by EngenderHealth and UNFPA in 2003 highlighted awareness, treatment, and reintegration as the main components in the prevention and reduction of OF. Prevention is the key to decreasing OF, particularly preventive measures that create an impact at the community level. Many of these measures were previously discussed in relation to better access to health care especially maternal health, access to education and accurate health information, improved infrastructure, the need for gender parity, and the rejection of harmful cultural practices (i.e. child marriage, female genital cutting).

Awareness. Awareness creation is the first component in OF care. It is suggested that many individuals are misinformed about OF and its causes. The word obstetric fistula lacks meaning for most people outside a health care field. For example, community members in Tanzania, the site of research exploring the perceived causes of OF, were not familiar with the term obstetric fistula (Kazaura, Kamazima, & Mangi, 2011). Instead OF was referred to by its local names all associated with urine such as “homa ya mkojo” meaning urine fever or “tatizo la mkojo” meaning the problem of urine. While the need for culturally appropriate words are important to describe the condition, accuracy in naming is essential, particularly among health care professionals. In the same study, the most frequently perceived causes of the “urine fever” were identified as the wrong operation during the Caesarean section, the baby being too big causing a ruptured uterus, poor family planning, the baby passing through the wrong path, and sex during the puerperal period. Similar findings have been reported with the addition of sorcery, evil spirits, adultery and the length of a TBA's finger nails as perceived causes of OF (Keri, Kaye, & Sibylle, 2010; Tsui, Creanga, & Ahmed, 2007; Velez, Ramsey, & Tell, 2007; Wall, Karshima, Kirschner, & Arrowsmith, 2004). Findings suggest only 3% of participants (n=334) attribute OF to prolonged obstructed labour (Kazaura et al., 2011). There has been much attention directed towards information sharing about OF, dispelling myths and providing community education that focuses on OF prevention (de Bernis, 2007; Miller et al., 2005; Velez et al., 2007; Wegner, Ruminjo, Sinclair, Pesso, & Mehta, 2007).

Despite not knowing what causes OF, women do comprehend that OF, is physiologically abnormal. The majority of women (80%) were unaware of available treatment (Cook, Dickens, & Syed, 2004; Kalembo & Zgambo, 2012). Women may live with the negative consequences of OF for years before ever receiving treatment. Awareness campaigns about OF and OF treatment have been successfully implemented in many sub-Saharan African countries. Community governance as well as partnerships with local and government stakeholders, in Guinea, for example, has helped to promote OF awareness (Fistula Care, 2010). Campaigns to end fistula have been implemented in Ghana since 2005 to sensitize the community, HCPs and the media about the causes and availability of OF treatment (Pathfinder International, 2009). In a cross-sectional study conducted in northern Ghana, 2,648 individuals were surveyed to assess their awareness and knowledge about OF. The sample was composed of 466 males and 1982 females. Findings indicated that the level of awareness is low and may be attributed to the low literacy and the lack of awareness programs in the area (Saeed, Alhassan, Opare-Asamoah, & Kuubiere, 2014). Sensitization programs in sub-Saharan Africa usually occur through radio announcements, printed materials, village theater, and health education in schools, churches, and markets (Kalembo & Zgambo, 2012; Wegner et al., 2007). World Fistula Day is observed on May 23 to raise global awareness about the condition (Ghana Web, 2014). Community ambassadors, women who have undergone OF repair, are obliged to become fistula advocates as a means of giving back to others for the help they received. These women show great potential for information sharing about OF within the community since they can testify to the availability of effective medical treatment and management of OF (Kalembo & Zgambo, 2012). These women become important figures in the lives of those affected by OF because of their willingness to counsel and share their experiences with others. The voices of many women who have experienced OF (Bangser, 2007; Mwini-Nyaledzigbor et al., 2013; Yeakey et al., 2011) and the stigma and negative social consequences that frequently follow (Bangser, 2007; Mselle et al., 2012b; Roush, 2009; Weston et al., 2011) have been explored and reported.

Treatment. Treatment, the second component of OF care, often requires specialized physicians and surgeons trained to surgically repair and care for OF patients since most fistulas do not heal on their own. The surgical success rate for the closure of a simple fistula is approximately 70 to 90% with more complex and complicated cases ranging between 30 to 60% (Creange et al., 2007). Greater success is achieved with first-time repairs and those with minimal scarring (Munoz et al., 2011). Success rates vary among countries depending upon the country's resources and available skills. It is suggested that training for surgeons should be a minimum of one to three months, and OF surgeries must regularly be performed in order to maintain proficiency. Refresher courses are offered to surgeons who have the basic skills but lack practice hours (Fistula Care, 2012). A team-based approach is considered optimal since nurses play a key role in pre- and postoperative care and counselling. Likewise, depending upon individual health needs, physiotherapists, nutritionists, social workers, and other health professionals play a significant role in the care of a woman with OF. Capacity building with money earmarked for OF training of qualified medical, nursing and allied health professionals has been one of the mandates of UNFPA Ghana (UNFPA, 2012a).

The average cost for OF surgery, postoperative care, and physical rehabilitation is reported to be between 350 and 450 dollars U.S (Fistula Foundation, 2012). This is an enormous sum for many women living in sub-Saharan Africa. Currently, many government and nongovernmental agencies provide financial and human resources to subsidize and support women who need OF surgery and care (Nanda, Switick, & Lule, 2005). Ghana is one of the African countries that receive assistance.

The surgical approach for repair of a VVF is usually through the vagina, but occasionally an abdominal approach is needed. Conservative management can be employed using urinary catheterization for an extended period of time if the fistula is diagnosed within the first few days after it develops or if the fistula is small (Garthhwaite & Harris, 2010). RVF repair options include local repairs, tissue transfer techniques, and abdominal operations (Rivadeneira, Ruffo, Amrani, & Salinas, 2007). There is much scholarly literature pertaining to OF surgical repair techniques and OF complications (Arrowsmith et al., 1996; Kalembo & Zgambo, 2012; Kalilani-Phiri et al., 2010; Muleta et al., 2008; Wall, 2006).

Reintegration. Reintegration is considered the third and final component of OF care. It is a core element of UNFPA's program to end fistula and consists of education, counselling, skills training, and social and financial support for the purpose of assisting women to reconnect and rebuild their lives post-OF (EngenderHealth & UNFPA, 2003). The word "reintegration" can be deconstructed where “re” signifies “back to the original place” and “integration” denotes “renewal or restoration” (Harper, 2014). With respect to OF, reintegration is defined as:

> …a process of helping women to return to the life they lived before they developed fistula. This includes how women adjust and reconnect to employment, families, communities, and social life in order to restore their dignity and respect and to increase their self-esteem (Mselle, Evjen-Olsen, Moland, Mvungi, & Kohi, 2012a, p.928).

Researchers and women’s health organizations have argued that reintegration, particularly social reintegration, is the most important aspect of OF care next to the surgery itself (Capes et al., 2011; Muleta et al., 2007; Women’s Dignity Project & EngenderHealth, 2006). When health is defined as “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (WHO, 2016b, Constitution of the World Health Organization: Principles, para. 1), it is difficult to challenge the importance of reintegration in OF care. Furthermore, when “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being” (WHO, 2016b, Constitution of the World Health Organization: Principles, para. 2), it is essential to make reintegration a priority. There is a small but growing body of research that explores the experiences of women post-OF repair (Browning & Menber, 2008; Castille et al., 2015; Donnelly, Oliveras, Tilahun, Belachew, & Asnake, 2015; Fistula Care, 2010; Gebresilase, 2014; Johnson et al., 2010; Khisa & Nyamongo, 2012; Lombard, de St. Jorre, Geddes, El Ayadi, & Grant, 2015; Mohammad, 2007; Mselle et al., 2012a; Muleta, Hamlin, Fantahun, Kennedy, & Tafesse, 2008; Nathan, Rochat, Grigorescu, & Banks, 2009; Nielsen et al., 2009; Pope et al., 2011; Turan, Johnson, & Polan, 2007; Umoiyoho, Inyang-Etoh, Abah, Abasiattai, & Akaiso, 2011;Velez, Ransey, & Tell, 2007; Wilson, Chipeta, Kalilani,Toulo, & Tsui, 2011; Women’s Dignity Project & EngenderHealth, 2006;Yeakey et al., 2011; Young-Lin, Namugunga, Lussy, & Benfield, 2015).

Reintegration programs. Reintegration programs are organized, well researched, and culturally appropriate strategies to help individuals and groups to achieve a state of unity within themselves and their community. Reintegration programs have been associated with rehabilitation and assimilation and are utilized for diverse populations. For example, reintegration programs have been implemented for inmates, drug abusers, those experiencing stigmatizing and chronic illnesses (i.e. HIV/AIDS, leprosy, cerebrovascular accident, work related injuries) with the aim of restoring harmony within themselves and being part of and accepted by the community. Reintegration programs may consist of but are not restricted to family and community sensitization, community follow-up from health professional(s)/access to health care services, skills training and education, financial assistance, support, counselling and advocacy, and depending on the cultural context traditional practices or ceremonies (de Bernis, 2007; Williamson, 2006). Reintegration programs for OF can be delivered by way of rehabilitation centers or community-based programs, which have been proven to be more effective (Capes et al., 2011). The best approach to reintegration post-OF repair varies from country to country (Capes et al., 2011).

The Foundation for Women's Health Research and Development (FORWARD) was instituted in Nigeria in 1999 to take a holistic approach to OF care. This program provides surgical repair and rehabilitation, and cares for a woman's social, emotional and economic wellbeing (Mohammad, 2007). The program aims are to reintegrate women who have experienced an OF repair into their community by creating community awareness about the condition, and through providing follow-up and monitoring of OF clients. Women who enter this program are not viewed as patients or victims but as clients who come to stay at the Nigerian residential center for ten months. Once the OF is surgically repaired, women begin to learn about income generating activities, food preparation, personal hygiene, and decision-making skills. At the end of the program, women are given a loan to start a business. This loan is paid back over several months with zero interest. There is evidence to suggest that the FORWARD initiatives are helping women who have experienced an OF to return to their communities as leaders. Reintegration, is not a new concept in Nigeria; since the mid-1970's, a local teaching hospital has been initiating skills training and follow-up visits to fistula survivors who had no place to go (Ahmed & Holtz, 2007).

The Hamlin Fistula Clinic[2] in Ethiopia is another example of a health care clinic where women who seek OF repair are treated holistically. Women who travel to this clinic and undergo OF repair can also access health services such as physiotherapy, psychological counselling, stress incontinence management, education (literacy classes), skills training (embroidery, knitting, basket making, and cooking classes) and extended medical care if they suffer from malnutrition, anemia, malaria, tuberculosis and/or kidney disease. When these women are completely "cured" of their medical condition they are given a new dress to wear home, signifying a new beginning. Women typically stay at the clinic for four to six weeks before returning home. Some women may not have homes to which they can return if their families and communities have rejected them and prevented their reintegration. In Ethiopia these abandoned women go to Desta Mender ("Village of Joy" in Amharic), a hostel outside the cities' capital, which provides technical training for women who received OF surgery and have no home.

The Kissidougou, Guinea district hospital has also implemented a program where they work closely with EngenderHealth, the Urban Development Commune, and the local government to improve fistula prevention, treatment, and reintegration (Fistula Care, 2010). This

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[2] Information pertaining to obstetric fistula care (programs) at the Hamlin Fistula Clinic was gathered during visits to the clinic in 2010 and 2011

program has four interventions, the first being the market town approach that has been critical in increasing the district's revenue through improved management of the central market. A portion of these funds is allocated to supporting public services and assisting in raising awareness about OF. The safe motherhood committee uses volunteers to educate and engage the community in maternal health practices. "Waiting homes" are being used to assist women who lack a place to go prior to OF surgery. Women can stay in the waiting homes for two weeks prior to having OF surgery and are provided with important pre- and post-OF repair instructions. Finally the program provides "host families" who complement the waiting homes after OF surgery. These families help to facilitate a woman's transition home and her participation in family life. Similarly, Ghana's reintegration program post-OF repair is community-based and delivered through existing networks and organizations such as UNFPA. It is acknowledged however, by UNFPA (2012b) based in Ghana that this component of OF care is not as comprehensively addressed as the other two components (i.e. awareness and treatment).

Reintegration: A Review of the Literature

Conducting the Review

There is a need for more research regarding the reintegration of women post-OF repair (Ahmed & Holtz, 2007; Bangser, 2007; Capes et al., 2011; Muleta et al., 2008; Roush, 2009). With assistance from a research librarian from the John W. Scott Health Science Library at the University of Alberta a systematized review was conducted on the topic of reintegration post-OF repair. Key search terms included: sub-Saharan Africa, obstetrical fistula, obstetrical fistula repair, vesico-vaginal fistula, recto-vaginal fistula, obstructed labour, reintegration, follow-up, rehabilitation, convalescence, assimilation, recovery, social implications, support and experience. Each term was entered separately and combined in CINAHL, MEDLINE, Global Health, Soc

Index, ProQuest, Pub Med, EMBASE, SCOPUS and Google Scholar databases as well as government and NGO websites (World Health Organization, Engender Health, Fistula Foundation, Government of Ghana, and Ghanaian newspapers such as GhanaWeb or Joynews) to search for appropriate resources and existing evidence. The search yielded a total of 174 studies, and all abstracts were reviewed. For articles to be included in the systematized review, studies had to be conducted in sub-Saharan Africa and contribute to a body of knowledge about the rehabilitation and/or reintegration needs and/or experiences and/or follow-up with women who had an OF repair and/or those individuals (family members, HCPs) who participated in a woman's care post-repair. Only articles written in English were considered. Likewise, articles related to the topic but published after March 2015 were not considered in this review. A total of 21 peer-reviewed articles met the inclusion criteria, and are presented in Appendix A.

Five studies were directly related to reintegration post-OF repair (Donnelly et al., 2015, Mselle, et al., 2012a; Pope et al., 2011; Turan et al., 2007; Women's Dignity Project & EngenderHealth, 2006); seven studies explored the experiences of women following an OF repair (Gebresilase, 2014; Khisa & Nyamongo, 2012; Muleta et al., 2008; Nathan et al., 2009; Umoiyoho et al., 2011; Wilson et al., 2011; Yeakey et al., 2011); two were follow-up studies assessing the quality of life post-OF repair (Browning & Menber, 2008; Nielsen et al., 2009); one study explored the perceptions of HCPs about the reintegration of OF patients (Young-Lin et al., 2015); four studies described the impact of interventions (counselling, physiotherapy, education) for women who had an OF repair (Castille et al., 2015; Fistula Care, 2010; Johnson, et al., 2010; Mohammad, 2007); one was a systematic review (Lombard et al., 2015) and one was a needs assessment (Velez et al., 2007). Although studies were organized according to their main themes, most addressed more than one concept relating to reintegration.

Literature Review

The majority of the research related to reintegration post-OF repair occurred in East Africa. There were five studies in Ethiopia, three in Tanzania, and two in Eritrea, Benin, Malawi and Nigeria. One study was conducted in each of the following countries: Democratic Republic of Congo, Guinea, and Kenya. There was also one systematic review and one multi-country needs assessment published. No studies conducted in Ghana were found. The majority of these studies were qualitative and were limited to health facilities. Most follow-up studies with women upon their return home (Castille et al., 2015; Johnson et al., 2010; Mselle et al., 2012a; Muleta et al., 2008; Nielsen et al., 2009; Yeakey et al., 2011) had small sample sizes, and authors recommended that follow-up be replicated with larger populations. Cost and the difficulties in tracking and accessing participants once they had left the health facility contributed to the small sample sizes. In one study the experiences and perceptions of women post-OF repair were explored using a slightly larger sample (n=51) but participants were not followed up with interviews in their homes (Donnelly et al., 2015). Instead, the researchers invited participants to be interviewed in a central office or health facility in the community setting. Interviewing participants in the home environment can reveal knowledge about a participant's reality, their ability to follow through with post-operative instructions, and their level of support in the home environment. In a cultural setting where participants are illiterate and disempowered, there is the potential that they will want to please the researcher or HCP and so may provide inaccurate information about their situation or feelings (Browning & Menber, 2008; Mselle et al., 2012a). Conducting follow-up interviews in a participant's home may be beneficial, increasing their willingness to be honest about their reintegration experiences.

An individual is understood to be part of larger entities, their family, and their community. When OF occurs in an individual in sub-Saharan Africa, it most often affects her family and community. Family support after OF surgery is noted to be an important factor in assisting a woman to reintegrate into her community (Pope et al., 2011; Young-Lin et al., 2015). Family support typically comes in the form of a blood relative since, unless her marriage has produced children prior to developing the OF, a woman's partner or husband often will desert her.

It is essential when discussing matters pertaining to reintegration not only to explore the experiences of the individual but also the experiences of the family and the community. The social implications of OF can affect many family members in a woman's personal sphere, thus creating significant worry and burden. In a small number of studies, the perspectives of the spouses and family members were explored to help understand the impact of OF on a woman's social relationships (Women's Dignity Project & EngenderHealth, 2006; Yeakey et al., 2011). It is recommended that further inquiry into the perceptions or beliefs of a woman's family, husband, and community members is needed since they are the ones who often find it difficult to accept women when they return to their community (Khisa & Nyamongo, 2012). It is suggested that counselling can benefit family members, husbands and community members and is important in a woman's recovery and reintegration (Fistula Care 2010; Johnson et al., 2010; Lombard et al., 2015; Nathan et al., 2009; Velez et al., 2007).

It is essential to understand a husband's perception and the level of support he is prepared to give to his wife because men typically play a key role in decision-making about health and may affect a woman's ability to utilize post-operative instructions and her ability to successfully reintegrate into the community (Gebresilase, 2014; Khisa & Nyamongo, 2012; Nielsen et al., 2009; Turan et al., 2007). As well, peer support from women who have previously experienced an OF repair is documented to be valuable in encouraging participants to carry on and follow through with post-OF rehabilitation and healing (Gebresilase, 2014; Mohammad, 2007). Peer supporters also serve as role models, educating the community about OF and advising women not to conceal their problems (Yeakey et al., 2011). Women's willingness to talk openly about OF has assisted in creating awareness and in reducing the shame, which is frequently associated with the condition (Johnson et al., 2010). It is reported that women who developed OF after 1990 experienced less shunning and this was associated with an increase in public campaigns and comprehensive fistula programs (Pope et al., 2011). In contrast, a study in Eritrea where the investigators sought to improve medical and social services for women experiencing OF noted that participants were reluctant to speak and share their experiences (Turan et al., 2007). Findings documented the shame participants felt and their fear that no one would listen to the plight of women who experienced OF (Turan et al., 2007). Likewise, Nielsen et al., (2009) noted that only four of 44 affected women encouraged other women to seek treatment and three stated that their reason was because they were afraid to discuss the problem. The authors recommended the need for more community awareness and sensitization programs.

The timing of data collection should be carefully considered when evaluating the studies retrieved. For the majority of the studies identified, data were gathered during the post-operative period when women and families were happy and excited about having a successful surgical outcome (Donnelly et al., 2015; Gebresilase, 2014; Yeakey et al., 2011). There is evidence to show that women who have an OF repair have a significant improvement in their mental health. For example, women reported an increase in their self-esteem, sleeping patterns and ability to concentrate post-operatively (Umoiyoho et al., 2011). Additionally, improvements are noted in a woman's physical health with the healing of perineal sores and the reduction in perineal pain (Castille et al., 2015; Umoiyoho et al., 2011; Women's Dignity Project & EngenderHealth 2006; Young-Lin et al., 2015). Quality of life scores increase as women become more likely to socially interact and participate in community activities post-repair (Castille et al., 2015; Nielsen et al., 2009). Some women do report problems with fertility, amenorrhoea, foot drop and stress incontinence (Donnelly et al., 2015; Muleta et al., 2008; Pope et al., 2011; Turan et al., 2007; Wilson et al., 2011) but for women who experienced only slight urinary incontinence satisfaction post-operatively was reported (Turan et al., 2007; Yeakey et al., 2011). Despite this evidence it is difficult to make any inferences as to whether these findings carry over to the home community over the long-term, thus affecting reintegration (Browning & Menber, 2008; Turan et al., 2007). A six-month follow-up study was reported to be inadequate to evaluate the outcomes and quality of life after women had OF surgery since the time interval between surgery and follow-up was too short to fully evaluate social change (Browning & Menber, 2008). During the convalescent period at home issues arise that create tension within the family unit, such as a woman's inability to return to her regular work activities, her inability to have sexual intercourse with her partner, and concerns about future fertility (Donnelly et al., 2015; Muleta et al., 2008; Wilson et al., 2011). For some women, the timing of reintegration can also be coupled with the psychological distress of losing a child (Khisa & Nyamongo, 2012). The findings from another follow-up study conducted 14 to 28 months post-repair that addressed urinary, reproductive and quality of life issues were similar (Nielsen et al., 2009). Khisa and Nyamongo (2012) suggest that women who have unsuccessful repairs do not reintegrate well since they are viewed as cursed and are frequently not accepted back into the community

The successes of reintegration are linked to complex factors associated with living with OF. Women typically report fear related to reintegrating into their communities post-surgical repair (Gebresilase, 2014). This fear is rooted in their concerns about the future of their married lives, sexual relations, social interactions and economic survival (Donnelly et al., 2015; Khisa & Nyamongo, 2012; Lombard et al., 2015; Mselle et al., 2012a ; Muleta et al., 2008; Pope et al., 2011; Umoiyoho et al., 2011). Women fear the reoccurrence of an OF and often doubt that they are truly cured (Donnelly et al., 2015; Nathan et al., 2009; Pope et al., 2011). The degree of fear that they experienced was associated with the number of years a woman lives with OF. It is documented that women who have timely care reintegrate into society more successfully (Mselle et al., 2012a; Pope et al., 2011). The more years a woman lives with OF the greater her exposure to physical, emotional, social and economic hardship.

Many of the participants in the studies reviewed were divorced or separated from their partners. Women often suggest marriage is not compatible with OF because they are unable to meet their expectations as a wife, leaving men to view the condition as a bad omen (Khisa & Nyamongo, 2012). Many women report being afraid to have intercourse even after the recommended time period had elapsed, believing it could result in a reoccurrence of fistula (Muleta, et al., 2008). One study suggested women preferred to sleep away from their husbands post-OF repair so to avoid intercourse altogether (Donnelly et al., 2015). In many African societies where the status of a woman is connected to having children, the fear of being childless is also distressing especially when most women who develop OF are primiparous and might develop secondary infertility (Holme, Breen, & MacArthur, 2007). In some cases women associated having an OF repair with infertility (Wilson et al., 2011). This can greatly impact upon their marriage. There are success stories of women who returned home post-repair and subsequently gave birth via Caesarean section (Muleta, et al., 2008). Recommendations such as those made by Women's Dignity and EngenderHealth (2006) to improve antenatal care services, information on birth preparedness, access to emergency obstetric care, high quality fistula repair and post-operative teaching will assist women to have safe deliveries after OF and reduce their chance of secondary infertility.

In some cultures, women who have lived with OF must overcome an image of shame associated with the condition. "Illness carries meaning both on the concrete level of symptoms and on the higher level of the cultural significance attached to the disorder, which is often stigmatized" (Mselle et al., 2012a, p.936). There are many subtle and blatant manifestations that marginalize women and families of women who experience OF. Women recounted their experiences of not being allowed to cook or serve guests in the home despite being cured of their illness since it is believed that the condition is dirty, sinful and can be spread through food preparation (Khisa & Nyamongo, 2012). Beliefs such as these, contribute to the reason why women affected by OF isolate themselves (Mselle et al., 2012a). Needing to avoid the past trauma of stigma and discrimination was cited as one of the main reasons why participants did not want to reintegrate into their communities (Gebresilase, 2014). Programs outlined by Fistula Care (2010) and Mohammad (2007) show the benefits of providing a safe haven for OF patients who have recently had a repair, allowing them to gain the skills and confidence to overcome the perceived stigma and to successfully reintegrate.

There is a close association between being independent and regaining dignity as a woman in sub-Saharan Africa (Mselle et al., 2012a; Pope et al., 2011). Women especially gain respect from their husbands when they are able to provide for themselves (Mselle, Kohi, Mvungi, Evjen-Olsen, & Moland, 2011). It is documented that a woman's return to work is her greatest challenge along with her ability to carry out daily chores post-repair (Khisa & Nyamongo, 2012; Umoiyoho et al., 2011). This is because women cannot engage in strenuous labour for at least one year following surgery (Pope et al., 2011). Many women who experience OF endure financial difficulties because it prevents them from working and being able to generate capital, thus threatening their already tenuous livelihood (Donnelly et al., 2015; Lombard et al., 2015; Nathan et al., 2009).

The northern region of Ghana, West Africa is an appropriate setting for further research to explore the reintegration of women who have experienced an OF repair. Although there are studies where women's experiences were explored, no studies were found that purposefully explore a culture of reintegration. This sort of inquiry would demand examining the values, beliefs, practices, traditions and customs of a particular society or community as it relates to a woman's reintegration post-repair. This exploration could potentially advance the discussion about what it means to be a Ghanaian woman reintegrating into society after a potentially stigmatizing condition. Knowledge development that focuses on reintegration must be based on a woman's needs and a communities' cultural context, and should significantly contribute to improving the quality of life for women who experience OF.

There is some evidence that counselling in addition to capacity building related to OF care through vocational training has been invaluable, but more follow-up is required to support women's physical and psychosocial needs after returning to their communities (Johnson et al., 2010; Mohammad 2007; Young-Lin, et al., 2015). It is recommended that further research be conducted in other sub-Saharan African countries, with equivalent social economic status, for the purpose of supporting women who experience an OF repair (Turan et al., 2007; Mselle et al., 2012a). From the review of the literature, it is evident that future research should take a holistic approach, incorporating the perceptions of the women who have experienced an OF repair, their family members, HCPs, and community since few studies have been found that take this approach. When possible, participants should be interviewed in their home or community setting or an area they identify as safe and comfortable. Attention to ensuring that participants are in different stages of the reintegration process is recommended since emotions run high during the initial stage when participants are experiencing dramatic improvement and regard the surgery as “a miracle” (Women’s Dignity Project & EngenderHealth, 2006). It is also suggested that sample sizes should be large enough to obtain rich data on the reintegration of women post-OF repair (Nielsen et al., 2009).

Researchers exploring the experiences of women who are or have reintegrated into their community post-OF repair must understand the multisystem consequences of OF because the experiences prior to surgery will impact the hopes and concerns for how women will reintegrate. It is also important to consider the value of reintegration and what elements are beneficial in OF care since Nathan et al. (2009) noted that 49% of participants did not want reintegration assistance outside of the surgery. There is little known about women after they leave OF treatment facilities in Ghana or about how women reintegrate into their communities post-OF repair. This gap has been identified by UNFPA Ghana as well as through a review of the literature, and has led me to my research question: “What is a culture of reintegration for women who have experienced an obstetrical fistula repair in northern Ghana, West Africa?”

The Study

Research Purpose and Objectives

The purpose of this study was to explore a culture of reintegration for women who have experienced an obstetric fistula (OF) repair in northern Ghana. The objectives were:

- To identify the cultural contexts which shape the lives of women post-OF repair.
- To explore the roles of the family, HCPs, and community in the reintegration of women post-OF repair.
- To identify the social determinants of health which impact upon maternal and reproductive morbidities, with respect to OF repair.

Theoretical Underpinnings

When exploring complex matters a single theoretical standpoint can rarely be used to provide a definitive answer. Critical ethnography requires employing a number of perspectives to adequately guide the inquiry. Habermas' interpretation of the critical social theory, Nussbaum's capabilities approach, and Gyekye's ideology of culture in African society formed the theoretical perspective for this ethnographic work.

Habermas and the critical social theory. I draw on the work of Habermas since he is one of the most recognized second-generation critical thinkers. His, "significance lies in rescuing critical theory from the shackles of self-critical negations… which his predecessors had made it into" (Sudersan, 1998, p.264). Habermas "reoriented the critical social theory to make it less critical, negative, more systematic and more cohort from the social point of view" (Mosqueda-Deaz, Vilchez-Barboza, Valenzuela-Suazo, Sanhueza-Alvarado, 2014, p. 358). The main components of Habermas' work focus on oppression resulting from power imbalances, and the need to move toward emancipation. His theories are built on the Enlightenment tradition, which emphasizes language, logical reasoning, standards of social critique, and a dialectical manner toward emancipatory ideals (Hammersley, 1992). The first phase of Habermas' work was a critique of positivism where he argued that knowledge was not singular. Edgar (2006) notes Habermas held the view that there was predominately three types of knowledge. These were empirical knowledge which assisted us to control the world, hermeneutic knowledge that allowed us to understand the world and emancipatory knowledge to support individuals to have greater autonomy and self-determination (Edgar, 2006). Habermas saw weaknesses with both empirical and hermeneutic knowledge. He remarked that the empirical paradigm was authoritative and unable to reflect on its own limitations while hermeneutics failed to see the external forces at play within the cultural realm which had a cause and effect relationship. Habermas straddled both paradigms and believed that emancipatory knowledge drew assumptions from both domains which produced different but equally important kinds of knowledge. Habermas needed to justify his ideas of emancipation as they were said to be abstract and theoretical. He argued that cognitive interests were not just intellectual categories, but represented intuitive knowledge that was firmly established. Habermas claimed that individuals had a deep seated need to control the world which produced science and that individuals needed to work cooperatively to ensure their wellbeing that was contained in hermeneutics. The challenge was to establish a claim that individuals had a need for emancipation. It was through language, which is well grounded in hermeneutics, that Habermas realized that critical theory shared a commonality with hermeneutics. “The pursuit of emancipatory knowledge through critical dialectic, leads to self-reflection and freedom of oppression” (Mill, Allen, & Morrow, 2001, p.112). This provided Habermas with the basis for the second phase of his work, a theory of communicative action which explores the questions of what we mean, or what refers and how (Habermas, 1991a; 1991b). The theory was post-metaphysical, indicating the nature of knowledge or insight starts from within. He believed society yearned for a dialogue to address persistent problems and this required an “ideal speech situation”. He believed that in seeking the truth individuals must enter into a discourse where they are expected to be open and responsive to counter viewpoints with the aim being rational agreement.

In this study, I believe that emancipatory knowledge about a culture of reintegration for women who experienced OF emerged by using a dialogical approach. Insight from women, families, HCPs and the communities' began from "within" their own situation or position to better understand the nature of their reality.

Nussbaum's capability approach. Nussbaum's (2000) capability approach is a framework that describes and analyses wellbeing and quality of life in terms of what is realistically possible to achieve. This approach highlights "an individual's values, real opportunities and freedom of choice as well as the visualization of wellbeing as inherently multidimensional" (Chiappero-Martinett & Venkatapuran, 2014, p. 709).

Five concepts compose this approach: capability, asking "what is the person able to do and to be" (Nussbaum, 2011, p.20); "functionings", or the realization of those opportunities; agency, a person's ability to pursue goals that they value; endowments, describing the resources available that affect or promote higher quality of life; and conversion factors denoting how "free" a person is to convert their resources into achievable opportunities. Ten central, morally significant capabilities, or real opportunities, which correspond with a person's basic human rights and should be guaranteed by society are delineated by Nussbaum (2011). The central capabilities include: life, bodily health and integrity, senses, imagination and thought, reason, emotions, affiliation, play, concern for nature, and control over one's environment. According to the theory, personal, social, cultural and environmental factors may impede a person's capabilities.

This framework is appropriate to explore the capabilities of women to reintegrate post-OF repair since equality is not just about treating individuals equally, but also their ability to transform their resources. The framework can assist in identifying where potential health equality/inequality exists and the circumstances that support these assumptions. For example through empowerment, women can become aware of potential gender inequalities and the need to speak out on their own behalf as well as on behalf of their families and communities. In doing so it highlights where communities need to focus health programs to enhance initiatives directed towards post-OF care.

Gyekye's philosophical concepts. Gyekye is a Ghanaian philosopher whose work includes concepts of democracy, representation, the politics of inclusion and exclusion, and the significance of cultural values in national orientation. He provides an appropriate guide to understanding the views most prominent in contemporary African and specifically Ghanaian social, political and moral experiences, and culture (Gyekye, 2013). Gyekye's work reflects on indigenous Ghanaian cultural values, beliefs, practices, traditions, and institutions (Gyekye, 2003). In attempting to challenge the status quo by exploring a culture of reintegration, it was vital to identify with Ghanaian culture and philosophical thinking since my way of knowing and reasoning came from a Western standpoint. Gyekye's work provides a philosophical foundation to assist in providing a conceptual and critical response to the concept of reintegration for women post-OF repair in northern Ghana (Gyekye, 2004).

Ethics Approval

Ethics approval for this study was granted by the Human Research Ethics Review Board at the University of Alberta, Canada and at the Navrongo Health Research Center, Institutional Review Board, Ghana. A request for ethics renewal was made to extend the project's expiry date, which was granted by both agencies. Ethics approval documents can be viewed in Appendix B.

Research Methodology

Design. This study was conducted using a critical ethnographic design. Ethnography is one of the oldest qualitative methods dating back to the 19th century and has been traditionally rooted in anthropology (Atkinson & Hammersley, 1994). Ethnography is "the art and science of describing a group or culture" (Fetterman, 1989, p.1). It is characterized by

> a written description of a people that focuses on selected aspects of how they lead their routine, remarkable, and ritual lives with each other in their environment and of the beliefs and customs that comprise their common sense about their world (Muecke, 1994, p.189-190).

There are many different forms of ethnography in addition to the conventional or systematic approaches. The evolution of ethnography to include adaptive forms has led to a stimulating discourse among scholars (Wolcott, 1999). Critical ethnography is an analysis and discourse that is embedded within conventional ethnography for a political purpose allowing us to “expand our horizons for choice and our experimental capacity to see, hear and feel” (Thomas, 1993, p.3). Critical ethnography questions and exposes hidden agendas, power centers and assumptions that inhibit, repress and constrain. It disrupts the status quo, and since its theoretical underpinnings are situated in critical social theory, it moves the discourse from describing, “what is” to the realization of “what could be” (Bronner, 2011; Calhour, 1995; Madison, 2012). Critical ethnography, unlike other conventional ethnographies, is analytical rather than descriptive.

OF patients are extremely vulnerable according to the seven categories of vulnerability proposed by Kipnis (as cited in Wall, 2014) for generally accepted principles of biomedical ethics. It has been suggested that classical forms of ethnography used to study vulnerable or marginalized populations only perpetuate the dominant images and stories (Faubion, 2001; Skeggs, 2001). When considering a culture of reintegration for women who have experienced an OF repair in northern Ghana, a critical ethnographic approach calls for action to rethink comfortable thoughts, to attempt to connect the "meaning of the meaning to a broader structure of social power and control" (Thomas, 1993, p.6). Critical ethnography not only describes but prods deep, stripping away the familiar social and perceptual harmony that anchors common sense and challenges the dominant features of social structure. If anything was to be learned about a culture of reintegration for women who have experienced an OF repair in northern Ghana, it would be gained only by using all my resources, skills, and privileges to challenge dominate discourses and to deconstruct the words and the experiences of participants. These efforts will thus expose the taken for granted perceptions about the world in which these women and their families live and how communities and/or cultures think about reintegration. The aim was to facilitate movement towards emancipatory knowledge and the capacity to envision alternative possibilities.

Ontological assumptions of critical ethnography. Ontology describes the nature of reality (Tuli, 2010) or "something fundamental about the phenomenon of inquiry" (Flaming, 2004, p. 225). Ethnography is a qualitative research design that assumes reality and meaning are socially constructed. It accepts that individuals make sense of their own reality and that there are multiple truths. Critical ethnography unveils underlying issues that create reality but which are not linear or conclusive. It is grounded in historical realism, the view that "reality has been shaped by social, political, cultural, economic, ethnic and gender values" (Guba & Lincon, 1994, p.110). Critical ethnography accepts that people's views emerge from somewhere and that an ethnographer's role is to deconstruct these historical events to disclose the cultural foundation or habitus; the lifestyle, character, values, expectations of a particular group which are acquired or influenced by worldviews, experiences and cultures (Pollner & Emerson, 2001). In Ghana, for example, the historical events of the slave trade, the traditional role of women, and the north/south, urban/rural socioeconomic and political differences contribute to peoples' realities. Critical ethnographers believe there is something "out there" to know and assume that it lies beneath the surface, an invisible sphere of meaning that organizes people and allocates power and resources in ways that are understated and unjust. Critical thought deems there is something better out there and the goal must be to work towards it (Thomas, 1993).

Epistemological assumptions of critical ethnography. Epistemology is the nature of knowledge and addresses the questions: what is the relationship between the knower and what is known, how do we know what we know, and what accounts as knowledge (Tuli, 2010)? Critical ethnography assumes we cannot separate ourselves from what we know. Crotty (1998) reminds us "we come to inhabit a pre-existing system and to be inhabited by it" (p.53). This suggests we are born into a world, a culture, in which meaning has already been made. Critical ethnographers frequently start to explore a phenomenon recognizing their own preconceived ideas while seeking to expose underlying meaning(s) with a goal for change (i.e. social justice). Critical ethnographers are frequently not strangers to their research topics and usually have a vested interest (Thomas, 1993). Critical ethnographers assume contemporary societies have systematic inequalities, which are maintained and reproduced by cultures that constrain human existence (Cook, 2005; Thomas, 1993).

Knowledge is created through a dynamic interaction or dialogue between the researcher and the participant, the emancipation of both, and the transformation of the lived reality (Gordon, Holland, & Lahelma, 2001). The goal of the research is to discover what is blurred or distorted, and through the process of praxis to transform reality. Critical ethnographers assume reality can be changed through human activity beginning with consciousness-raising and critical review that in turn may bring about an emancipatory function of knowledge, which addresses matters of social justice.

Positionality. Critical ethnography is subjective, using “self” as a key instrument, and so self-reflection or “turning back” on ourselves must be a vital part of the research process (Roper & Shapira, 2000). It is important to “acknowledge our own power, privilege, and biases just as we denounce the power structures that surround our subjects” (Madison, 2012, p. 8). Critical ethnographers must likewise address how subjectivity (perceptions, experiences, personal, and cultural understanding) influences reality and informs or is informed by their engagement and representation of others. Emic and etic are two terms that help round out the ethnographic picture of how researchers position themselves within the research as an insider or an outsider. These two constructs are tied to the epistemological principles and address how knowledge is acquired and to what extent a particular entity can be known (Headland, Pike, & Harris, 1990).

Upon reflection of my emic and etic position I approach this research as an outsider for I am not of Ghanaian descent nor have I been raised in or influenced by Ghanaian culture. I am not a mother nor have I experienced an OF repair or a potentially stigmatizing condition. Instead, I am a graduate nurse educated in Canada, who might be perceived as privileged. I have previously worked in a developing country in the Middle East where men were socially advantaged. I have also volunteered in East Africa with women who have OF and have seen and heard their plight. These experiences have given me some insight and prompted my research inquiry. This is not an uncommon happening for critical ethnographers who often relate subjectively to their topic and feel passionately about their research (Hardcastle, Usher, & Holmes, 2006; Thomas, 1993).

Axiology assumptions of critical ethnography. Axiology is synonymous with value theory where "values", in the broadest sense, can mean ethics, religion, economics, politics, aesthetics, and/or science (Encyclopedia Britannica, 2015). Critical ethnography starts with an ethical responsibly to address unfairness and injustice. Researchers feel an obligation to make a contribution toward improving liberty and equity, and challenging issues of power, control and oppression (Madison, 2012). Critical ethnography has a political component that makes visible the plight of women who have experienced an OF repair. Raising awareness in conducting a critical ethnography exploring a culture of reintegration post-OF repair will lead to consciousness-raising about OF and OF care and the need for improvements in maternal, reproductive and community health care. Although achieving an ideal society free of repression may not be possible, I believe it is worth striving for since every step is a move towards a society which is just and free. Ultimately this supports a woman who has experienced an OF repair to "be able to do and to be" (Nussbaum, 2011, p.20).

Culture, a key concept in critical ethnography. The concept of culture is embedded into ethnography, however, the term is difficult to define. The idea of culture in ethnography aims to explore and understand "what is going on here" (Wolcott, 1999). The most meaningful and comprehensive definition of culture that I have found recognizes not only the behavioral, materialist and cognitive perspective but also the environmental landscape or environment.

> …culture is the acknowledgement that each is a unique and ever-changing constellation we recognize through the observation and study of its language, religion, social, political and economic organizations, decorative arts, stories, myths, ritual practice and beliefs, and a host of other adaptive traits and characteristics. The full measure of a culture embraces both the actions of a people and the quality of their aspirations, the nature of the metaphors that propel their lives. And no description of culture is complete without

> reference to the homeland, the ecological and geographical matrix in which people have determined to live out their destiny (Davis, 2009, p.33).

It was through this broad concept of culture that I began to understand a culture of reintegration. For the purpose of this study, a culture of reintegration for women who experienced an OF repair in northern Ghana was defined by these women, their family members, HCPs and community stakeholders who cared for or had an invested interest in their wellbeing. It is assumed that how a culture of reintegration is expressed would vary since culture is not static and is based on a woman′s, her families′ and communities′ values, experiences, beliefs and practices about OF care, embedded within social, political, economic, and historical factors.

Setting

Geography and demographics. Ghana, formally known as the Republic of Ghana, is centrally located in West Africa and borders three French-speaking nations (Burkina Faso, Côte d'Ivoire and Togo) and the Gulf of Guinea. Geographically its size is approximately 238,533 square kilometers, and it has an estimated population of 26 million (Central Intelligence Agency, 2014).

This study was conducted in northern Ghana, which is composed of three regions, Northern, Upper East, and Upper West, and accounts for 44.9% of the country's total landmass, with a combined population of approximately four million people. Northern Volta was also included in the study's catchment area since the Volta region is divided in two by the Volta Lake; this forces residents in northern Volta to seek services in the northern Ghana region. The people and tribes who live in the north are culturally, religiously, linguistically, politically and economically diverse and differ in many respects from those in central and southern Ghana (Government of Ghana, 2016). The dominant ethnic group in the north is the Mole-Dagbani meaning Great Warriors who are understood to be a relatively oral culture with little written text

(P. Naa Boakye, personal communication, March10, 2014). Within the Mole-Dagbani there are five subgroups--Mamprusi, Mossi, Dagomba, Nanumba, and Gonja--of which the Dagomba are the most prominent.

Ghana is a multilingual country with over 80 languages spoken. However, the official language is English with Dagbani widely spoken in the north (Ghana Embassy, 2015; Paul, Simons, & Fennig, 2015). More than half of the people living in northern Ghana are Muslims (56.2 %) followed by Traditionalist (21.3%) and Christians (19.3%) (Government of Ghana, 2016). The majority of the people are employed in agriculture cultivating maize, yam, millet, cassava, soya bean and rice (Yakubu, 2011). There is deep appreciation for communal social structures where family is defined beyond the nuclear family to include the extended family and even those not genetically related (Gyekye, 2003). Ghanaians refer to these family clusters as a clan, which has a patriarchal hierarchical structure, placing the eldest male as the head of the household. Elders are held in high esteem and are believed to hold the repositories of knowledge and wisdom because knowledge is derived from life experience and must be respected (Gyekye, 2003).

Tamale, the fourth largest city in Ghana, is the capital and largest city of the northern region. The capitals of the Upper East and Upper West regions are Bolgatange and Wa consecutively. All three regions have sparsely populated communities spanning kilometers over remote countryside (Government of Ghana, 2016). Tamale was the center of operations for this project for three reasons. First, it is the location of the TFC, the main site for participant recruitment. Second, it is centrally located in the north, making access to other areas feasible in terms of distance and time. Finally, in Tamale, supplies and provisions could be easily obtained for the research project or before traveling to remote areas to interview and recruit potential participants. A map with a list of the communities visited can be viewed in Appendix C.

Government. Ghana was the "first sub-Saharan country in colonial Africa to gain its independence in 1957" (Keller, 1995, p.158). Ghana asserts a constitutional democracy founded on open and free elections. Each region in Ghana is divided into districts that are overseen by a District Chief Executive (DCE) appointed by the central government but receiving authority to implement policies at the grass roots level from an elected assembly (Government of Ghana, 2016). Ghana's government structure is presented in Appendix D. Ghana maintains a traditional political system. A chief is appointed for each cultural tribe, although chiefs hold no official power in the central government, they have considerable political influence (Gyekye, 2003). Chiefs are not directly elected by the people, although "a chief is a chief by the people" (p.110), suggesting a close partnership between the people and chiefs (Gyekye, 2003).

Health care. Health care services are provided through the Ghanaian government with the exception of a few clinics and hospitals run by religious organizations. The MoH along with GHS are responsible for the management of primary, secondary and tertiary health services, which are organized at the community, sub-district, district, regional and national levels. Community-based Health Planning Services (CHPS), adopted in 1999, was a national health policy designed to provide outreach programs for residents needing public health care services including maternity care in accessible community centers (International Organization for Migration, 2011; Nyonator, Awoonor-Williams, Phillips, Jones, & Miller, 2005). This initiative led to health care reform in Ghana with community-based care being accessed in some of the poorest areas of the country thus improving the overall health and wellbeing of citizens (Awoonor-Williams et al., 2013). Health care clinics in the community provide basic health services and work with district hospitals as referral points for patients who require more complex care. Regional hospitals, in turn, provide advanced care including the management of high-risk pregnancies. Teaching hospitals answer directly to the MoH providing specialized care and are involved in research and teaching initiatives. Finally, health policy and strategic planning, and the implementation, monitoring, and evaluation of health services take place at the national level. Appendix E provides an outline of Ghana's health care system.

Ghana's health care system traditionally relied on public resources and donors, but today health care is mainly funded through Ghana's NHIS which is subsidized through government investments and value added taxes (Dixon et al., 2013).

Gaining Access and Building Community Partnerships

This research began with the support of two community partners, individuals who initially were gate openers, facilitating access to the community and functioning as cultural brokers. My initial community partners were:

- Dr. Patience Aniteye, a lecturer and Department Head for Community Health Programs at the University of Ghana. Her program of research focuses on women's reproductive health.
- Ms. Pricilla Naa Boakye, a native Ghanaian nurse-midwife holding a Master's degree in Nursing and currently living in Tamale. Ms. Boakye is a lecturer at the University of Development Studies-Tamale. Her area of expertise is maternal-child health.

These partners provided a level of legitimacy for me as a researcher and for the research process, saving me much time and resources. Ms. Boakye was especially valuable for she had the knowledge, influence, professional links and cultural insight to connect me with formal and informal community stakeholders (i.e. the village chief and/or magajias[3], TBA, department

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[3] Female community leader(s) in northern Ghana

administrators with GHS) and to facilitate my acceptance by the community. Acceptance into the community began with Ms. Boakye's cultural advice on how to dress, speak simple phrases in the local language, and greet elders and prominent people, in order to build trust and respect. Ms. Boakye later took on the role of my research assistant and was responsible for translating and interpreting, contacting participants, obtaining consent and administrative tasks.

Gaining access into the community was multilayered and included seeking approval from Dr. Barnabas B. Naa Gandau, an obstetrician/gynecologist who was in a leadership position at the TFC at the time of this research. Approval was additionally sought and granted from GHS, a government agency responsible for the administration of health care, and administrators from the Christian based agencies visited. At a grassroots level, permission was sought from village chiefs and household/family heads before engaging with potential participants.

This study was community-based. I collaborated with community stakeholders and potential participants, recognizing the unique strengths each brought to the research process. Many times throughout this research I was reminded of the hidden and internal nature of culture. Although I spoke the same language as many of my community partners, I perceived the world through a western lens. This forced me to be open to new and creative ways of working with and conducting research so to respect the rights of Ghanaians while meeting my research objectives. Throughout the research, I practiced cultural humility and self-reflection. I was receptive to learning about Ghanaian cultures, asking questions and sharing my newfound insights. I frequently sought validation and participated in open communication and active listening with participants and others. I believe this approach enhanced capacity building and co-learning, benefiting all members and reducing the researcher-researched power imbalance.

Methods

Sample and Recruitment

A total of 99 participants were recruited over two time periods, from March to June 2014 (n=95) and April to May 2015 (n=4). Follow-up interviews (n=14) were also conducted during the April to May 2015 period. Recruitment used a combination of convenience, purposive and snowball sampling techniques. A table outlining a summary of participant sample and recruitment is presented in Appendix F. Demographics of women participants with OF can be seen in Appendix G.

Deciding who could provide the most relevant information to inform this inquiry required some consideration. Since I was a foreigner in Ghana, it was important to understand the landscape (cultural, social, political, historical, economical, and geographical). Initially, a “big net approach”, a sort of mix and mingle, was initiated by having informal conversations with the Ghanaian community members and observing them in their daily practices. These interactions assisted me in identifying key informants, those individuals who possessed “insider knowledge” and who had the most knowledge to support me in exploring a culture of reintegration post-OF repair. Participants recruited for this study were as follows:

- Women who had experienced an OF repair a minimum of three months prior to being interviewed. There were no maximum timelines following repair for being interviewed. Eligible women were interviewed in their “home environment”, the place where they were living or staying post-repair.
- Family members of women who had experienced an OF repair and were involved in their care pre- and post-OF repair, or post-OF repair only. Only those identified as family members of women interviewed were considered.

- HCPs who cared for women who experienced an OF repair (i.e. nurses, doctors, traditional birth attendants, traditional healers).
- Community stakeholders, those in leadership positions, or who provided service to the community, and were involved in OF care at the community, regional or national level (i.e. government officials, nongovernmental organizations, religious leaders, magajias).

Women who experienced an OF repair were recruited from a follow-up client list or medical records from the TCH fistula clinic. With the assistance of the nursing staff at the OF clinic, potential participants who had an OF repair (n=89) and met the inclusion criteria, were contacted. Potential participants were asked if a Canadian nursing researcher could call to set up a visit in their home or community to discuss their experiences returning home post-OF repair. Many potential participants and community members knew of additional women who had experienced an OF repair. In these instances, my contact information was provided and forwarded to other potential participants. A total of 41 women agreed to participate in the study.

From the 41 women who participated, family members who were involved in their pre- and post-OF care or strictly post-OF repair care were invited to participate. There were no restrictions on the number of family members from one household who could participate providing they met the study requirements. A total of 24 family members participated with two households having more than one family participant. HCPs and stakeholders were recruited based on what they knew about OF care post-repair or involvement in post-OF programs, however, others were selected by “word or mouth”. A total of 17 HCPs [nurses/nurse-midwives (n=5); physicians (n=3); community health nurses (n=2); nurse administrators/leaders (n=3); traditional birth attendants (n=2) and traditional healers (n=2)] and 17 stakeholders [women leaders (n=3); women’s right/advocacy groups (n=4); religious leaders (n=2); nongovernment organizations (n=4) and government ministries/departments (n=4)] were recruited.

From all those invited to participate a few women and family members declined due to work or family commitments. Additionally, some potential participants who had agreed to participate could not be reached due to logistical constrains (i.e. poor roads, flooding, tribal conflicts). I was the first point of contact for HCPs and community stakeholders. The first point of contact for women and their family members was either my research assistant, the charge nurse at the OF clinic or one of seven translators located in the community setting. All participants were given an incentive or honorarium for participating. After discussions with my Ghanaian partners, it was agreed that it was culturally appropriate to give ten Ghana Cedis to each participating woman and family member. HCPs and stakeholders also received a small token of appreciation. This was culturally respectful and not considered coercive. All participants were reimbursed for expenses incurred as a direct result of the research project (transportation, child care, etc.).

Data Collection Methods

Observation, formal and informal interviews, and gathering of relevant and available documents were utilized as data collection methods (Roper & Shapira, 2000). Multiple methods were used to enhance my understanding of the phenomenon in question, assisting me to probe below the surface and “adding rigor, breadth, complexity, richness and depth to the inquiry” (Flick, 2002, p.229). Habermas (1979) noted the way in which methods were used could significantly “shape the critical potential of a project” (p.25). While observation was employed as a method it was not key, as is the case with conventional ethnographies. Alternatively, interviews, the hallmark of critical ethnography, were the chief method utilized (Carspecken, 1996; Cook, 2005; Mantzoukas, 2010).

Observation. There are four participant observation levels that may be employed; participant, participant as observer, observer as participant and observer (Roper & Shapira, 2000). Appendix H is a visual representation of how these terms relate to one another along with the concepts of emic, etic, subjective and objective. Simply put, emic and etic refer to the researcher's viewpoint as an insider (emic) or outsider (etic) of a culture whose beliefs and behaviors are being studied. A researchers' position as an insider or an outsider determines their level of subjectivity or objectivity and their degree of participation as a full participant, full observer or somewhere in between. I strove to fluctuate between observer as participant and participant as observer since this was where I could retrieve the most valuable data (Roper & Shapira, 2000) and begin to establish an insider identity.

As the study advanced, the nature and depth of my observations evolved. Initially, I observed the behaviors of the community, how they interacted and communicated with one another in public and private spaces. I observed the environment in which people lived, worked and played. I deemed this helpful in understanding the cultural values of the participating communities. I additionally took the opportunity to attend traditional Ghanaian ceremonies (weddings, funerals, naming ceremonies known as outdoorings) and to shop in the marketplace. I volunteered my time and services at the TCH fistula clinic participating in clinic activities (i.e. basic nursing care and housekeeping duties). My observations became more focused as I engaged with the OF community, those who experienced an OF or OF repair, or who were directly or indirectly involved in OF care.

I kept two notebooks, one to record my observations or field notes and another to record my personal feelings, thoughts, and queries. Capturing my observations about how people interrelated or what they deemed to be important about a culture of post-OF care and reintegration helped me to think about “what was really happening” and to develop interview questions that were provocatively challenging to the community’s dominant stories, to address “what should be really happening”. DeWalt, DeWalt, and Wayland (1998) describes field notes as both data and analysis, as the notes provide an accurate account of what was observed and are the product of the observation process. “Observations are not data unless they are recorded into field notes” (Kawulich, 2005, Keeping and analyzing writing up the findings, para. 6), therefore, I aimed to record my notes immediately after the observed action. However, when this was not possible notes were jotted down until more substantial notes could be written or audio recorded. My observations were guided using Spradley’s (1980) framework and are highlighted in Appendix I. This framework assisted to systematically document my observations, identify underlying patterns and develop further questions.

Formal and informal interviews. I conducted both informal and formal interviews. The formal interviews consisted of a critical, dialogical, and reflective format to overcome the cultural, political and personal rhetoric (Hardcastle et al., 2006; Thomas, 1993). Although the aim of the inquiry took the approach of what *ought to be happening,* many participants needed to start the interview by describing *what was happening*. This was deemed to be important within the cultural context, and permitting this illustrated respect for the participants and facilitated my own understanding of their views. Interview questions were semi-structured and evolved over the course of the study, continually developing as I immersed myself in the context. There was great flexibility in the questions asked which was crucial in pursuing follow-up information. See

Appendix J for the interview guides for participants (i.e. women who experienced an OF repair, family members, HCPs and stakeholders). It was not my intent to represent the participants' world in a linear and conclusive fashion from the interview but to disclose the underlying factors which created their reality.

Due to the stigmatizing nature of OF and the sensitivity of the data I was seeking, the majority of interviews were conducted one on one. Three focus groups were conducted but were deemed largely ineffective since participants were unable to contribute openly, opting to follow the dominant group discourse. The majority of participants were interviewed only once due to their geographical location and accessibility. I decided before the start of the study to first interview participants who were most accessible and thus a return visit to fill potential knowledge gaps, to validate overlooked realities during the early stages of the research and to challenge foremost ideas was attainable. In total there were 14 follow-up interviews.

Interviews with women and family members lasted from 30 to 70 minutes. It was challenging to get these participants to commit to an interview of 60 minutes since it interfered with daily work practices. This challenge was compounded by the fact that I had to work through a translator, which greatly increased the time needed to complete the interviews. HCPs and stakeholder interviews lasted approximately 60 to 90 minutes with four of the 34 interviews requiring a translator. All but three interviews were audio recorded. In three instances follow-up interviews were granted, but recording was refused.

Field notes were written after each participant encounter, to capture the interview notes and observations as a result of formal or informal interviews. Any questions, comments or quirky notes were recorded in my journal. Reflexivity is an important aspect of critical ethnography because it prompts researchers to think carefully about the research, how it is being conducted, under what conditions and for what purpose (O'Reilly, 2009). Reflexivity was accomplished through the act of recording daily accounts in my field notes and personal journal.

Documents and artifacts. Critical ethnography is a holistic appraisal that requires examining past or historical documents in order to understand the current situation (Germain, 1986). Government documents and websites related to OF care and social programs (i.e. LEAP, NHIS), documents highlighting the history of UNFPA and other NGO involvement in OF care-Ghana, documents on historical events within the country (i.e. slave trade), and news clips about maternal health care issues or populations who received socially unjust care or treatment were examined to identify dominant discourses within society. Cultural artifacts (i.e. ruminates of the slave trade, handmade products produced by OF clients for sale) and photographs were also considered important sources of data and were recorded in my field notes for analysis.

Data Analysis

A considerable amount of data was collected during the seven months spent in the field, requiring time and rigorous attention. Data analysis occurred concurrently with data collection allowing concepts to arise and guide further inquiry (Hammersley and Atkinson, 2007), however, this was not, in reality, a linear process. Hammersley and Atkinson (2007) approach to ethnographic analysis was used along with Nvivo 10.0 software for data management. Data analysis occurred as follows:

I immersed myself in the data, reading and rereading the written accounts of what participants said and did, and my own responses while in the field. The process of assimilating and reflecting on the data and the research process was difficult but it was an important part of the critical ethnographic process (Thomas, 1993). There were no clear-cut techniques for doing this; it was simply shuttling between detailed material and the wider social milieu that was at the core of a dialectically generated critique.

A subset of the data which included interviews from the women who had experienced an OF repair, family members, HCPs and stakeholders were used to develop a coding framework. The data subset was read line by line and keywords were coded to capture key ideas. Next, the subset was read a second time and notes were added in the margins about my initial thoughts, generating concepts. These concepts were then organized into categories based on how the concepts related to one another. There were ten main categories with several subcategories. This was then placed in a tree diagram. See Appendix K for tree diagram.

Once the coding frame was developed, it was tested by myself and my supervisor who used randomly selected interviews from the larger data pool. Once the coding frame was deemed appropriate for critical analysis, it was applied to the remaining data. In analysis of the remaining data outliers surfaced which did not fit with the rest the data. This data were used to broaden the overreaching categories, and to offer knowledge that would lead to greater understanding and explanation of the findings. I had taken note of personal reflections, comments, and memos gathered during data collection. This was beneficial in helping me to make connections within the data, what Miles and Huberman, (1994) call “little conceptual epiphanies” (p.74). Although being immersed in the data allowed for data analysis, this process had to be carefully balanced with interpreting the data since the goal was to bring insights gained back to the center “to raise havoc with our settled way of thinking and conceptualization” (Marcus & Fischer, 1986, p.138). This required distancing myself from the “taken for grantedness” of what I saw to allow me to see more critically. The analysis of the data went beyond the coding of categories to examine, the disconnection between the participant’s perspective and my own, what Cook (2008) called “rich points”. When deconstructed, these rich points exposed underlying assumptions about power, domination, inequities, and cultural knowledge. This involved intense reflection on the deeper meaning of a culture of reintegration for women who experienced an OF repair. Critical reflection was, therefore, important during the analysis to ensure that I was aware of the process and consequences of any knowledge I produced. Bourdieu (1991) reminded me that I have the power to define and disseminate reality.

Trustworthiness

Qualitative researchers opt to use the term “*trustworthiness*” instead of “*rigor”* when describing the reliability and validity of their research (Raines, 2011). Regardless of the terminology used, the process implemented in achieving sound and steadfast results is important. Obtaining valuable results requires an active approach, building strategies into the methodological design to affirm that the methods and procedures employed are appropriate. Trustworthiness can be achieved using verification strategies which include: investigator responsiveness, methodological coherence, appropriate sample, collecting and analyzing data concurrently, and thinking theoretically (Morse, Barrett, Mayan, Olsen & Spiers, 2002). These strategies were implemented throughout the research process to ensure the quality of the findings.

Investigator responsiveness. I approached this study open-minded, flexible, and culturally aware. I immersed myself into the field for seven months, continuously documenting and reflecting on the research process, particularly during data collecting, analysis, and knowledge interpretation and production. Since this was an international project, cultural attention was given to methodological adaptations. My emic and etic perspectives were also explored through writing about and reflecting on preconceived ideas, prejudices, or bias about my research inquiry prior to the start of the project.

Methodological coherence. Participants were recruited into the study for what they knew pertaining to the inquiry. Although interviews were the main source of data collection, observations, and review of documents was extremely valuable in allowing me to identify inconsistencies and to question the status quo. Due to the large sample, there was an attempt to conduct focus groups, however this failed to provide rich data requiring follow-up. It was apparent that interviews had to be conducted one on one so to challenge the truth about taken for granted ways of thinking. For cultural reasons, many female participants had a family member present during the interview process. Although this was not how the interview process was initially planned, it was culturally appropriate and yielded rich results. Guidelines were implemented for family members who were present during the interview since many wanted to interject and had to be reminded that their views would only be heard independently of their family member. Family members who failed to comply were asked to sit outside the auditory range of the interview since their comments could potentially influence the exposition of underlying truths.

Appropriate sampling. A total of 99 participants were recruited through convenience, purposive and snowball sampling. All participants had knowledge from different perspectives concerning a culture of reintegration for women who experienced an OF repair. Participants included women who experienced an OF repair, their family members, HCPs, and stakeholders.

The comprehensive nature of the sample led to rich and holistic data. A total of 14 follow-up interviews were conducted with women, HCPs, and stakeholders, which allowed for the closure of knowledge gaps and member checking to support my understanding.

Collecting and analyzing data concurrently. Data was collected and analyzed concurrently. This allowed for the constant revision of data collection tools to yield rich data. A stepwise procedure was implemented where both my supervisor and I analyzed a subset of the data separately and then compared results. This procedure aided to ensure that connections and linkages within and between categories were reliably identified.

Thinking theoretically. Data was collected in seven languages. Translators were trained to interview participants. Questions were piloted and revised according to the cultural contexts. Likewise, data was backward and forward translated so ensure accuracy.

My field notes, reflections, memos and personal queries about what I had heard or observed assisted me to support the data. Writing my reflections each day and talking with key people (my supervisor, research assistant/cultural broker, and HCPs) advanced my thinking about the research process and the cultural context to identify where knowledge gaps existed.

Ethical Considerations

In Canada, human research is guided by the core principles of justice, autonomy, non-maleficence, and beneficence (Pollock, 2012). These principles are clearly outlined in the *Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans* (2010) and were upheld throughout the entire research process.

The ethical principles of justice, autonomy, non-maleficence, and beneficence can serve as a guide to moral conduct, assisting the researcher in taking a systematic approach. Their application is often considered prima facie since the principles are relative to one another (Keatings & Smith, 2000). These principles are familiar to Western researchers (nurses and anthropologists) because they are entrenched in our professional code of ethics, but they do not necessarily have the same value or meaning in Ghana. Ethical conundrums arose throughout the study based on the need to respect the principles of cultural relativism and cultural universalism, and the need to avoid judgments about other cultures. This resulted in the review of the United Nations (1948), Declaration of Universal Human Rights document. Whiteford and Trotter (2008) note that, in spite of this, many concepts involving cross-cultural research are not universal. I strove to employ practical wisdom moving beyond ethical guidelines.

Respect for justice and inclusion. The principle of justice is based on the notion of fairness. Decisions about which communities would participate in the research were made based on the number of participants in the area who met the inclusion criteria. Attempts to access participants in remote rural areas were sometimes impossible due to the road conditions or unsafe circumstances. It was recognized that there were social, economic and political benefits to participating in the study. Participants were compensated for their time (10 Ghana Cedis) and any expenses incurred as a result of the research. No participant who met the inclusion criteria and was accessible was refused from participating.

Respect for human dignity and vulnerable persons. Accessing a vulnerable population and asking to hear their personal insight came with great emotional and psychological risk. I worked with community leaders to ensure that psychological health services and resources were readily available to participants. I budgeted for a counsellor to address any arising psychological health issues as a result of this research. There were instances where women, being interviewed, asked to be counselled by a nurse-midwife, and these services were provided. Participants showing signs of psychological distress were always reminded that participation was voluntary.

I aimed to be culturally sensitive in my actions, way of dress and approach to asking questions. Since translators took part in data collection, attention was given to the gender and comfort level of participants in relating with them. Participants were given a choice in the gender of the translator.

Respect for free and informed consent. Ensuring the autonomy of participants through the use of voluntary informed consent was vital. Informed consent was an ongoing process that started with my first contact with participants and continued until the study ended. Participants were told that participation was voluntary and that they could choose to withdraw their consent at any time. An information sheet highlighting the purpose of the research, the risks and benefits of participating, the researcher's expectations of participants, the data collection methods employed (observation, and taped interviews), how long data would be kept and how it would be stored was provided to participants. The content of the information and consent forms was explained to participants in their local language by a translator. Translators were trained by myself to provide participant information that was consistent and accurate. Participants were provided with the opportunity to ask questions prior to consenting to participate. Only participants who could demonstrate an understanding about the study were allowed to participate. Participants received a copy of the information/consent(s) form which can be viewed in Appendix M and N. Two consent forms containing the same information but structured differently were used to meet my ethical obligations with the ethics review boards (ERB) in Canada and Ghana. An assent form was approved by ERBs but was not required since all participants were of legal consenting age. See Appendix L for a copy of the assent form. Although photography was not used to collect data, photographs of the environment were taken for contextual reasons and consent was obtained from the appropriate individuals. A copy of the consent form for permission to take photographs can be viewed in Appendix N.

Participants were given the option to sign the consent forms either by signature or thumbprint. All participants who signed using their thumbprint or who needed a translator were required to have their consent witnessed. Participants in follow-up interviews were reminded about the terms and conditions pertaining to consent. Additionally, participants were given the option to withdraw consent until June 30, 2014 for the first series of interviews and June 30, 2015 for the second series. Individuals with whom I had informal and friendly conversations were informed about my research inquiry since they were considered to be sources of data.

Respect for privacy and confidentiality. I maintained participant privacy and confidentiality offering to discreetly interview and interact with participants. Due to the cultural context, it appeared that many participants viewed privacy differently than my Western ideology and made my presence known to the community. Whiteford and Trotter (2008) note privacy is a cultural concept in Western society and "that privacy is about a participant and their sense of being in control of the access of others to themselves" (p.53). Although participants were offered and informed about their right to privacy, many asked a family member to be present during the interview process.

All individuals who had access to research data, for example, transcriptionists and translators, were required to sign an oath of confidentiality as illustrated in Appendix O. Confidentiality was also by having pseudonyms assigned to interview transcripts and no identifiers attached to participant observations. Consent forms were linked to pseudonyms and were kept in separate locations from written and audio taped interviews and transcripts. While in Ghana, all data was kept in a locked container. USB keys and laptop computers were encrypted and kept locked. In transit from Ghana to Canada research data (i.e. field notes, consent forms etc.) was always in my possession.

The Health Research Data Repository (HRDR) at the University of Alberta, Canada provided a secure and confidential virtual research environment (VRE) for this research project. The mission of the HRDR is to stimulate all research while building a collaborative culture of respect relating to data management and confidentiality (James Doiron, Manager of HRDR, personal communication, November 10, 2015). The HRDR's secure VRE provided a secure method to transfer files (i.e., audio interviews) from the field in Ghana to a secure project folder at the University of Alberta with access rights assigned to my supervisor, Dr. Solina Richter, and I. Since returning to Canada the data remains stored within the HRDR.

Balancing non-maleficence and beneficence. Every effort was taken to minimize harm and to maximize benefit for participants. Participants were informed about the potential benefits of this study, but there were no guarantees that they, their family member or organizations would benefit directly. I strove to carry out my research *with the people* instead of *on the people* so to counteract any power imbalance. Power imbalances can be a potential source of harm. For example, Western researchers who arrive in low resource countries might be placed in elitist positions by potential participants because of their foreign-ness. On the other hand, researchers may place themselves in positions of power because of their expert knowledge. I worked with gate openers, community members and participants to overcome my foreign-ness, and through journaling, I was able to maintain an awareness of power imbalances. Power imbalances were not necessarily in my favor for many times the power rested with external sources (family members, community or government organizations), which had to be managed so not to cause real or potential harm to participants. Participants were informed that the findings of this study would be published and presented in professional journals and conferences. Every precaution has been taken to safeguard against unwanted exposure and potential harm to participants.

Overview of the Manuscripts

The following is a synopsis of five discrete manuscripts prepared for submission to peer-reviewed journals. Manuscripts are presented in chapters two through six and provide insight and understanding into a cultural of reintegration for women who experience an OF repair in northern Ghana. One of the six manuscripts has been accepted for publication pending revisions.

Manuscript 1: Dilemmas in International Research and the Value of Practical Wisdom

When conducting research in an international setting, in a country different than that of the researcher, unpredictable circumstances can arise. A study conducted by a novice North American researcher with a vulnerable population in northern Ghana highlights these happenings with an emphasis placed on the ethical challenges encountered. An illustration from the research is used to highlight an ethical dilemma while in the field, and how utilizing a moral decision-making framework can assist in making choices about a participant's right to autonomy, privacy, and confidentiality during the research process. Moral frameworks, however, can never be enough to solve a dilemma since guidelines describe only what to aim for and not how to interpret or use them. Researchers must, therefore, strive to move beyond these frameworks to employ practical wisdom or *phronesis* so to combine the right thing to do with the skill required to figure out what the right choice is. The skill of practical wisdom must be acquired because without it international researchers indecisively fumble around with good intentions, often leaving a situation in worse shape than they found it.

Manuscript 2: Exploring Reintegration Post-Obstetrical Fistula Repair in Northern Ghana: An Analysis using Nussbaum's Capabilities Approach

The high prevalence of obstetric fistula (OF) in sub-Saharan Africa is an outcome of maternal/reproductive inequities. OF care includes awareness, treatment (surgery) and reintegration where reintegration is known to be a neglected component. Using Nussbaum's capability approach (CA) this paper explores family and community reintegration of women who have experienced an OF repair in northern Ghana. Ninety-nine participants were recruited from 24 rural communities in northern Ghana using convenience, purposive and snowball sampling. Semi-structured interviews were the main method employed in data collection followed by observation and a review of documents and artifacts. Hammersley and Atkinson's (2007) approach to ethnographic analysis was used to analyze the data. Participants identify OF teaching, skills training, community follow-up, awareness campaigns, family support and existing health policies as opportunities or resources to assist women in successfully returning home post-OF repair. However, using Nussbaum's CA brings into focus the economic, societal, systemic and cultural constraints that come to bear upon the outcomes or "functionings" of women post-OF repair. Highlighting the equities/inequities that exist when discussing reintegration post-OF repair is vital in exploring the ability of participants to convert their resources into outcomes that are freely chosen and valued. This study can inform public policy about reintegration, maternal and reproductive health of women affected by OF worldwide.

Manuscript 3: Exploring the Needs and Challenges of Women Reintegrating Home After Obstetrical Fistula: A Critical Ethnography

Obstetric fistula (OF) is a maternal morbidity affecting women in Ghana and although the precise prevalence is unknown it is estimated that between 500 and 1000 new cases are diagnosed annually. OF affects a woman's physical, psychological, and sexual health as well as their social and economic status. The approach to OF care is threefold: awareness, treatment, and community reintegration. Reintegration is concerned with assisting women to reconnect with the life they lived prior to having OF. A critical ethnographic design was used to explore the needs and the challenges affecting women in northern Ghana as they resume their day-to-day lives, culturally, socially and economically, post-OF. Ninety-nine (n=99) participants were recruited using purposive, convenience and snowball sampling. The sample consisted of women (n=41) who had experienced an OF repair and their family members (n=24). HCPs (n=17) and stakeholders (n=17) who worked with or had knowledge about OF care or reintegration programs at a community of national level were also included. The main recruitment site was the Tamale Fistula Center along with 24 rural communities in northern Ghana. Observation, semi-structured interviews, and a review of documents were employed in data collection. Data was coded and analysed according to Hammersley and Atkinson's (2007) approach to ethnographic analysis. Women identified their economic, social, cultural, and political needs and challenges returning home post-OF repair. Many needs and challenges were historically and culturally rooted. A woman's inability to work while having the OF and the cost of seeking OF treatment exaggerated her need for capital post-OF repair. Skills training programs offered some assistance but was often not suited to a woman's physical capability or geographic local. A woman's need to be accepted back into her community post-OF is significant to her wellbeing. Many women felt they had to "prove" themselves worthy and hid any signs of urinary incontinence post-OF for fear of being rejected. Ghanaian cultural values, beliefs and practices impact how the community views OF not as a medical condition but as an inherent curse. Many women who have experienced OF, along with women leaders, have initiated OF awareness campaigns in their communities with the aim of overcoming the challenges and improving the reintegration experiences of others who have had OF-repair. Developing awareness about the needs and challenges of women post-OF is an important step forward in creating social and political change in OF care/reintegration.

Manuscript 4: Reintegration of Women Post-Obstetrical Fistula Repair: Perspective of Family Caregivers in Northern Ghana

Family is the traditional social safety network in northern Ghana, where family includes extended kin. However, due to a variety of social shifts, a change in family structure towards nuclear households is evident. This has implications for the care of women post-obstetric fistula (OF) repair and their family members who assist them to reintegrate into their lives before developing OF. This study draws attention to the experiences of family caregivers of northern Ghanaian women post-OF repair and highlights the coping strategies adopted to offset potential stressors, as well as available supports as perceived by family caregivers. Findings suggest that family caregivers are pleased to have their family member return home post-repair, but there are many unanticipated physical, emotional and economic needs. Family caregivers identify the resources as well as formal and informal coping strategies assisting them to provide care post-OF repair. Improved understanding of the roles and responsibilities of family caregivers in northern Ghana can inform decision-makers about the significant need for adequate formal care giving support. Recommendations for improving family support and resources are discussed.

Manuscript 5: Reintegration Post-Obstetric Fistula in Northern Ghana: Recommendations and Implications for Policy Development and Nursing Practice

A critical ethnographic study exploring a culture of reintegration with women who have experienced OF repair in northern Ghana, West Africa pointed to public health policy recommendations. These recommendations are based on three prior manuscripts prepared for publication (Jarvis et al., 2016a; Jarvis et al., 2016b; Jarvis et al., 2016c) and provide meaningful information regarding how to improve the post-OF reintegration process for affected women, their families, HCPs and community stakeholders. It is clear that providing support for reintegration post-OF repair is complex and entails a holistic multidisciplinary approach and a strong commitment from all government levels. OF is a preventable maternal health condition, an issue of social justice, and a global health concern. It is the responsibility of nurses worldwide to speak out clearly with one voice against maternal and reproductive injustices and to advocate for improvement in OF care. Nurses are well situated to influence change and to ensure healthy public policy on this issue.

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Chapter 2: Dilemmas in International Research and the Value of Practical Wisdom[4]

When difficult choices and dilemmas arise in daily life we resolve them based on the contexts in which they occur, and guided by our personal beliefs and morals acquired through family, education, religion or in social settings (Resnik, 2015). In the same way, professional ethical behaviour is dictated by the guidelines developed by professional organizations. Likewise, conducting research is guided by ethical standards described as "what a researcher ought or ought not to do or the set of ethical principles that should be taken into account when doing research" (Hammersley & Traianou, 2012, p.17). Ethical principles and guidelines have been established in research protocols to promote the goal of the research while also protecting participants from wrong doing or harm. However, when conducting research, ethical dilemmas ranging from unanticipated consequences of the research design to conflicts between stakeholders to clashes in ethical principles inevitably arise. This can be particularly noticeable when researchers conduct research outside of their country or culture. As a novice researcher from Canada conducting community nursing research with women who had experienced obstetrical fistula (OF) in remote rural communities in northern Ghana, I experienced firsthand the difficulties of melding values and cultural views to maintain ethical research practice. In this diverse cultural setting, my understanding and application of ethical principles and guidelines were challenged, and I was forced to establish new ways of thinking about research ethics.

In this paper, I explore how my experience of conducting research in rural Ghana changed the way that I think about the ethics of cross-cultural research. Using an example from my research, I highlight how cultural differences in values and understandings created an ethical dilemma, and describe how I was guided to reflect on the ethical questions required to resolve

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[4] Jarvis, K. (2016). Dilemmas in international research and the value of practical wisdom. *Developing World Bioethics.* This chapter was accepted May, 5 2016.

the dilemma. I conclude that international research requires researchers to move beyond their familiar moral framework to employ practical wisdom, the Aristotelian *phronesis*.

Phronesis

Aristotle describes phronesis as the right way to do the right thing in a particular situation (Kinsella & Pitman, 2012a). It is a virtue crossing both cognitive and affective domains, and providing direction for other virtues (Sellman, 2012). Aristotle distinguishes phronesis from *episteme* and *techne,* and emphasises that *phronesis* is the most significant since it goes beyond analytical and instrumental judgement (Kinsella & Pitman, 2012b). *Episteme* gives us scientific knowledge of the unchanging world; *techne* gives us technical knowledge or knowledge of a craft; but *phronesis* gives us practical wisdom or knowledge of a changing world (Surprenant, 2012). *Phronesis* is an activity whereby value and instrumental rationality intersect to balance each other out, to give wisdom relevant to practical matters (Flyvbjerg, 2004). This is important because we live in a complex and ever changing world where the quandaries we face are embedded in our everyday practice. *Phronesis* must be considered necessary for any researcher but especially for those conducting cross-cultural global research. It has been suggested that *phronesis* is often disregarded in research, as scientific and technological development frequently takes place without ethical checks and balance (Flyvbjerg, 2001). Habermas suggests that many researchers lose their way when they ignore *phronesis,* and opt instead for theoretical or technical knowledge. These researchers endeavour to discover universal truths in a world filled with possibilities (Dunne, 1997).

Phronesis is not a fixed or circumscribed entity (van Niekerk & Nortjé, 2013). Aristotle believed that making ethical choices is rarely straightforward since the context in which we find ourselves is constantly changing. This is why Aristotle believed that ethics could not be a science and that ethical decision-making could never originate from rules and principles. The application of *phronesis* calls for deliberation and reflection, the rational interchange between the requirements of societal norms acquired through education, religion and conscience, and the requirements of the situation bearing in mind the consequences. More importantly, *phronesis* is knowing how to act in a practical situation where norms and rules must apply. We are unable to predict the future but we can use our experiences to deliberate about and reflect on what actions might be most beneficial (Surprenant, 2012). It is certain, however, that to think the right thing is not enough. Action is also required-- "*phronesis* is wisdom of action, for action, in action" (van Niekerk & Nortjé, 2013, p.30).

Background to the Research

OF is recognized as a significant community health problem in poorly resourced countries around the world. OF is defined as a hole between the vagina and the *bladder* and/or the rectum that occurs as a result of prolonged, obstructed labour when emergency maternal health care is inadequate (Arrowsmith, Hamlin, & Wall, 1996). When left untreated, OF results in uncontrollable seeping of urine and feces from the vagina. Women who develop an OF can experience chronic medical problems such as perineum sores and foot drop, as well as social impairment and psychological trauma related to economic disparity, grief resulting from loss of a child, abandonment by family and friends (Mwini- Nyaledzigbob, Agana, & Pilkington, 2013), ostracism from communities, and the resultant feelings of powerlessness (Gebresilase, 2014). More than two million women live with untreated OF in Asia and sub-Saharan Africa (Johannes, 2010). In Ghana, the incidence of OF is estimated at 500 to 1000 per year but is probably much higher because of the hidden nature of the condition and the inconsistent way that vital statistics are reported to government departments and international agencies (Danso, Opare-Addo, &

Turpin, 2007). Northern Ghana is described as having the highest rate of OF in the country (Ghana News Agency, 2015).

I became interested in the condition after spending time at an OF clinic in East Africa. Here women and young girls received holistic care consisting of surgery, counselling, physiotherapy, spiritual healing, and skills training. While it was gratifying to observe them thriving in this environment, I began to ask questions about what happens when these women return home to their communities given that, for many, the condition is associated with shame and humiliation (Roush, 2009). Would they be accepted and supported in their communities once the OF was surgically repaired? I discovered that, while social reintegration is seen as crucial to successful treatment, little has been written about how women reintegrate into their communities post-surgical repair (Capes, Ascher-Walsh, Abdoulaye, & Brodman, 2011; Muleta, Fantahun, Tafesse, Hamlin, & Kennedy, 2007; Women's Dignity Project & EngenderHealth, 2006). I began to conceptualize my doctoral work as an exploration of a culture of reintegration for women who had experienced an OF repair in northern Ghana.

Methodology

The research employed a critical ethnographic design applying a social justice lens to describe, analyze, and expose to scrutiny a culture of reintegration post-OF repair with the intent of raising social consciousness about OF care, specifically reintegration and the need for action. The study took place in northern Ghana which is composed of three regions: Upper East, Upper West, and Northern. The people who live there are religiously, economically, linguistically, culturally and politically diverse, and differ in many respects from those in central and southern Ghana (Government of Ghana, 2016). Nationally, the rate of poverty is recorded to be the highest in the north (Ghana Statistical Service, 2015).

Participants were recruited through a local OF clinic using convenient, purposive and snowball sampling. Observation, field notes, personal reflections and journaling, semi-structured interviews, and the assessment of relevant government and country specific documents were utilized to collect data. I visited more than 20 rural communities and interviewed a total of 99 participants. Participants included women who had an OF repair, their family members, health care-providers and key stakeholders (community members, government officials). With the aid of local translators, I conducted most interviews in the local language of the participants. The data were analyzed according to Hammersley and Atkinson's (2007) approach to ethnographic analysis. Ethics approval was received from the University of Alberta, Canada and the Navrongo Health Research Center, Ghana. Participation was voluntary, and participants were informed of the known risks and benefits to participation and were asked to give consent.

The data used to inform this article were limited to my personal reflections and journal entries allowing for an analysis of the ethical challenges encountered while in the field exploring a culture of reintegration post-OF repair.

Ethical Challenges in the Field

Ethnographers immerse themselves in the ways of their participants by studying real life situations as they occur in the natural setting (Roper & Shapira, 2000). Researchers who conduct cross-cultural research need to adhere to the guidelines and values of their own culture, the international community, and the culture in which they are studying. There is a need to respect the person as well as the cross-cultural variations about how ethical concepts are understood (Chattopadhyay & De Vries, 2013; Whiteford & Trotter, 2008).

Cultural diversity is an undeniable reality since we share the planet with billions of people from many countries who live in the "context of a determined personal biography or a particular form of social life" (Semplici, 2013, p.657). For that reason, respect for diversity cannot exist without recognizing the diversity in moral worldviews. Despite this, moral frameworks built upon "universally recognized principles of conduct which have a basis in elementary truths concerning human beings…" (Hart, 2012, p.193) and the world in which they live are often used and considered necessary to prevent unjust practices such as discrimination and oppression (ten Have & Gordijn, 2013). However, it is questionable whether Western socio-cultural-moral constructs fit all the world's cultures since beliefs, ethical values and cultural norms substantially differ (Chattopadhyay & De Vries, 2008; Chattopadhyay & De Vries, 2013). This may be most noticeable when considering the requirements for informed consent; disclosure, privacy, confidentiality and autonomy.

Matters of privacy, confidentiality and autonomy in cross-cultural research are complex and beg the question of whether ethical principles are universal across cultural groups or whether they are relative to a particular setting or culture (Mill & Ogilvie, 2002). It is believed by some that applying cultural relativism to a particular practice will benefit only the over-riding group in society; however, accepting an unexamined stance of cultural universalism is risky since ethical values are informed by culture (Baker, 1997; Kleinman, 1995; Lipson, 1994).

Informed consent is important to the integrity of any study involving human subjects since it acknowledges 'choice', but it is especially important when working with populations who are illiterate and do not speak the researcher's language. Comprehension is an essential element to informed consent, but the degree to which it is achieved is often unknown (Hyder & Wali, 2006). In research environments where the literacy rate is low, lengthy and involved consent forms are not feasible (Priestley, Campbell, Valentine, Denison, & Buller, 1992). A study in East Africa demonstrated how participants in a low income setting did not understand what was written within the consent, but believed that they had to participate or be refused care (Molyneux, Peshu, & Marsh, 2004). Potential participants often believe that volunteering to partake in research guarantees them or their family member better care. Additionally, it has been shown in West Africa that few participants believe they can withdraw from a research study (Ekouevi et al., 2004; Ellis et al., 2010; Krosin, Klitzma, Levin, Cheng, & Ranney, 2006; Manafa, Lindegger, & Ijsselmuiden, 2007; Oduro et al., 2008; Pace et al., 2005) since withdrawing would demonstrate disrespect to the researcher conducting the investigation (Krosin et al., 2006). One approach to overcoming the many issues concerning informed consent is to employ a translator/interpreter. It is suggested, however, that the terminological or ethical concepts used to describe a study may not always correctly translate the meaning (Oduro et al., 2008). While full disclosure is an accepted component of informed consent, it has been suggested that in Ghana the relationship of the researcher with the community may be more important than the information that is disclosed through the consent process (Adongo et al., 1997; Tindana, Kass, & Akweongo, 2006). It has been revealed that trust and social norms are significant, and must be balanced with international ethical guidelines and the local community's expectations.

To help researchers avoid ethical dilemmas, the 1948 United Nations *Universal Declaration of Human Right* (UDHR) document provides guidelines for cross-cultural research promoting accommodation of these rights while at the same time being sensitive to cross-cultural circumstances on a local level (Whiteford & Trotter, 2008). These guidelines were a beginning point for me to analyze my approach to ethical concerns within my research and in relationship to Ghanaian culture. Two cultural observations proved to be particularly significant: the collectivist orientation of Ghanaian society and the position of women within the culture.

As I immersed myself in Ghanaian culture, I observed that Ghanaians place great emphasis on communal values. This is reflected in their practices and heard in their metaphors, such as “one finger cannot lift up a thing” (Gyekye, 2003, p.37). My observations in the field reinforced my conclusion that the welfare of each Ghanaian is dependent on the welfare of all Ghanaians. Ethnographic research often requires that the researcher get consent of the community prior to having the opportunity to acquire consent from an individual participant (Whiteford & Trotter, 2008). It became evident that these communal considerations could jeopardize the individual rights of potential participants but it was also evident that not accepting these considerations was an attack on Ghanaian societal values.

Because of the traditional role of women, and the manner in which land and property are inherited, northern Ghana has been regarded as a patriarchal society (Adoo-Adeku, 2014). In this setting, issues of autonomy, paternalism, privacy and confidentiality weighed heavily on my mind as I considered how to minimize harm to the vulnerable women participants in my study (Kutsoati & Morck, 2012). I was challenged to reconcile opposing cultural understandings of these issues in order to meet the ethical obligations of my research. For example, if one culture views voluntary participation as being submissive to authority and another views voluntary participation as completely autonomous, how is a researcher obliged to fulfill the ethical standards of both cultures (Whiteford & Trotter, 2008)?

Ethical Dilemma: An Illustration

My ethical dilemma began to unfold upon arrival in a rural northern Ghanaian community where I had to first greet the chief. Culturally, the chief is the head of the community and holds much power and respect among its people. Greeting the chief required bringing a gift, an offering as a sign of respect. In western culture, ‘the gift’ could be seen as coercive since the chief is the main gatekeeper to the community and to the participants. The discomfort that I began to feel around this ritual was the first hint of opposing values and understandings to yet be revealed in this cross-cultural research project.

Many of the chiefs I encountered requested that I state my intention. Why had I traveled so far to come to their village? What was my business and who had I come to see? To say that I was a Canadian nurse and a researcher who had come to talk with some local people about OF was insufficient to persuade the gatekeepers whose duty it was to protect the community. To gain access to female participants, I had to somehow discretely disclose my intent to not only the chief but to multiple layers of gatekeepers including the household head and the husband, father and/or son of the participant. I was reluctant to do this because of the negative perceptions associated with OF within the community (Mwini-Nyaledzigbor, 2013).

I acknowledge that my presence as a white foreigner in a rural community in northern Ghana drew attention and suspicion. Often gatekeepers would generate excitement around my visit, creating a situation where many community members knew of my purpose. This led to a potential breach of the participants' privacy and possibly influenced their willingness to participate in my study. Male family members of female participants frequently insisted on being present during the interview process. It became clear to me that privacy and confidentiality are arguably western concepts that have a different cultural meaning within northern Ghana. Participants unquestioningly waived these rights by allowing family members to be near. It is difficult to assess how receptive to the study participants would have been in the absence of their family members given the communal and patriarchal nature of northern Ghanaian society.

As a researcher conducting a critical ethnography using a social justice lens, I sought to expose and challenge conditions or circumstances where power and control impinged upon individual freedoms (Calhoun, 1995). I aimed to contribute to emancipatory knowledge and discourses of social justice where participants could exercise a choice to speak freely without constraint. Pardoning actions that were in opposition to this way of thinking, a Western way of thinking, created for me an ethical dilemma. I held that the multiple layers of gate keeping increased a participant's risk to exposure in a small rural community and restricted their ability to choose whether or not to participate. I believed that permitting family members to be present during the interview violated the participant's right to privacy and confidentiality. This forced me to challenge my assumptions and biases about how to conduct ethical research in an international setting when my concept of 'ethical research' did not flow with how local participants conceptualize individuality, privacy, confidentiality and autonomy. If I were to resolve my ethical dilemma while honouring local cultural practices and beliefs, I would have to be open-minded, self-reflective, and self-critical upon the origin of my ethical tensions. MacDonald's 2010 'Guide to Moral Decision-Making' provided a systematic way to begin to think about this dilemma. The guide suggests consideration of eight steps as highlighted below.

Recognizing the Moral Dimension

Although the research process and the ethical standards were the same as what I experienced in Canada, what differed in the patriarchal society in northern Ghana was the cultural context and how these ethical principles and standards were understood or interpreted (Atuoye & Odame, 2013; Odame, 2013). This difference in ethical understandings was the source of tension for me as an outsider to Ghanaian cultures.

The participants I wanted to recruit were vulnerable women who had experienced a potentially stigmatizing condition. As the research unfolded, it became apparent that negotiating access was not merely about recruiting participants but about a complex social process that at times was in direct conflict with my professional value of protecting a participant's right to autonomy, privacy, and confidentiality.

Additionally, a participant's failure to be interviewed alone without a family member present or nearby lead me to question the amount of control or power a participant had over the research process. Given the situation, I had to consider my choices on how best to proceed.

Who are the Interested Parties? What are Their Relationships?

The more visible parties involved were those closely linked to the situation: participants, their families, chiefs of their communities, and me. I was considered an outsider while the others were insiders to the Ghanaian community and cultures. Although our perspectives differed, I had a responsibility to my participants to interpret and recognize how my perspective impacted the findings and the cultural relevance to knowledge development (Naaeke, Kurylo, Grabowski, Linton, & Radford , 2011). Excluding this, I was responsible for ensuring that I upheld the participant agreement, contained within the informed consent document, outlining a participant's ethical right to privacy, confidentiality, and autonomy. Community members, particularly the gate keepers, were accountable to each other and to the community to protect their members from outside harm.

However, when examining the parties involved and their relationships, it is necessary to think widely so to get a comprehensive view on the matter. The research ethics boards (REB) in Canada and Ghana were accountable to the public to ensure that the research was conducted in an ethical manner. As the researcher, I was responsible to the REB. The government of Ghana, particularly the Ministry of Health and the Ministry of Gender, Children and Social Protection, and United Nations Population Fund (UNFPA) Ghana, an nongovernmental organization involved in OF care, are responsible to the Ghanaian people to improve health outcomes. They are acutely aware of the problem of OF in their country and have collaborated on the ‘Campaign to End Fistula’. The findings of this study had the probability to inform stakeholders about OF care and to lobby for improved maternal and reproductive health care policies in the country. It was important that the research was rigorous and respectfully reflected the views of the participants.

What Values are Involved?

Human research is guided by the core principles of respect, justice, autonomy, non-malfeasance, and beneficence. These principles are clearly outlined in the World Medical Association (2013) *Declaration of Helsinki*, the *Belmont Report* (1979), Council for International Organization of Medical Science (CIOMS) (2002) *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, Tri-Council Policy Statement (TCPS) (2010) *Ethical Conduct for Research Involving Humans* and the United Nations (1948) *UDHR*. All research involving human subjects must be rigorously evaluated according to the core ethical principles in order to identify ethical issues and safeguard against potential harm. These principles are also articulated in the International Council of Nurses (ICN) (2012) *Code of Ethics for Nurses,* the ethical guidelines which are utilised by the Ghana Registered Nurses Association (GRNA).

Privacy and confidentiality are important principles in research for they emphasize the virtues of respect for the participants and integrity for the research process. The aim of the principles is to protect participants. In disclosing my intent to various gatekeepers in the community, I unintentionally placed participants at risk for prejudice, embarrassment, or loss of reputation. Furthermore, permitting family members to be present during the interview impeded the participants’ right to privacy and confidentiality and in theory constrained their ability to speak openly. I began to appreciate how the issues of cultural relativism and cultural universalism must be weighted when considering human rights. I became conscious of the dilemma posed by personal values and ethical codes endorsed by national and international guidelines and professional disciplinary associations when conducting international research.

Weigh the Benefits and the Burdens

A benefit of the research was the likelihood to inform policy development regarding maternal and reproductive health and equip stakeholders with more scientific knowledge needed to initiate changes in OF care. Accessing this knowledge came with some benefits and risks to participants as is the case with most types of inquiry. While the knowledge generated from this study could assist women with OF to reintegrate into their communities, there was no guarantee that the participants themselves would benefit directly. My options were additionally influenced by my financial, academic and emotional investment in this project. I had too much invested to discontinue the study without finding a solution that was morally right.

Respectful collaboration with all community partners was one beneficial aspect of my work. I recognized collaboration as an opportunity to foster relationships, and to better immerse myself in the Ghanaian cultures. Respect involves listening and understanding. I listened to the gatekeepers and family members and respected their duty to protect participants since I also had a duty to protect them and to uphold the ethical integrity of the research.

Autonomy, privacy, and confidentiality are moral rights that should be afforded any participant who takes part in a research study. If these rights are not upheld, the ethical conduct of the researcher and the trustworthiness of the study are called into question. However, I began to realize that the participants’ values and needs with respect to these ethical principles were also important to consider.

It is argued that human rights are a product of culture, and how they are protected should be determined by individual societies (Brink, 1989). In addressing matters pertaining to autonomy, privacy, and confidentiality many Ghanaian nursing professionals admit there are tensions between the ICN's Code of Ethics and local cultural beliefs (Donkor & Andrew, 2011). For example, an individual’s consent to care is seldom an individualistic right to self-determination; instead it is collective and involves the family and the community.

I held there was no intent to do harm either on my part or that of the gatekeepers, but finding a solution would require more reflective and introspective thought. The concepts of autonomy, privacy and confidentiality differ from culture to culture and may require in-depth considerations and creative adaptation in order for cross-cultural researchers to meet their ethical obligations (Whiteford & Trotter, 2008).

Looking for Analogous Cases

I began to reflect on the literature and on my previous international experiences and work. I knew what was cited in the academic literature but what did it mean to me as a researcher conducting international work in Ghana, and what did it mean for my participants?

My prior international experience taught me that cultures are dynamic and distinct. It taught me about cultural humility that goes beyond conveying knowledge about cultural practices to reflecting and being self-critical of one’s values, beliefs, and attitudes concerning individuals who are different than oneself (Tervalon & Murray-Garcia, 1998). In thinking about my culture, which is known to be individualistic, privileged, consciously or subconsciously biased, and partaking in stereotyping activities, it was easy to see why a Ghanaian community would be mistrusting of my presence. The history of colonization and economic exploitation of Ghana by western countries has undoubtedly deeply influenced how some Ghanaians perceive visitors from the west. It was also noted that in earlier times anthropologists, who historically conduct ethnographies, were thought to be spies employed by their local governments to gain private and personal knowledge about communities (Owens, 2003; Whiteford & Trotter, 2008). This stereotype still exists today.

If I were to build a trusting relationship with the community, it was important that I be seen as more than an 'exploitive interloper' (Hammersley & Atkinson, 1995). It was conceivable to me that issues concerning autonomy, privacy and confidentiality were about the communities' and family members' mistrust of me and their need to maintain control over the research process to ensure their welfare. This is congruent with the high emphasis many Ghanaian cultures place on communal values (Gyekye, 2003).

Discuss with Relevant Others

I discussed and verified my conflicting thoughts and experiences with my Ghanaian partners and supervisory committee, and I began to journal, a method often used by ethnographers to expose unreflective elements for the purpose of self-vindication. This allowed me to grasp the deeper, more clandestine aspects of this situation. In doing so, it became apparent that I had to be humble enough to let go of the false sense of security that came from following a rigid western research protocol. I also had to reflect on the processes of ethics approval in both my home and host country. I concluded that the 'western way' of conducting research did not fit comfortably into the Ghanaian cultural context. I became convinced that the approach to ethical conduct needed to be malleable and respectful of a participant's rights. There was also a need for better understanding of what 'rights' are and how they are conveyed cross-culturally.

It has been highlighted how North American theories "presumingly universal, imposes itself as hegemonic in the international nursing community" (p.20) despite their unsuitability to the context (Santos – Salas, 2005). I have witnessed the futility of introducing North American theories outside a western context, leaving out important local socio-cultural considerations. One might suggest that the west has dominated because low middle income countries have been slower to produce ethical and theoretical knowledge. Regardless of whether or not this is true, there is the need to embrace cultural differences when research is conducted in an international setting so to develop approaches that are more culturally and ethically applicable.

Does this Decision Accord with Legal and Organizational Rules?

There were no legal implications to consider in this dilemma. There were, however, good practice guidelines about how research is conducted with vulnerable and indigenous populations as outlined in the *TCPS* (2010) and the *UDHR* (1948) documents. Accessing online ethical guidelines and documents in Ghana was more challenging, but administrative personnel at the Navrongo Health Research Center were available to direct my ethical queries. These guidelines reinforced the need to collaborate and to respect the culture, traditions and knowledge of the community.

The guidelines and rules helped me to balance conflicting principles. The right balance in decision-making is not an arithmetic average but what Aristotle called 'the mean,' the right balance for a particular situation, known as practical wisdom (Schwartz & Sharpe, 2010). As a novice researcher, I became aware that organizational guidelines exist and must exist, but they are insufficient without practical wisdom. I also became convinced that ethical situations cannot be reduced to a simple prescribed response found in rules and guidelines.

Am I Comfortable With my Decision?

Upon reflection of my choices, it was logical for me to choose to comply with the gate keeping process and with how the research was conducted within the society under study. However, this was not the choice I thought I would make at the start of this project. Seldom are situations straightforward. Aristotle recalls a story about how he observed carpenters and shoemakers going about their trades. He noticed that these tradesmen were not regulated by rules (i.e. a blueprint for making a pair of shoes) because the leather they used was too irregular, causing every pair of shoes to be made slightly different than the last. Carpenters during that time period, when constructing circular columns, were unable to use the tools they possessed for the task at hand until they thought about bending the ruler to better suit their purposes (Schwartz & Sharpe, 2010).

Likewise, my tools for conducting ethical research did not fit a Ghanaian context, and I had to learn how to 'bend and mold' my tools to match the situation, all the while knowing no one solution would fit all situations. Being open minded to my choices and to the possibility that I did not know as much as I thought I did, or that my thoughts might be inaccurate helped me to develop practical wisdom (Sellman, 2009). Self-reflection and self-criticism also helped in interpreting and balancing the conflicting demands of conducting international research. It created the opportunity to act appropriately, with non-malfeasance intentions to do no harm and respect participants in their cultural context. Practical wisdom was about examining many ideas and views and then doing something because it is the right thing to do. At the end being practically wise allowed me to build trust, negotiate disagreements, solve problems, and obtain rich data from participants.

Conclusion

It is not easy for novice researchers to know what to do when an ethical dilemma occurs. Although frameworks like MacDonald's (2010) guide to 'Moral Decision-Making' can assist with making choices, it can never be enough because guidelines tell us only what to aim for, never how to interpret or use them. Alternatively, rules may keep us from understanding what we are really doing, or what we need to do to nurture practical wisdom (Schwartz & Sharpe, 2010). Providing testimony about my experiences and how I laboured through the difficulties can be a valuable catalyst to initiate a discussion on nurturing opportunities and anticipating challenges when conducting international research. More importantly, it may initiate a dialogue about how to overcome ethical challenges using practical wisdom. The skills of practical wisdom must be acquired because without them international researchers may indecisively fumble around with good intentions but leave a situation in worse shape than they found it (Schwartz & Sharpe, 2010). Perhaps it is time to consider and begin shaping a new global ethics.

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Chapter 3: Exploring Reintegration Post – Obstetrical Fistula Repair in Northern Ghana: An Analysis using Nussbaum's Capabilities Approach[5]

The United Nations Convention on the Elimination of All Forms of Discrimination against Women, Article 14(2)(b), requires measures to ensure that women "have access to adequate health care facilities, including information, counselling, and services in family planning" (United Nations Women, 2009, para. 28). This has significant implications for maternal, reproductive and women's health, particularly in low and low-middle income countries (LMIC) where women continue to experience health inequities because of inadequate access to health services and a lack of control of their own maternal/reproductive health (Paruzzolo, Mehra, Kes, & Asbaugh, 2010; World Health Organization [WHO], 2009).

Health inequalities emerge when there is inadequate attention by health care administrators and providers to the economic and social determinants of health (Flaskerud & DeLilly, 2012; WHO, 2005) at the global, national and local level. Health disparities have been traditionally measured and analyzed in terms of income, material resources, and civil liberties; however, deeper insights for understanding the phenomenon can be gained by applying a multi-dimensional framework such as Nussbaum's (2000) capability approach (CA).

The CA is an analytical and normative framework used to assess an individual's wellbeing, to make judgements about the level of social development, and/or to design policies about social change in society (Chiappero-Martinetti & Venkatapuram, 2014; Robeyns, 2003a). In contrast to the traditional perspective on health disparities, the framework emphasizes the opportunities, not just the resources, that people have to lead lives that they have reason to value

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[5] Jarvis et al. (2016). Exploring reintegration post – obstetrical fistula repair in northern Ghana: An analysis using Nussbaum's capabilities approach. *Social Science & Medicine*. This chapter has been prepared for publication.

(Nussbaum, 2000), and highlights both personal values and freedom to make choices as intrinsic to wellbeing. By turning attention to the opportunities and capabilities of individuals to make choices and lead lives that are coherent with personal, family and cultural values, Nussbaum's approach assists in speculating about the notions of wellbeing and equality.

The aim of this paper is to use Nussbaum's CA to analyze the data of a research study that focus on family and community reintegration of women who have experienced an obstetric fistula (OF) repair in northern Ghana. To provide context for the analysis, the paper begins with a description of OF as a significant women's health issue in Ghana, as well as a discussion of Nussbaum's CA, its strengths and its criticisms. The paper goes on to describe the study methods and findings, and analyse the findings from the perspective of the CA to expose potential or actual constraining systemic inequities for women who are reintegrating after receiving an OF repair. The paper concludes with recommendations for effective public policy generated to positively impact women who are experiencing the physical, psychological, social and economic consequences post-OF.

Background: Obstetric Fistula

OF is a serious childbirth injury affecting two to three million women in low and LMIC (Avevor, 2013), and having far-reaching physical, psychological, social and economic effects. It is particularly prevalent in rural communities in sub-Saharan Africa (Tebeu et al., 2012). OF is a hole between the vagina and bladder and/or rectum following childbirth (Banke-Thomas, Wilton-Waddell, Kouraogo, & Mueller, 2014). It typically follows obstructed and/or prolonged labour when emergency obstetrical care is unavailable, leaving women incontinent of urine and/or feces.

The high prevalence of OF in sub-Saharan Africa is illustrative of serious global inequities in women's maternal and reproductive health (Osotimehin, 2014). Prevention programs which include access to high quality maternal care and family planning have helped to lower the incidence of OF, but have done little to alleviate the suffering of women who live with the condition (Donnay & Weil, 2004). It is recognized that a threefold approach including awareness, treatment (surgery), and reintegration is necessary for optimal treatment (EngenderHealth & United Nations Population Fund [UNFPA], 2003).

In many parts of Ghana, OF care typically concludes with surgery. Reintegration and rehabilitation have been neglected components in OF care despite recognition that social reintegration is the second most important aspect of care (Capes, Ascher- Walsh, Abdoulaye, & Brodman, 2011; Women's Dignity Project & EngenderHealth, 2006; Muleta, Fantahun, Tafesse, Hamlin, & Kennedy, 2008). Currently, OF rehabilitation and reintegration services in Ghana, especially in rural areas, are fragmented.

The Ministry of Health, Ministry of Gender, Children and Social Protection, and the UNFPA in Ghana have recognized OF care as an important issue within the country and recently commissioned a study to begin to address OF concerns. One aim of this study was to "identify opportunities for rehabilitation and reintegration of its victims into the community" (Ghana News Agency, 2015, para. 6). Reintegration programs post-OF repair usually include but are not restricted to client teaching/education, skills training/ income generating activities, community follow-up from health professional(s)/access to health care services, family and community sensitization, and emotional support services (i.e. counselling, advocacy) (de Bernis, 2007). Reintegration programs for OF can be delivered by way of rehabilitation centers or community-based programs (Capes et al., 2011). The best approach to reintegration post-OF repair, however, is dependent upon the country (Capes et al., 2011).

Conceptual Background: Capability Approach

The CA dates back to Aristotle, Adam Smith, and Karl Marx (Nussbaum, 2003) but its present form was pioneered by Amartya Sen (Nussbaum, 2003; Sen, 1999). While many scholars have advanced the framework, Martha Nussbaum has made a significant contribution using the approach as the basis for a partial theory of justice (Nussbaum, 2000; Nussbaum, 2011). Sen and Nussbaum share similarities in their thinking but there are differences in their versions of the CA. In contrast to Sen's broad conceptualization that is attuned to quantitative experiential applications, Nussbaum's approach is more specific, engaged with qualitative texts, and seeks to understand an individual's hopes, desires, motivations, decisions and aspirations (Robeyns, 2003a). The framework can be utilized in many ways and in a range of fields. In a broader sense, the CA assesses not only wellbeing but also an individual's ability to act in a given context and considers the process of fair and transparent decision-making. Considered a flexible and multipurpose framework rather than a precise theory, Nussbaum's CA assists in speculating about the notions of inequality and wellbeing rather than explaining these concepts (Chiappero-Martinetti &Venkatapuram, 2014; Robeyns, 2003a).

Five concepts are described within the CA: capability, "functionings", agency, endowments, and conversion factors. Capability identifies "what is the person able to do and to be" (Nussbaum, 2011, p.20). Nussbaum, (2011) notes that there are ten central capabilities that ensure wellbeing and human dignity. These include: life, bodily health and integrity, senses, imagination and thought, practical reason, emotions, affiliation, play, concern for nature/species, and control over one's environment.

Many of Nussbaum's central capabilities are similar to and protected as basic human rights, and address an individual's freedom to choose or to realize opportunities. Nussbaum (2011) notes that "rights have been understood in many different ways, and difficult theoretical questions are frequently obscured by the rights language, which can give the illusion of agreement where there is deep philosophical disagreement" (p.97). Nussbaum, therefore, argues approaching matters of social justice from the perspective of the value of capabilities as opposed to "rights", and poses that all governments should endorse these central capabilities into their constitutions.

While capabilities are an individual's talents, internal powers, and abilities or real opportunities, "functionings" are the individual's ability to turn opportunities into achievable outcomes which are logically, morally and politically important. "Functionings" and capabilities are therefore interrelated and reinforce each other, creating the potential for more capabilities and "functionings". It is important to realize, however, that two people can have the same potential capabilities or capabilities set and end up with different levels of achieved "functionings". This is because people make different choices based on what they value to be a good and flourishing life, and which are influenced by family, religion, and cultural background (Robeyns, 2003b). It is essential to understand a person's living situation and not simply their visible material resources when considering which "functionings" can be achieved. Capabilities and "functionings" interact with and are dependent upon a person's agency and endowments, and the conversion factors which are inherent in a situation.

Agency is described as the ability to define and act upon valued goals to bring about change that can be judged on the basis of an individual's values and objectives (Chiappero-Martinette & Venkatapuram, 2014). It is often operationalized as "decision-making" (Kabeer, 1999, p.438) where an individual makes purposeful and “free” choices from presented possibilities. Agency is influenced by an individual’s health, education, social belonging, sense of identity, leadership, self-esteem, self-confidence, and ability to imagine and aspire to a better future (Samman & Santos, 2009). Nussbaum (2000) makes agency an integral part of her central capabilities with the inclusion of “affiliation” and “practical reason”. These capabilities allow for “freedom of assembly and political speech” and “the ability to form a conception of the good life and to engage in critical reflection about the planning of one’s life” (Nussbaum, 2000, p.79).

Instrumental to creating capabilities are an individual’s endowments, which may include biological and intellectual attributes, talents, wealth, and public goods and services. Conversion factors influence how “free” a person is to convert these endowments into “functionings” or achievable outcomes. Personal, social and environmental conversion factors reinforce or impede an individual’s ability to convert his/her endowments into valued outcomes.

Nussbaum’s CA has not been without criticism. Her call for her central capabilities to be included in the constitutions of all countries has been deemed naive in its assumption of the existence of benevolent governments (Menon, 2002). The notion also stands in contrast to the views of some critical theorists who believe dominant institutions such as governments are contributing to societal injustices due to their power and influence (Menon, 2002).

Questions have also been raised regarding what constitutes a “central capability”, and the possibility that some capabilities might be missing from the list or need to be challenged (Jagger, 2006). Nussbaum acknowledges this claim, recognizing that her framework is constantly subjected to revision and suggests that her list is a guideline representing “years of cross-cultural discussion” (Nussbaum, 2000, p.76). She indicates that additional capabilities may be needed depending upon the country or community in which persons or groups are situated. However, critics cite the potential for the misuse of power should dominate groups dictate what contributes as a central capability.

Nussbaum has also been considered paternalistic by some critics who believe it is inept to determine the capabilities of other cultures, and who advocate for a more participatory approach (Clark, 2002; Stewart, 2001). Historically, the separation of human from *other* has been seen as a colonialist approach (McReynolds, 2002), and language used within the framework, particularly the phrase “what is truly human” (Nussbaum, 2000, p.79), has been criticized as being inappropriate in the context of international development. It is suggested that alluding to such demarcation should be avoided.

In spite of the criticisms, Nussbaum’s framework is appropriate for discussing equalities/inequalities for women who are reintegrating post-OF repair, and for exploring how women post-OF may cultivate their capabilities. Women’s issues have been at the heart of Nussbaum’s CA which provides a multidimensional perspective on the complex circumstances surrounding inequities in women’s health and wellbeing, particularly maternal and reproductive health matters. Nussbaum is concerned with the prevalence of discrimination against women in low and LMIC and acknowledges that the “consideration of justice for women has been disproportionately silenced in many debates about international development” (Nussbaum, 2000, p.33).

This perspective can be particularly enlightening in a country such as Ghana, where decisions about maternal and reproductive health are heavily influenced by a woman’s access to and knowledge about available resources such as prenatal care and family planning; where factors such as inadequate infrastructure (i.e. road networks, lack of skilled birth attendants and inadequate literacy rates) (Association for Safe International Road Travel [ASIRT], 2014;

Government of Ghana, 2016; Kruk et al., 2010) can impede a woman's ability to act; where patriarchal gender relations place women in a position subordinate to men (Ganle & Dery, 2015); and where women are "perceived to be less 'empowered' to take their own decision as a right" (Darteh, Doku, & Esia-Donkoh, 2014, Introduction, para.1; Ganle et al., 2015).

Methods

Study Design, Setting, and Sample

A critical ethnographic design was utilized to discern the meaning and point of view of participants about a culture of reintegration post-OF repair. An underlying assumption of the study was that the process of reintegration occurs in a socio-historical milieu, and that only in challenging common everyday assumptions could the underlying truth about reintegration emerge, providing insight into where health equality and inequality exist post-OF repair. Thus, critical social theory, Nussbaum's capability approach, and Gyekye's philosophical thoughts about contemporary Ghanaian society guided the inquiry.

Fieldwork was carried out in northern Ghana, which is comprised of three regions-- Northern, Upper East, and Upper West-- spanning 238,533 square kilometers. Northern Ghana is considered to be remote and economically disadvantaged in comparison to other regions of the country. Northern Ghana has the highest rate of OF and the second highest rate of OF repairs in the country (Ghana Health Service, 2015).

The Tamale Fistula Center in the northern region, the only government run clinic dedicated specifically to fistula care, was the main center for participant recruitment. Inclusion criteria were: women who had experienced an OF repair three months prior to being interviewed; family members of the women interviewed who were involved in post-OF care; HCPs involved in post-OF care and rehabilitation; and stakeholders who were involved in or had knowledge of

OF care and rehabilitation/reintegration programs. A total of 99 participants, 41 women, 24 family members, 17 HCPs, and 17 stakeholders from 24 rural communities in northern Ghana, were recruited using convenience, purposive and snowball sampling.

Data Collection Methods

Data were collected over two time periods, from March to June 2014 and April to May 2015. Interviews, ranging from 30 to 90 minutes each, were conducted with each participant and were audio recorded. Fourteen follow-up interviews were conducted to validate the findings and to explore the unanticipated responses gathered during the initial interviews. Interviews were conducted in seven different languages with the support of translators. Translators were provided training at the start of the research project. Questions were open-ended and provoked responses that allowed for a dialectical discourse between interviewer and participant to expose the underlying assumptions distorting the respondents' perceptions of their day-to-day reality. Interview guides covered a range of topics about experiences with reintegration such as challenges, needs, resources, ability to create change, and the responsibilities of individuals, communities and government in reintegration post-OF. Field notes were recorded after each interview or observed event to capture the contextual details and nonverbal expressions. Relevant United Nations-Ghana, World Health Organization, and country documents related to OF were critically reviewed for their significance. Recruitment continued until no new relevant knowledge emerged.

Ethics approval was obtained from the Human Research Ethics Review Board at the University of Alberta, Canada, and at the Navrongo Health Research Center Institutional Review Board, Ghana. Participation was voluntary. Participants were informed of their rights as well as the risks and benefits of participating before obtaining consent. Participants were given the option to communicate in English or in their mother tongue via a translator.

Data Analysis

The recorded interviews were transcribed and then forward and backward translated to capture an accurate interpretation of the data. Hammersley and Atkinson's (2007) approach to ethnographic analysis was used to analyze the data. A data subset was randomly selected and hand coded by two members of the research team to ensure trustworthiness of the data. The data were read line by line, and keywords were highlighted. The data were then re-read noting initial thoughts and reflections so to generate concepts. These concepts were then organized into ten categories. A coding framework was developed and tested on randomly selected interviews from the main data set. Adjustments were made until the coding frame was deemed appropriate for critical analysis and then applied to the remaining data. Nvivo software 10.0 was used for data management.

Findings

Nussbaum's framework identifies agency, endowments, and conversion factors as facilitating or constraining a woman's capabilities and her ability to convert them to "functionings". After describing the sample characteristics, the study findings are discussed in terms of agency, endowments and conversion factors influencing the capabilities and "functionings" of women who are reintegrating into their communities post-OF repair.

Sample Characteristics

Participants were women who had received an OF repair and their family members who had taken care of them, HCPs (physicians and nurses at the OF clinic, community health nurses, nurse-midwives, nursing administrators, and traditional birth attendants) experienced in working with women who had an OF repair, and stakeholders (government and nongovernmental agencies and ministries, religious leaders, community leaders, women advocacy groups) who had knowledge about OF care and reintegration programs at a national or community level. All participates were able to provide rich and diverse perspectives about a culture of reintegration post-OF repair.

Agency: A Woman's Decision-making Ability

In this study, agency is associated with the ability of participants (women who experienced an OF repair) to initiate the goal of reintegrating into family and community life. The 41 women with OF who participated in the study were in various stages of reintegration. They ranged in age from 18 to 52 years. Many of them did not know the number of years they had experienced the ill effects of an OF, but most remarked having had two or more surgeries before being "cured". All women lived in northern Ghana, with the majority living in remote rural communities, and were employed in farming, or petty trade.

The hegemonic culture in Ghana holds communal values. It is believed that an individual lacks autonomy and the ability to succeed independently of others (Gyekye, 2003). This can be heard in their metaphors as one family member explains the supportive relationship a husband has with his wife and how they function as a unit in order to be effective. "Nu bli gaŋ ku pii kugli", he says, literally translated as "one finger cannot pick up a stone".

Decisions about family matters including health care, however, are made by the male household heads since it is culturally believed that they hold a repository of wisdom. This is highlighted by this family member:

> I am the head. So anything affecting the clan [my family], I sit with them to solve it. If it's beyond me, I take it to the chief. When she [female participant] went into labour they [the family] came to tell me that she [female participant] was going into labour and that they [the family] want to take her [female participant] to the hospital and I

> gave them the permission to take her to the hospital. So anything, concerning them, they must first consult me before they go ahead to do anything.

Furthermore, the majority of women in this study were from the Mole-Dagbani tribe whose social structure is patrilineal and predominately of the Muslim faith. Many of these women indicated being in polygamous marriages, which Sossou (2006) suggests reinforces the inferior position of women in traditional Ghanaian society. Clearly, agency for the participant women in this study was heavily reliant on the influence of the family and community, particularly of the dominant male members. Alternatively, attention must be given to what establishes a Ghanaian woman's authority in the home and community since this differs cross-culturally. Ghanaian women are noted to achieve power in their role as a mother and in their ability to do traditional household tasks as one stakeholder comments "a women's status and legitimacy within the family comes from their ability to reproduce…the more male children the better…then you know she is building a home and carrying the family". The majority of women in this study reported having one or more children and it can be assumed that this established their authority and position within the family.

Endowments and Conversion Factors

In relationship to this research, endowments refer to the resources available to women to help facilitate their reintegration. Resources frequently reported by women in this study were the information they received at the OF clinic, skills training provided by UNFPA, follow-up conducted by the community health nurse, awareness campaigns allowing for community sensitization, support from family members, faith in God, and health policies which assisted in equitable and affordable health care. These resources were essential for women returning home to their families and communities post-repair. However, conversion factors, or the issues and circumstances surrounding the acquisition of these resources, also hampered reintegration.

Teaching and education. All women interviewed stated that they had received teaching by a HCP at the OF clinic, typically regarding the performance of Kegel exercises, the avoidance of strenuous activities, and curtailment of sexual intercourse for a minimum of six months. As one participant stated:

> When I was going home they [HCPs] told me no sex, I shouldn't lift any heavy thing and no hard working, for some time. They [HCPs] told me no vigorous exercise, these vigorous things, walking very long distances, they said just to stop it because it can cause the sickness [fistula] to come back and to do pelvic exercise too.

However, the cultural value of motherhood proved to be a constraining factor for the wellbeing of women reintegrating post-OF repair. Women frequently expressed the desire to become pregnant soon after their OF repair because being a mother in Ghana holds great significance (Gyekye, 2003). A woman stated, "my husband did not invite me to his room when I was smelling. Now that I'm cured of the sickness I wish to have many children".

Cultural openness to discussion of private physical or sexual matters was another constraint on the acceptance of health education. Though it was recognized by HCPs that women post-OF required education on early and regular pregnancy monitoring, family planning and two-year pregnancy spacing, sexual and reproductive health education post-OF was suggested to be vague and ambiguous. A midwife remarks:

> …in Ghana it is difficult to talk about sex and sexual body parts. It is not culturally acceptable. Can you image trying to teach women about their bodies and you cannot say the word vagina? You cannot ask a woman if they are having intercourse with their husbands. That is why you will hear the nurses telling patients at the fistula clinic "not to meet with their husbands for some time". They are telling them in around about way no sex. Most women understand what you are telling them but some do not.

It is understandable, then, that reoccurrence of fistulas was a common problem even though women were given information about post-OF care, and were able to verbalize taught instructions. However, HCPs attributed this to noncompliant behavior. One HCP stated:

> I can say about 90 percent, do not listen to us. When you tell them not to have sex they will go and immediately start having sex. There was a woman who was here for six months, I think she went back [home] they started having sex, and she came back [to the clinic for another repair]. When we repaired it the second time she stayed here [fistula clinic] for six months away from the husband… now she is fine.

The majority of HCPs strongly believed that women were not taking note of post-OF instructions. However, the noncompliant label failed to take into account the social context in which many of these women live their lives. Non-compliance was a reflection of the underlying social circumstances which constrained these women, not of their choice to disregard post-OF instructions. A woman commented that she understood the risks associated with having sexual intercourse with her husband soon after her OF repair, but she believed she did not have the authority to refuse him.

> It was hard to be doing all what we were told at the clinic…there were things they told us but I couldn't do. I tried to tell my husband [no sexual intercourse] …and he told me "how can you then be looking so lovely"... A woman can't be refusing her husband like that.

For a variety of reasons, husbands were seldom included in educational sessions even though they were recognized as dominant decision-makers in the home. Women reported that their husbands were not interested in attending classes or doctor's appointments to learn about their care, and relegated that duty to other relatives. A HCP commented that husbands often had limited involvement because culturally "the direct relative shouldn't get the direct impact about their wives' illness, so another relative from his family will go to the hospital to get the information and consent for care".

Additionally, HCPs also recognized the importance of an appearance of wellbeing, since women often had to “prove” their wellbeing to community members for community reintegration to be successful. Women were provided with information about the importance of maintaining their appearance in order to reduce speculation about ill health. A woman recalls; “they [HCPs] told us that when you wake up we should bath and make our dresses look nice so those [people in the community] saying bad things will stop”.

Skills training and economic support. UNFPA-Ghana, and the Ministry of Gender, Children and Social Protection facilitate skills training as a valuable component of the reintegration process. One government stakeholder remarked:

> The reason for the skills training is because normally when women get this condition [OF] the community has a bad perception about them. The community does not want them to be a part of the public…We did some little study and realized that most of them were struggling to gain their self-confidence so we conceived this idea of training them. We did the first training in 2010 in the three northern regions. So when they recover from surgery we cannot just send them back to society. That is the reason why the training.

However, the issues facing women post-OF repair are not so easily fixed. Community stakeholders who are contracted to implement skills training programs for women post-OF repair spoke of the benefits gained:

> Economic empowerment supports women with the necessary skills to be able to setup their own business, manage it and run it. In so doing giving them the opportunity and the ability to demand their rights in society. Like this woman here, [showing picture] when she went back to the community they had no use for her, the community regarded her as “this thing”. But giving her some special skills to do, things the community needed like producing soap from shea butter made her somebody. Nobody in the community knew how to produce soap. So the community was forced to buy the soap from her and she was able to employ some people in the community to help her run the business.

On the other hand, some women reported that the options presented were not suitable to their situation or geographical location, and many believed the resources used for skills training could have been better invested.

> I was called to come for training and I learnt how to make the dough loaf, and since I cannot walk long distances and also this area does not fancy it [the dough loaf is hard for me to sell]. Left with me alone the money should have been given to me, and I would have added it to my kola business. The flour to make the dough loaf is costing too much and I am losing capital. My husband told me to stop but the people who trained me said I must try. It is causing a whole lot of confusion in my marriage.

In a follow-up interview nine months later, this woman indicated that she had completely stopped making and selling dough loafs and had invested her capital into selling kola in the market. She found this to be a more profitable enterprise. Skills training was intended to be provided to all women who receive an OF repair in northern Ghana. However, there were reports of women who have failed to receive training because they were unaware of such support, or because they were of retirement age.

Follow-up care. Women were routinely given a follow-up appointment at the OF clinic three months post-repair to reassess physical and emotional wellbeing and to confirm continence of urine and/or stool. This was also the time when women were invited to participate in skills training opportunities. Two of the 41 women interviewed noted they were unable to return for follow-up citing financial reasons. One woman stated, “the nurses were calling me to come for follow-up but I had no money to pay the lorry fare”. Many other women had to delay their follow-up appointment until they could afford transportation to the clinic.

Though follow-up care in the community by a community health nurse (CHN) was available, it tended to be fragmented since there was no formal community referral system in northern Ghana. A HCP in a leadership position shared:

> We don't have any formal referral system or anything. We just inform our public health team that a woman from village A came and had fistula repair and she has gone home so anytime you get to that area just try and find out how she is doing. So somebody probably gets there with the motorbike …but I can’t say for sure.

Women who did receive follow-up care indicated that they and their families reaped the benefits and many expressed gratitude for being valued and having their health concerns addressed.

> I sincerely thank Madam [CHN], now I can go anywhere. She visited me when I came home, she fed my children, she counselled my husband to stay…She paid my lorry fare to town for the skills training and she made me demonstrate [the skill taught] by making some small soap…I give my life to Madam may God bless her.

Unfortunately, the challenges inherent to providing care in the remote northern regions meant that the degree of follow-up support was inconsistent. The inaccessibility of some communities and safety concerns were the most significant problems faced by CHNs responsible for follow-up care. One nurse described her challenge with post-OF follow-up care in her health district:

> When they [women with OF repair] come home from the clinic I [CHN] try to visit them [women with OF repair] but it's hard because of the transportation, it's a real challenge. Sometimes it's a safety problem traveling in small boats to the other side of the river. People die in the river and women are raped in the bush when they travel alone on a motorbike. I want to visit but sometimes I cannot go.

Community and family awareness. A national community awareness campaign spearheaded by EngenderHealth and UNFPA (2003) provides education about the causes of OF and where to seek treatment, aids to dispel myths, and aims to prevent those who have experienced the condition from being ostracized within their communities. Despite the work done to create community sensitization, women struggled to regain their status in the community. One woman stated, "I no longer leak urine but they [the community] still do not buy from me, they think I am selling the sickness". This suggests that women continue to have difficulty to make a living upon returning home as a consequence of the stigma attached to OF. Another woman described having to prove to the community that the OF surgery was successful stating “I had to strip my clothes and expose my body to show them [the community] I was not leaking”.

Emotional and material support. Women with an OF repair noted that the emotional encouragement received from other fistula survivors, and their faith in God was helpful to them during the reintegration process. One woman recalled a fistula survivor coming to her home “assuring me there was a solution to my problems [reintegrating] that is how the whole thing started… we prayed together that God would open – open the way for us”. Another woman stated:

> When things are hard I pray. It is God and God alone who gives life and takes life away. I pray for God to give me a good life. He [God] took the illness and I pray he [God] will help me recover and be counted among women again.

As the women were unable to do strenuous work in the home post-OF repair, material support was as important as emotional support for the reintegration process. One woman stated, “it is my husband who is doing everything, there is just a borehole, a pipe, in this area and it is my husband who fetches water for me”.

Unfortunately, family environments that supported their physical and emotional needs were sometimes not available, as this women stated:

> When I went back they [HCP] said I shouldn't do certain things. And it was like a burden on the second wife. It was a whole confusion between us because the woman thinks that fetching water for me to bath is a bother to her. I cannot be sitting down and she will fetch water for me. And, you know, once she sees that our husband is supporting her she will have … something like upper hand. My husband says at least I should be able to do some things for myself. It means that I shouldn’t just be sitting down without doing anything. So if I need water my friends will come and fill my containers and give me firewood too.

Community reintegration is particularly difficult for women who continue to experience a small amount of incontinence post-OF repair. Husbands were reported to abandon women who continued to leak post-repair and, should a woman have her uterus removed during the repair, divorce was usually imminent. Many of these women were cared for by their natal families as one woman described:

> I think and think and my brother will come and tell me not to cry that now I am home. My husband's family were fed up with me and said I was not the only wife. They told him [husband] he wasted his money. I can't have children and I still smell? He [husband] started maltreating me and I packed my things and went to my father's house. I am not a woman in this village… as I sit here, I have no children and I leak urine small small.

It is suggested that women who can retain the support of one family member may reintegrate into the family and community more easily than a woman who has been abandoned post-OF repair (Yeakey, Chipeta, Rijken, Taulo, & Tsui, 2011).

Policies and politics. The Ghanaian National Health Insurance Scheme (NHIS), operated under the National Health Insurance Authority (NHIA), assists with equitable access and affordable health care for Ghanaians (Blanchet, Fink, & Osei-Akoto, 2012). The cost of OF surgery and access to follow-up medical care post-OF repair is covered by the NHIS, but the care of women who depend on the services of the NHIS is endangered by threats of economic mismanagement (The Herald Team, 2014). Currently, many hospitals in Ghana have had to turn away patients covered under the NHIS due to the failure of the NHIA to pay for medical services. This has been a persistent problem and it is now reported that the NHIA owes approximately 460 million Ghana Cedis (roughly 120 million US dollars) to health facilities, pushing Ghana towards a cash-and-carry health care system (Gadugah, 2015; The New Statesman, 2015). There is also evidence of tension, disagreement, and accusations of dishonesty among key stakeholders who are involved in administering and funding OF care. One OF stakeholder stated when asked about the amount of monies or resources the Ghanaian government dedicates to maternal and reproductive health care that it was their opinion that

> …the largest component of the health care budget goes to pay salaries of the health staff. Very often there is very little for investments in health programmes. That is why most of

> the time we [Ghana] have the donor partners taking up those other parts. You know [maternal health] is an area that attracts a lot of sympathy like maternal death is really tragic. Therefore it’s very easy for us [Ghana] to mobilize funding when you have maternal health as the focus. So very often the government thinks that if we leave this area [maternal] we will get donors who will come and support, so we can concentrate efforts in other areas. That is what I think because it’s been difficult. We’ve [OF interest group] been pushing and pushing but we are not making much headway.

Women also asserted that they did not know where to voice their needs or concerns regarding the post-repair reintegration process. Women were unable to identify with government agencies. Instead, they placed their trust with nongovernmental organizations (NGOs) and the “white man”. One woman stated:

> I don’t have any relationship with the government but the NGO helped me, they were involved and it was a white man that cured me, even when I went for training it was the white people who came to see me.

This account suggests that government agencies, administrators and politicians who ultimately provide and facilitate services in OF care are not visible and are out of touch with the needs of women post-OF and their families.

Capabilities and “Functionings”

In order to “live a good life”, in Nussbaum’s terminology, women who have had an OF repair must be concerned with the central capabilities, particularly bodily health, health integrity, affiliation, emotions and control over one’s environment if they are to build the “functionings” of successful reintegration to the lives they lived prior to OF. It is clear that there is an attempt by government and key stakeholders to implement the resources or endowments required for reintegration post-OF repair. Resources such as education, skills training, community follow-up and awareness, and enhanced support networks are being utilized and are playing a valuable role in allowing women to reintegrate. There are, however, a number of conversion factors that are either inhibiting or potentially inhibiting a woman’s ability to reintegrate post-repair. Most notable here is the traditional role of women in Ghanaian society, and the lack of control that they have in circumstances related to their own health.

Ghana is largely a pronatalist society where being a mother and a wife is highly respected (Gyekye, 2003). Women frequently have little decision-making ability about their reproductive health which impacts their ability to comply with post-operative instructions should their husbands request sexual intercourse (Darteh, Doku, & Esia-Dpnkoh, 2014). Culturally, women in northern Ghana are unable to participate in family planning without the consent of their husbands (Modern Ghana, 2009). This was validated by stakeholders at Marie Stopes International Ghana, a nongovernmental organization where quality family planning and reproductive health care is provided. A spokesperson noted, "women who do partake in family planning often hide it from their husbands". Diminished control over reproductive choices is also noted for women who are in polygamous marriages where women average between five to six children per wife (Altman & Ginat, 1996).

Women who conceive children post-OF repair may lack the autonomy to make decisions about maternal health and place of delivery (Gebresilase, 2014; Khisa, & Nyamongo, 2012; Nielsen et al., 2009; Turan, Johnson, & Polan, 2007) despite being instructed to return to the OF clinic for follow-up and delivery by Caesarean section (Mselle, Evjen-Olsen, Moland, Mvungi, & Kohi, 2011).

Furthermore, the traditional role of women in rural Ghana is physically demanding (United Nations Economic and Social Council, 1963), making restriction of strenuous activity nearly impossible. A professor of Gender and Women's Studies in northern Ghana suggested that it is women who are responsible for providing food for the household, carrying water from the well, searching for and carrying firewood, and attending to household chores. Women labour in the fields and sell in the markets often with a child on their backs. All of these issues challenge a woman’s ability to achieve bodily health and bodily integrity. Family-based education that ensures husband/partner involvement would go far in facilitating a woman’s right to reintegration.

Economic empowerment through skills training provides women with the tools to strengthen their health and wellbeing for themselves and their family. Though a right to a livelihood is not viewed as an international human right (Hill, 2011), economic empowerment does have a positive impact on increasing a woman’s feeling of self-worth, self-esteem and decision-making abilities about reproductive health. Economic empowerment is interconnected with social and political liberation and emancipation, giving voice to women when it otherwise may be muted (Hill, 2011). Economic empowerment provides women with more control over their environment. Although skills’ training was available to women in this study, the type of skills acquired, as noted by some women, did not always fit the local environment or their physical condition, rendering the skills ineffective. Many women indicated they had abandoned their learnt trade and had used their capital to seek more lucrative opportunities in their community. This suggests that women must be allowed to participate in the planning of skills training activities.

Follow-up care post-OF was recognized by many women participants as a valuable resource that supported their successful reintegration. All women who received an OF repair were asked to follow-up at the OF clinic three months post-repair to assess the success of the surgery. However, the majority of women in this study lived in rural areas away from where the OF clinic was located, and many indicated they had to delay their follow-up appointment or in some cases were unable to attend because they could not afford the lorry fare. A lack of funds for transportation is a serious barrier, impeding a woman's ability to access OF follow-up care (Avevor, 2013; Fiander & Vannester, 2012). OF follow-up care within the communities is also noted to be fragmented and inconsistent with no formal referral system in place to adequately address the health needs of women. As well, many CHNs indicated that the inadequate road network and unsafe work environment in rural communities prevented them from reaching remote communities to provide proper follow-up care for women post-OF repair.

Community awareness about OF is known to reduce social stigma which can be associated with the condition (Saeed, Alhassan, Opare-Asamoah, & Kuubiere, 2014). Some women in this study had to "prove" themselves worthy to be accepted, which greatly affected their ability to connect and be active members of their community. This finding was more likely to be reported by women who returned home still experiencing some level of urinary incontinence. Similar findings have been reported by Nielsen et al. (2009) who assessed urinary and reproductive health and quality of life for women post-OF repair. "Women affected by fistula and the meaning that she and others attached to it became an embodied part of her sense of self" (Mselle, Evjen-Olsen, Moland, Mvungi, & Koli, 2011, p.936). The stigma of OF also deterred women from receiving the social support and attachment to others that was identified as being a significant component for successful reintegration.

Women noted obtaining social support from various individuals including other fistula survivors whose knowledge of the experience was comforting and encouraged them to keep going (Gebresilase, 2014). Family support, in particular, was significant in assisting women to transition back into their communities (Pope, Banger, & Requejo, 2011; Yeakey et al., 2011). Women reported that support came from children, other wives, older female relatives, and their husbands. Acceptance and support from husbands was particularly appreciated given the gender role expectations in Ghanaian culture, and the economic and social burden placed on the husband when a wife is ill.

Although some husbands stayed committed to their wives through their illness trajectory and reintegration, many others deserted their spouses. In some cases, women had been abused physically and emotionally due to the secondary effects of having the OF surgery (i.e. unable to have children). There is a strong need to implement counselling into reintegration programs post-OF repair. This would require qualified professionals who are skilled in dealing with individuals who have experienced abuse, chronic illness, loss of a child, and abandonment. Counselling programs, including reproductive counselling, which has been implemented in another sub-Saharan country may be beneficial (Johnson et al., 2010).

Viewing the study results through the lens of Nussbaum's CA, it is clear that post-OF health education, skills training, follow-up care, community awareness, support networks and health policies are theoretically available to women in northern Ghana who are reintegrating post OF repair. However, this lens also brings into focus the economic, societal, systemic and cultural constraints that come to bear upon the outcomes or "functionings" of these women. While some women integrate well, others do not, suggesting that inequities exist. This study identifies potential areas of inequities to assist policy makers and opinion leaders with the knowledge needed to begin a discussion of the care of women reintegrating post-OF.

Recommendations

CA illuminates the inequities that exist when discussing reintegration programs post-OF repair. Women in northern Ghana have the desire and the will to reintegrate but have challenges related to their ability to convert resources into outcomes that are freely chosen and valued. Many external conversion factors exist over which women have little control or influence. Effective change tackling the inequalities in OF care will require a multi-factorial approach involving stakeholders from the grass roots to government level in the creative exploration of how known conversion factors might be minimized or eliminated. This will demand a strong focus on the social determinants of health, ensuring that women have the necessary services and support available for successful reintegration post-OF repair.

Commitment, leadership and financial support from all levels of government and administration will need to continue in order to reduce the incidence of OF, and to assist women who experience an OF repair to reintegrate effectively. However, policy makers must also recognize that any intervention needs to be region specific due to the vast cultural, physical, and economic differences country wide, and to the exceptionally rural nature of northern Ghana.

Women who have experienced an OF repair must be regarded as a valuable resource in addressing the issue of OF, and they must be invited to participate in moving OF care and reintegration guidelines and policies forward. Leadership must be provided for women to become motivated to lobby for inclusion in the decision-making processes which impact upon their health and wellbeing post-OF repair. For example, women need a say in the type of skills they need to develop to gain valuable employment.

Family-based education that includes males (husbands, fathers, sons) is critical to improving a woman's ability to reintegrate post-OF repair since males are predominately the decision-makers in the north. Similarly, community awareness with a strong emphasis on dispelling the myths about OF is crucial if women are to return home post-OF repair and resume their lives as productive and valued members of society.

Access to follow-up care is required for women post-OF and serves to sustain positive outcomes. Follow-up is essential to better understand a women's reintegration process, as well as their health status. The barriers to accessing follow-up care post-OF should be further explored and strategies implemented. One way to improve access is through the reimbursement of transportation costs. A program utilized in Tanzania where mobile phone technology permits funds to be transferred to a woman to cover the transportation costs frequently associated with follow-up care is an example of using technical innovation to combat practical problems (Fiander & Vanneste). Additionally, improving the co-ordination of referrals between fistula hospitals and community health clinics must be addressed. Realizing that geographical barriers exist in northern Ghana, providing follow-up counselling and information about who to contact should health issues arise is necessary prior to discharge. Culturally appropriate counselling should be incorporated into OF care to improve a woman's physical and mental wellbeing (Johnson et al., 2010). Women post-repair stress the need for family members to be involved in OF counselling so that health information is consistent once a woman returns home and confusion around post-OF instructions is decreased (Johnson et al., 2010). Further exploring these recommendations would potentially assist women "to do and to be" (Nussbaum, 2011, p.20).

Conclusion

Health inequities that exist in low and LMIC are clearly illustrated in the experiences of northern Ghanaian women who have undergone OF repair. Nussbaum's CA offers a lens for a deeper understanding of the circumstances surrounding these inequities.

The women in this study identified endowments related to post-OF repair: education, skills training, community follow-up and awareness, and enhanced social support. However, they often were not able to capitalize on these endowments to gain "functionings" or valued outcomes such as bodily health and integration, strong social affiliations, emotional support, and control over their environment. As a result of traditional cultural beliefs and practices Ghanaian women lacked the agency needed to make decisions for themselves and gain control of their environment. As well, conversion factors arising from Ghanaian cultural beliefs and practices, community resistance to reintegration, and the remoteness and diversity of the geography of Ghana militated against their successful community reintegration. It is essential to design and implement approaches and interventions that address these circumstances if women, post-OF repair, are to regain productivity and full status as valued members of their society.

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Chapter 4: Exploring the Needs and Challenges of Women Reintegrating Home After Obstetrical Fistula: A Critical Ethnography[6]

The Ghanaian maxim “there is no wealth where there are no children” (p.84) underlines the importance placed on the birth of a child in Ghanaian society (Gyekye, 2003). Traditionally, Ghanaian women establish their status in society after giving birth (Jansen, 2006). Birth is viewed as a natural process, a bodily experience frequently unattended by skilled birth attendants. It is estimated that 55 % of all deliveries in rural Ghana are attended by traditional birth attendants or family members (Nakua, Sevugu, Dzomeku, Otuoiri, Lipkovich, & Owusu-Dabo, 2015) who may not be prepared to respond appropriately when complications arise.

Obstetric fistula (OF) is one of the most serious and tragic childbirth injuries associated with prolonged, obstructed labour unrelieved by timely intervention. OF is an opening or openings between the vagina and the bladder and/or rectum that frequently leaves women incontinent of urine and/or faeces (Lewis & de Bernis, 2006). In Ghana, it is estimated that 500 to 1000 new cases of OF are diagnosed annually (Danso, Opare-Addo, & Turpin, 2007) affecting women’s physical, psychological and sexual health, and their social and economic status (Pacagnella et al., 2010). Northern Ghana has the highest number of OF cases in the country according to a recent study conducted by Ghana Health Service (2015).

The approach to care of women with OF is threefold and includes awareness, treatment (surgery), and community reintegration. Although there is much documented about awareness and treatment, little was found regarding how women reintegrate after their OF repair (Mselle,

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[6] Jarvis et al., (2016). Exploring the needs and challenges of women reintegrating home after obstetrical fistula: A critical ethnography. *International Journal of Nursing Studies.* This chapter has been prepared for publication.

Moland, Evjen-Olsen, Mvungi, & Kohi, 2011). This may primarily be because follow-up in low middle income countries (LMIC) can be challenging and time consuming.

The needs and the challenges affecting women in northern Ghana as they resume their day to day lives, culturally, socially and economically after their OF repair will be critically explored. Insight into the experiences of women within their cultural context and to generate emancipatory knowledge concerning reintegration following an OF repair will be organized around Habermas' critical theory (Edgar, 2006; Habermas, 1991a; 1991b; Mill, Allen, & Morrow, 2001; Singh, 1999). Emancipatory knowledge recognizes the social and political "injustices or inequity, to realize that things could be different, and to piece together complex elements of experience and context to change a situation as it is to a situation that improves people's lives" (Chinn & Kramer, 2011, p.64). Through dialectic communication with women and reflection upon their needs and challenges experienced after OF repair, it is anticipated that the knowledge generated in this study will inform public policy to maximize the health and wellbeing of women returning home after an OF repair.

Methods

Research Design and Setting

A critical ethnographic design was employed using a social justice/health equity lens to critically explore underlying historical, economic, psychosocial and political issues related to reintegration, after OF repair in northern Ghana. The design allowed engagement with participants that challenged dominant societal views and exposed the hidden structures that were oppressive or potentially oppressive. The aim of implementing this design was to consciously strengthen participants so that they were more able to reflect on actions that could be taken to change oppressive forces. Additionally, the design provided a view beyond the metaphors typically used in Ghanaian society, to aid in understanding the hidden meaning behind the importance of socio-economic reintegration after OF repair. Metaphors are often used in Ghanaian culture to speak the unspeakable because Ghanaians often dislike verbal confrontation which threatens social harmony and their own physical wellbeing and public image (Galyan, 1999). For example, an individual states “Baandɔɣu ku di naanzua ka di waligu puhi pololi” translated to mean “the lizard does not eat pepper for the frog to sweat” signifying how she, a woman who has experienced an OF repair, needs to be responsible for her own health actions and wellbeing.

This study was conducted in Upper East, Upper West and Northern regions of northern Ghana. Northern Ghana is known to be exceedingly rural as well as economically and socially disadvantaged (Tsikata & Seini, 2004). The main site for the study was the Tamale Fistula Center located in the northern region, the only state-run fistula center in the country. Additionally, 24 communities were visited for the purpose of data collection.

Sample

Ninety-nine participants were recruited using purposive, convenience and snowball sampling techniques. Participants consisted of women who had experienced an OF repair, family members who identified themselves as the primary caregiver for affected women, health-care providers (HCPs), and stakeholders who were involved in OF care, specifically reintegration. A list of potential participants (women) was retrieved from the Tamale Fistula Clinic (TFC); my primary recruitment centre. Women who met the inclusion criteria were contacted by a staff nurse at the TFC and invited to participate. A family member, if present, was also invited to participate in a separate interview. Women frequently knew of other women who had experienced an OF repair and referred them to the study as potential participants. HCPs and stakeholders were selected on the grounds of potential knowledge they had about OF care. They were initially recruited from the TFC, Ghana Health Service, Government Ministries, and later by word of mouth.

Fieldwork and Data Collection Methods

Fieldwork occurred over two-time intervals: March to June 2014 and April to May 2015. Although observation and the review of government, nongovernment, and TFC documents were used in data collection, semi-structured interviews with each participant were the main method utilized. Interviews ranged from 30 to 90 minutes in length. Participants responded in seven different languages which were translated with the support of a translator. Interviews took a dialogical approach which allowed for stimulating questions to conceptualize the hidden meanings, historically, economically, socially, culturally, and politically, behind the needs and challenges of reintegration post-OF repair.

Ethics approval was received from the ethics review board at the University of Alberta, Canada and the Navrongo Health Research Center, Ghana. The risks and benefits of participation were explained in the local language to participants who were not fluent in English. Participation was voluntary and consent was obtained by signature or thumbprint.

Data Analysis

Interviews were transcribed verbatim. Data were analyzed according to Hammersley and Atkinson's (2007) approach to ethnographic analysis. A subset of the data was randomly selected and read line-by-line to capture key ideas. Memos and reflections were placed in the margins to assist with generating concepts that were then organized into larger categories. Ten categories were used to construct a coding framework, which was then tested on other randomly selected interviews from the four groupings of participants (women, family members, HCPs, and stakeholders). Adjustments to the framework were made before being applied to the remaining data for critical analysis. Nvivo 10.0 software was used for data management. Trustworthiness was maintained by employing forward and backward translation and a stepwise replication procedure, where two members of the research team analysed a subset of the data separately and compared the results to ensure accuracy with how the data was understood.

Findings

Prior experiences shape who we are, influencing how we perceive and manage future events. All women discussed the economic and psychosocial impacts of living with OF, and how those experiences continued to affect their lives after OF repair. Understanding the needs of women after OF repair is complex since it is deeply embedded into the historical, economic, social and cultural fabric of Ghanaian society.

Demographics of Participants

Ninety-nine participants were interviewed. These included women (n= 41) who had experienced an OF repair and were in various stages of the reintegration process, and their family members (n=24) who identified themselves as caregivers; HCPs (n=17) consisting of nurses and physicians at the OF clinic, community health nurses (CHN), nurse-midwives, skilled birth attendants, and nurse administrators who provided care for women after OF repair directly or indirectly; and stakeholders (n=17) consisting of government and nongovernmental officials, religious leaders, community opinion leaders, and women advocacy group leaders who had knowledge about OF care and reintegration programs at a national or community level.

Historical

Individuals living in northern Ghana have fewer opportunities to access the social and economic determinants required for maternal and reproductive health related to inequalities in services. The Human Development Index (HDI) is a tool that measures wellbeing on three dimensions: income, education and health (United Nations Development Programme, [UNDP] 2015). Ghana's HDI is 0.579, giving the country a ranking of 140 out of 187 countries with comparable data and placing Ghana slightly above the regional average for sub-Saharan Africa (Index of Economic Freedom, 2015). While the overall poverty rate in Ghana has declined, in the northern regions it is two to three times the national average (International Fund for Agricultural Development, 2013). According to one government stakeholder:

> Northern Ghana has the highest rates of poverty, illiteracy, malnutrition, and maternal mortality and morbidity in the country. It is underdeveloped in terms of infrastructure; the roads going from community to community are very bad. Sometimes you can't get to a community because of flooding in the rainy season. It is extremely hard to get doctors and nurses to go to these areas and so many times communities are left without services but we are working to make changes but those changes can't happen overnight.

The women in this study who experienced OF repair all lived in the north. All of them were engaged in farming or petty trades except for two who held professional positions. Many women alluded to their troubling economic status that was further influenced by the inequalities between the north and south and the harsh climatic and geographical conditions such as drought, floods, pest infestation and the resultant low crop production. A stakeholder commented:

> We are an NGO… to help women be self-employed so that they [women] won't move to the South. But in the South, in urban areas, there is a lot of work. In northern villages, most of the schools are not effective and there are certain places where there are no schools. Where there are schools they mostly deny [the] girl child from attending school. By so doing she idles and joins women carrying people's goods for money "kayayo" [head porters]...If you ask where woman are, they [the community] would say they [women] have gone to the South to do 'kayayo'. Then you ask why do you allow them to do that? There is nothing we [northern community/family] can do, we don't have money and the farming we do is just a little. It cannot take us to the next season. Women go to 'kayayo' even though the work is tedious and difficult but they are able to work…buy cheap food and send to us. So don't you think that if they have something here [in the north] which can bring daily income, it would be good?

As well, because northern women live in a patrilineal society, women traditionally are unable to inherit or own property, perpetuating gender inequality and hindering economic prosperity. A stakeholder stated:

> Here in the north, we are a patrilineal society… men lower the importance of women traditionally-speaking but all families are different. Women have not been able to own or inherit land in the north. This one woman I know when the husband died the family took everything even the cloths she worn.

Many women also noted that they were unable to make health care decisions, such as whether to seek prenatal or maternity care when in labour, which could have an effect on their maternal/reproductive health. These decisions were often those of their husbands, fathers or other influential males. An elder male family member stated:

> They [the family] tell me when someone is sick and if it is troubling I tell them to go [seek medical treatment]. Here in this family, I tell them to go to the hospital especially when someone is pregnant now that we see what can happen when you don't go. But as head of this family they [the family] will always come and tell me first.

Economic

A condition such as OF impacts both the woman and the family unit, and can have devastating and long lasting effects. Women in this study recalled that working while having a fistula was challenging if not impossible. A woman stated, "when you are leaking urine, and you are smelling you are not trading. You are not working, there is nothing that you will sell, and they will buy. So already you are in a cash trap". Another woman stated:

> I couldn't go to the farm [be]cause it was hard to get water and soap to regularly clean myself. You can't be staying wet like that; the urine burns the skin and the smell, so I had to be sitting at home while my husband was doing the work in the farm.

Accounts such as these illustrate the economic burden OF can have in a society where financial security is dependent on the productivity of all family members. Family members frequently had to take on an additional workload or forgo the income of the family member who was unable to work because of the stigma or ill health of OF. A husband stated:

> When [his wife] came home … it was still big money problems [be]cause she was unable to work for some time. I [husband] had to leave the farm when she was sick and the weeds destroyed almost everything… My small boy would come assist me in the farm…I[husband] had to go to the bush, cut firewood and burn charcoal to sell to make some small money to buy food stuff.

Many women in this study also described the financial cost of seeking treatment. Women sought treatment from traditional and spiritual healers. Traditional Ghanaian medicine includes herbal remedies for specific diseases such as OF, as well as folk knowledge, traditions and health practices, costing the family money or valuable assets such as livestock (Tabi, Powell, & Hodnicki, 2006). One woman stated:

> I paid the juju man 100 Ghana, and he demanded one goat, one sheep and one fowl to sacrifice for pacification to the gods…if you are sick whatever it takes you have to do it… but nothing was helping me.

While OF surgery is publically funded in Ghana through the National Health Insurance Scheme (NHIS), women reported selling everything to pay for hidden costs, such as transportation, accommodation and medical supplies associated with seeking conventional health care. A woman recalls, "I sold all my belongings. My husband even sold the roofing sheets so we could get fuel to be going up and down [to the city] visiting doctors". Another woman commented, "when it was time to go home I had no money for lorry fare, if it wasn't for the nurses who paid I would still be waiting there".

After OF repair, women are instructed not to do strenuous work. This threatens their ability to earn money since in rural Ghana most work requires manual labour. While men work to provide for major cash expenditures (Harley, 2007), women's work provides for the family's basic needs. A woman's livelihood has implications not only for herself but for the livelihood of her family. In Ghana, the economic role of women is important since it is positively associated with wellbeing by way of more spending allocated to food in the home (Women's Economic Empowerment, 2013). A woman noted, “I need capital [economic] to buy food stuff and to provide for my children. That was my biggest worry coming home, finding capital to care for my children and my family”.

Being able to work and provide for one’s family is also a source of pride and intrinsic self-worth, as can be observed when women greet each other on the farm or in the market “adwuma, adwuna” meaning “work, work”. A woman noted:

> It is not easy for me to be sitting down, not to be going to the farm. Women can’t be sitting like that, they will call you lazy and if you need something you can’t buy it. You can’t expect your husband to buy for you.

Recognizing the importance that economics plays in the lives of women after OF repair, the United Nations Population Fund (UNFPA) Ghana and the Ministry of Gender, Children and Social Protection assist in providing skills training to northern women who have experienced an OF repair. One government stakeholder commented:

> The training is aimed toward economic empowerment to support women with fistula… To build their self-esteem and also their advocacy skills so that they can go back to their communities and be doing something. Economically they have not been engaged for some time so what we are doing is giving them something to make a small business.

Skills’ training was offered in soap or pomade making, confectionary, or batik tie-dying. More than half of the women in this study found the program to be beneficial, while those remaining women found it to be unfavourable to their economic plight. As one woman stated:

> It is good and not good. They taught me to make soap. It gives me something to be doing and I get soap to wash my things but the chemicals to make the soap are too expensive. I have to get the chemicals from Tamale, it is too expensive and you have to sell it, gather the money and then buy the chemicals. Sometimes I even have to sell some of my own property to add to go buy so it is not profitable.

Other women voiced similar concerns. Although they believed skills training was a good idea, they noted that the type of skills taught had to complement the economic climate and their physical ability to carry out their work. One woman stated, “they trained me to make batik but here in my village, they don’t buy. So I took the little capital I had to buy slippers, to be selling in the villages over there”. Similarly, another woman indicated she was trained to make dough loafs but she was physically unable to walk long distances to market and sell the loaves. This was because of foot drop, an abnormal gait caused by nerve damage and paralysis of muscles in the lower leg; often a side effect of fistula. She notes:

> I made these dough loafs [pointing to them] to sell but I can’t walk these long distances selling with my leg dragging like that. I had this small girl [daughter] helping me but she is not selling well and you can’t keep the dough loafs two or three days, they will not buy.

The kinds of work supported by the skills training were also deemed by some women to be foreign to the social nature of work that they were used to and preferred. Many of the women in this study were farmers and were used to socializing and sharing information as they did their farm work. A woman stated:

> I stopped doing the trade I was taught as they [community] were not buying. Now I go to the farm and work small. I sit with the others [other women] picking groundnut… I like this better [farming] than soap making; it is more profitable for me. We all go to the farm, even the children and if there is something I can’t be doing someone will help me…its better than sitting home.

This woman noted that she tells women at the farm and in her community about her experience with OF and how they should not delay seeking medical assistance once they are in active labour.

> I tell them. I go around this community and when I see they are pregnant I tell them not to delay. Even at the farm when we are sitting I tell them don’t delay that they don’t want to be suffering like that…to go to the health clinic when they are in labour [be]cause having this condition really hurts you. It affects your capital, relationships, health, and mind.

The health of women is a necessary precondition to a woman's economic strength. A woman who has OF is often unable to effectively obtain productive resources or take advantage of any opportunities from economic activities occurring around her. Equally important is the impact of economic empowerment on a woman's health after OF repair. Increases in a woman's income allow her to make more of an investment in her and her family's health and wellbeing, and government stakeholders can be encouraged to consider this a priority need for women reintegrating post-OF repair.

Psychosocial

After OF repair, women return to an environment where there are strong cultural values and beliefs about being a mother, a wife, and a productive member of society, as well as deeply ingrained beliefs about illnesses and their causes. One woman stated:

> I believed the sickness was bewitched on me by my husband's brother since we had been arguing with him before the delivery. It was not until after I went to the hospital that the nurses told me it was because I delayed in the house.

Additionally, many women and families believe that OF cannot be cured, especially when they had sought traditional treatments which were ineffective. As a result, after an OF repair, many women are stigmatized because of their community's perception of the condition. One woman stated that she became, "…less than human,… not to be counted among women, it is traumatizing. When you have this condition [OF], they [the community] see you as dead".

Some women reported that their husbands had divorced them and they did not have a home to return to, necessitating that they move back with their natal family. For many Ghanaian tribes, particularly the Dagaaba, to be unmarried or divorced is a stain on the clan or family's name (Abdul-Korah, 2014). One woman reported that she was forced to move to another community when her husband would not accept her nor did her natal family or her community accept her. She stated, “my friend had to rent me this room to isolate myself from the shame I brought to my family and community”. The majority of women in this study, however, stated they were welcomed back into their families and communities.

> They accepted me very nicely. When I came it was in the night. The next morning when I woke they could not believe it was me…I had become fat. People from the community passed through [the house] all day to greet me. They danced and sang with joy.

Another woman recalled “it was all joy when I came home. They even organized some drumming and dancing in my house. Everybody including my husband and children and the whole family was full of happiness”.

The feelings of acceptance that come from being acknowledged as someone who is worthwhile after experiencing OF is extremely important for these women. Being accepted in a communal society where individuals depend on and support each other is important for survival and wellbeing. Women who return home after OF repair do everything they can to reconnect with family and community. One participant talked about how community members visited when she was washing clothes:

> They come to see if I am washing rags, the rags I used when I had the sickness. When they see it is only my panties I am washing they go away…now I hang my panties out for them to see.

Another described proving herself to the community after her OF repair: “I had to strip my clothes and expose my body to show them [the community] I was not leaking”.

A common problem after fistula repair, however, is that women may be left with some degree of urinary incontinence, making acceptance into the community more challenging. One woman comments “they see the urine is still coming when I sit and then stand up. They tell me I have wasted my husband’s money looking for a cure…the sickness is a curse that can’t be cured”. Additionally, a HCP noted “women who continue to suffer from incontinence after surgery have a difficult time being accepted. Ghanaian women are supposed to be gentle, clean, and smelling nice…when her colleagues smell her stench they will still stigmatize her". Women who reported experiencing mild urinary incontinence post-repair hid that fact from others. One woman stated, "when I get out of bed it is a little wet…the doctor told me it is okay and I should do my pelvic exercise. I am worried my colleagues [friends] will see I am still leaking small small". This woman continued sharing why she feared others knowing. She stated:

> …if others know they will say I am not cured and I will not be welcomed to community programs. They will not say directly to me but they whisper and they will leave me when I sit. …it is important for women to be doing in the community like preparing food for outdoorings [baptism/ naming ceremony] and wedding if not they will be saying you are lazy and you cannot [be] cooking if you are leaking urine …even church they will not let you go, Muslims and urine, doesn't go, it is seen as dirty.

Women also noted challenges connected with marital intimacy during the illness, "we lived like brother and sister when the urine was flowing. I was not allowed to cook and you know the wife who cooks is the one who he [the husband] meets in the night". This participant continued that her husband told her "it was worrying to him. It wasn't an easy thing to have his wife with this kind of condition. Even now, he is worried, because he wants to have children but he is worried about the sickness coming back".

A woman's ability to have children was not only important for social status (Gyekye, 2003) but also for economic reasons in a country where social programs and old age security are limited. Furthermore, since some Ghanaian men pay a bride wealth,[7] it is expected that his wife will bare him many children. One woman described her need to become pregnant soon after having her fistula repair as well as her desire to have a male child:

> I hope to have a boy soon but the doctor says no sex for six months. I ask God why he has only given me girls because, in our tribe, it's boys who are valued because when you grow old it is the boy who will stay, take up the farming activity and provide for you but girls will marry and go… my husband's family is telling him I must have a boy child.

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[7] Money or goods given to the family of a bride by the bridegroom or his kin to establish his rights over the woman

Overall, women in this study suggested that being culturally accepted back into their community after OF repair was central to reintegration. However, acceptance came only when women could "be counted among women". This points to an increased need for OF awareness within northern Ghanaian communities.

Political/Emancipatory

Many women in this study acknowledged feeling powerless during various stages of OF and OF care. One woman stated she had suicidal ideations at her lowest point while experiencing OF. However, the desire to protect her reputation in the community combined with the fear of leaving her child without a mother gave her the strength to live and find a cure. She stated:

> I use to think of committing suicide, but then I thought they [the community] will know I have the sickness. They will say I have gone somewhere to develop that condition. You know blacks they will say I have gone to sleep with a different man or something. Who would care for my little boy? I needed to live, to find a cure to this sickness. It has not been easy but I am better now and look at my happy boy, he has his mother.

Women in this study verbalized a call to action to advocate for themselves and for others. When they spoke about persevering with little education in how to seek for care to find their way through a health system, they demonstrated remarkable resilience. A woman stated:

> You know, you become powerless to the system when you don't have knowledge. But you see, and then you don't have words to say it. I found somebody to direct me… show me that there is a place where they help people like me. But if I had a daughter like you, counselling me, who is educated, she'll be able to tell me this is how you do this, this is the information, and this is where you go.

Women were able to access the resources they needed to seek treatment for their condition despite many not having the ability to read and write. Through this process, they learned to be advocates for other women experiencing OF in their communities and provided emotional support for others who had returned home after OF repair. A community stakeholder and women's leader noted:

> I am the masiear [plays a traditional role, as a woman leader, in northern communities] of this community. I am chief of the women and I organize them [women] on their issues. I get the information that they need… Knowing women with the sickness [OF] in this community…whenever there is a program [meeting] we try to talk about it [OF] to educate women on it. Smaller groupings like outdooring [baptism/naming ceremony] we [women] also try to reach out and chat among ourselves as women so that we will know about it… We tell women it is not a curse but problems with labour.

Similarly, a CHN in a rural Ghanaian community initiated an OF awareness campaign to educate the community, including men and school children, about OF. She also stated that in the community, a play about OF was performed by school children as part of the awareness campaign:

> Education is the key… When you educate the children, girls, and boys, about seeing the dangers they will tell their mothers who are still of childbearing age. They will want to find out, Mama have you gone to the clinic, let me see your card… young boys learn not to refuse their wives from going to the hospital for whatever reason.

Women in this community who had returned home after their OF repair verbalized that the creation of awareness and the support from this nurse had assisted them to be accepted in the community and had encouraged them to push forward as valued human beings striving to reach their full potential. A woman stated:

> If it was not for Mama [CHN] I would be nothing. She helped me to be someone, to believe in myself when I came home [post-OF]. She let me work in the health clinic doing small things. Now I am learning to read and to type.

Many women also expressed feelings of obligation to have their plight heard, and in the process received a sense of authority and power over their situation.

> The white people come, wanting to know how it was [having OF] and so I tell them. I am responsible to tell them [be]cause they know the book [educated] and they know how to write about fistula for others to know.

Discussion

The majority of women in this study noted they were welcomed home post-OF repair. However, they did indicate that possessing economic capital and having social acceptance were essential to successful reintegration. These two factors are intertwined and historically and culturally rooted.

The "north-south divide" in Ghana places the northern people at an economic disadvantage, the result of unequal and uneven development inherited from British colonialism (Akologo & van Klinken, 2008). This underdevelopment and lack of adequate resources have increased the risk of maternal morbidities partially as a result of inadequate access to health care services in remote rural areas of the north. Cultural practices in northern Ghana regarding a woman's lack of autonomy over her maternal/reproductive health, the lack of skilled birth attendants, and the knowledge and preparation of those responsible for maternal health care delivery also contribute to the occurrence of OF.

An individual's prior experiences can greatly affect their perception of future events. Much of our knowledge about the external world is based on inferences that arise from our assumptions about the past. For example, in this study, a woman's account about her illness-treatment trajectory while experiencing OF and the financial difficulties incurred potentially shape her views about returning home after her repair. It is important to first understand and then acknowledge these assumptions, assess their impact and challenge current practices to move towards a way of reintegrating, which includes emancipatory knowledge. Habermas noted that emancipatory knowledge "involves interest in the way one's history and biography has expressed itself in the way one sees oneself, one's roles and social expectations" (Haneef, Zulfiqar, Alvi, & Faisal, 2014, p. 504). Engaging women in reflecting on their underlying needs and challenges post-OF repair leads to deeper understanding of a culture of reintegration in northern Ghana, and can help to bring about improved public policy in women's maternal and reproductive health.

Economic capital is a concern for women returning home since the ability to earn money ensures the basic livelihood and safety of the family (Opoku-Ware, 2014). Many of these women invested their life savings in seeking a cure thus placing them in a position of impoverishment upon their return home after their repair. Training programs offer women skills in soap making, confectionery, or batik tie-dye. Many women in this study found these skills to be inappropriate in remote Ghanaian communities where a limited market for such products exists. Women value the opportunity to take part in skills training programs but need to be involved in deciding the types of skills required for practical employment post-repair. Employment also offers women a sense of self-worth and dignity and defines the quality of the community. For example, suitable skills training assists women post-repair to move into progressively higher paying and more satisfying work with suitable remuneration, and gender equality (Somavia, 2014).

Many women in this study recounted how their social experiences were associated with the stigma of having OF. OF can bring great humiliation (Semere & Nour, 2008) and can have a lasting social impact for women even after having an OF repair. Ghanaian cultural values, beliefs, and practices impacted the reintegration process particularly in how many of the communities viewed OF not as a medical condition, but as a curse or a punishment for some wrongdoing (Nuertey, 2013). Acceptance into the community and family life as a wife and as a mother holds great cultural status (Gyekye, 2003), and the women in this study recognized that it is the responsibility of a woman returning home post-repair to verify that she is ‘cured’ and worthy of acceptance back into the community. However, women who continued to have urinary incontinence after their OF repair reported a more challenging reintegration experience as their condition reaffirmed the community and family’s belief that OF is untreatable.

Many who experienced OF, along with women leaders, have initiated awareness campaigns about OF in their communities with the aim of improving the reintegration experiences of others who have had OF-repair. Serving as fistula advocates these women promote improved maternal, reproductive, and fistula care within their communities. However, these grass roots movements are only the beginning. Political influence at the national level is necessary to initiate and sustain change. This can only be acquired by embracing the “wider range of historical and contextual considerations…emphasizes the fundamental intent to seek freedom from conditions largely hidden that restricts the realization of full human potential” (Chinn & Kramer, 2011, p. 87-88). Developing awareness of these factors is an important step forward in creating social and political change in OF care/reintegration.

Conclusion

Northern Ghana was overlooked during colonial times when government structures such as hospitals, schools, and roads were being built in the south, creating what has come to be known as the north-south economic divide. These effects are still experienced today, with the north being grossly underdeveloped in comparison to many areas in its southern counterpart. This contributes to a high rate of OF in the north in comparison to other regions of the country. The needs and challenges experienced by women who are reintegrating into their families and communities after OF repair are important. This knowledge can be developed to inform public policy about the reintegration process and to make recommendations where national priorities could focus. Many of the needs and challenges post-OF repair are historically and culturally rooted. Economic and psychosocial factors contribute to determining how successful women reintegrate after their repair. Securing capital is a huge concern for women who return home since most have spent their life savings seeking a cure. Skill generating activities have helped to offset the financial hardship for some but not all women post-repair. A closer look at the types and suitability of trades for women is necessary to strengthen a woman's economic capability.

Acceptance is a fundamental human need that brings about a sense of belonging or "being home". For many women, the need to prove themselves worthy post-repair to be accepted back into their communities is humiliating and demonstrates the need for more community awareness of the causes and treatment of OF. Many women, family members and those working with women post-OF repair acknowledge the importance of being able to fully participate in day-to-day life without fear of rejection. Despite the challenges, women post-OF repair demonstrated great resilience to seek out OF services and to educate themselves in order to reach their full potential. Additionally, many women post-OF experienced a sense of obligation to have their plight heard, which in the process gave them a sense of control over their situation.

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Chapter 5: Reintegration of Women Post-Obstetrical Fistula Repair: Perspective of Family Caregivers in Northern Ghana[8]

An obstetric fistula (OF) is a serious condition most often associated with prolonged obstructed labour (Semere & Nour, 2008) where emergency obstetrical care is frequently not accessed. 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). Between 2011 and 2014 a total of 1,538 women were reported to be assessed for OF in Ghana with the highest number of consultations occurring in the Northern region (Ghana Health Service, 2015; Ghana News Agency, 2015). This has dramatic obstetric and social consequences. Although OF can be surgically corrected (Avevor, 2013; EngenderHealth, 2004), life beyond the repair may cause intense emotional, social, and economic ramifications for women and their families (Yeakey, Chipeta, Rijken, Taulo, & Tsui, 2015). Family support is essential to assist women in reintegrating back to the life they had prior to the development of OF (Donnelly, Oliveras, Tilahun, Belachew, & Asnake, 2015). Since social reintegration after an OF repair is an important aspect of the healing process, women who have extended family support with day-to-day activities and financial help describe their "transition back into the community as being easy" (Pope, Bangser, & Requejo, 2011, p.866).

It is important to understand how family caregivers are affected by a woman's return after OF repair. The caregiver's physical and emotional health can influence a woman's health, welfare and successful reintegration (Bowen, 2006). The experiences of family caregivers of women after OF repair living in northern Ghana, the types of supports they perceive to be

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[8] Jarvis et al., (2016). Reintegration of women post-obstetrical fistula repair: Perspective of family caregivers in northern Ghana. *Journal of Family Nursing.* This chapter has been prepared for publication.

available, and the strategies they find helpful in managing family care giving will be critically explored.

Family is a fundamental and highly valued institution in Ghana, which customarily includes both nuclear and extended kin (Gyekye, 2003). Traditionally the extended family functions as a support group in which each member is responsible for and obligated to assist others, and is entitled to receive help when needed (Tettey, Puplampu, & Berman, 2003). There is a change in Ghanaian society with urbanization and migration slowly creating a shift away from a traditional way of life (Tettey et al., 2003). Change of this type challenges family values, creates a diminished reliance on the extended family and has implications for the provision of care where few formal supports exist. Families are troubled with providing unpaid informal care giving services when illness, disability, or hardship arise (Owusu-Ansah, 2015). This is the case in families whose members care for women reintegrating home after an OF repair.

Testimony about the roles and responsibilities of family caregivers in northern Ghana can inform decision-makers, opinion leaders, health-care providers (HCPs) and the general public about the significant role family members play in supporting women to reintegrate home after an OF repair. Moreover, the knowledge generated in this study can further inform those in government agencies about the need for enhancing formal supports for family caregivers of women experiencing OF. This is especially important given the country's emerging trend away from extended family and the erosion of traditional kinship ties.

Methods

Design and Setting

Critical ethnography was the methodology used in this study 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). Critical ethnographic methods help to engage with a potentially disenfranchised group (Madison, 2005; Thomas, 1993) such as family members caring for women reintegrating after their OF repair and to advocate for their needs.

The critical aspect of this approach necessitated taking an ethical stance against issues of injustice and making recommendations to promote equality. Through exploring the experiences, values, beliefs and practices of family caregivers, new insights emerge about a culture of reintegration post-OF repair. These insights lead to recommendations to enhance or develop the utilization of formal support systems for women who are reintegrating after receiving an OF repair.

This article reports on a segment (n=24 family members and n=17 HCPs) of a larger study (n=99) aimed at exploring a culture of reintegration post-OF repair. The research took place over two-time intervals from March to June, 2014 and April to May, 2015. The study location was northern Ghana known to be religiously, culturally, linguistically, economically and politically diverse (Government of Ghana, 2016). Ethics approval for this project 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 of the risks and the voluntary nature of participating.

Recruitment and Sample

Participants for the larger study were recruited using convenience, purposive and snowball sampling. The main recruitment sites were the Tamale Fistula Center, along with 24 northern communities. To be eligible, participants were:

- A woman who had experienced an OF repair a minimum of three 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 wellbeing of others in the family, while a secondary caregiver provides assistance to the primary caregiver (Goodhead & McDonald, 2007). Only family members of women interviewed were eligible.
- A HCP or community stakeholder who was directly or indirectly involved in OF care or reintegration post-repair.

A total of 99 participants were interviewed, including 41 women, 24 family members, 17 HCPs and 17 community stakeholders. The data used to inform the results in this article were limited to family caregivers and HCP. HCPs consisted of nurses and physicians at the OF clinic, community health nurses (CHN), nurse-midwives, nurse administers, traditional birth attendants, and traditional healers. Stakeholders consisted of government and nongovernmental officials, and opinion leaders.

Data Collection

Observations, semi-structured interviews and a review of government, and nongovernmental documents related to OF care, such as: the World Health Organization (WHO) Preventing Chronic Diseases: A Vital Investment; Africa Social Protection Policy, Ghana's Social Security and National Insurance Trust (SSNT), Livelihood Empowerment Against Poverty (LEAP) program were utilized in data collection. Semi-structured interviews were a key tool allowing for a dialogical approach that helped in examining the dominant beliefs shaping the reality of the participants (Sullivan, 2012). Interviews were conducted in seven different languages with the support of translators. Interviews were audio recorded and lasted 30 to 90 minutes. Field notes were written or audio recorded after each interview. The interview guide focused on questions related to 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 (i.e. education, medical/nursing follow-up, spiritual support). Data collection continued until no new information emerged which could inform the inquiry.

Data Analysis

Interviews were transcribed verbatim and a subset of the interviews were translated backward and forward to ensure accuracy. Data were analyzed using to Hammersley & Atkinson's (2007) approach to ethnographic analysis. A subset of the data was randomly selected and independently coded by two members of the research team and compared to ensure accuracy and consistency in interpretation. The data subset was read line-by-line and keywords and phrases were highlighted. The data were then re-read, and initial thoughts, reflections, and memos were noted in the margin, and finally concepts were generated. These concepts were organized into ten categories. A coding framework was developed and tested using randomly selected interviews from the main data set. After the coding frame was deemed appropriate for analysis it was then applied to the remaining data. Nvivo 10.0 software was used for data management.

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 males and two female identified themselves as primary caregivers. The rest were female family members who identified themselves as secondary caregivers. In many Ghanaian societies, senior males are responsible for overseeing family needs and the distribution of family resources (Gyekye, 2003). One household head, the senior male in the family, identified his role as family head as follows:

> For me, in this compound [family home] I'm like a wooden bar. You know when they build these round huts usually in the middle, of these thatch houses, there is always a bar that will hold the other pieces together. It's like a tree, the trunk of a tree with other branches hanging on it. That is my role in this compound. I am that tree trunk and the other members of this house are resting on me. Anything that concerns the welfare of everybody in this compound is my responsibility because I am the senior most brother.

All participating family members lived in northern Ghana, most in small rural communities with inadequate infrastructure in comparison to larger northern communities or metropolis areas. The majority of the 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 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 small things to get food stuff… Women are social creatures… seen in the community helping with outdoorings [baptisms] and all those things…they care for small children and the very old. But as for us men, we work hard in the fields from sunrise to sunset.

Twenty-two of the 24 family members who participated stated they were working outside the home, primarily in farm activities.

Experiences of Family Caregivers: Beyond Obstetrical Fistula Repair

Relieved from the burden of fistula. The majority of 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." Another husband stated, "when I look at her now I see peace in my spirit. The day she returned home we killed a fowl to make some celebration. …I'm very happy my wife is feeling fine."

However, it is assumed that a family member's needs may change as a woman progresses through the reintegration process. As this family member stated:

> We [the family] were all happy at first when she came home. We believed the sickness was no more and that she was coming home to be part of this family, working alongside me in the farm but that has not happened. After the operation, we thought it was all over but she still needs assistance [nine months post-surgical repair]. It's hard on me. Then she said a small amount of urine was coming. Doctor say its okay but how okay when she is like a small child needing care… even after the operation the sickness is still keeping us down …she can't do many things.

The reintegration period is a subjective experience and its duration is determined by the person who is reintegrating as well as 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. A woman recovering from an OF repair and reintegrating into her family may be exempt from her family and social responsibilities, thus displacing her duties on other family members. A family member commented:

> We [family] are being very cautious and therefore we 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. Since most women lived with an extended or polygamous family in a communal environment the burden of care was shared. This husband stated:

> In this compound, 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 fire-wood" (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, also known as rivals, caring for their husband's other wife post-OF. As one second wife commented, "why should I have to be carrying her [women with OF repair] things and for her to be lying down like that doing nothing." Additionally, some family members indicated that caring for a woman after OF placed their own health and wellbeing at risk. 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…

Emotional. 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, all reflected with sadness too when their family member had the condition. This suggests the powerful effect of OF and how the emotional baggage associated with the condition frequently extends into the reintegration period. A husband commented:

> I am overjoyed 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. I have to make her strong before I take her back so I sold everything and came here.

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. …they [the community] said it could not be cured but I know now they were "Doubting Thomases". 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 family members spoke about feelings of shame and remorse once their relative had recovered and returned home. This was especially true 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.

Additionally, 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 over time with 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 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. It was through my birth that she became sick.

Family members caring for women also discussed the emotional confusion of being stigmatized themselves 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…when it breaks down. Usually, I go around to houses in the village to collect money. And when I went out to collect money 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 to collect money.

Families grieved the loss of their unborn child as well as the loss of family hopes and dreams for the future. This was another sentiment identified by family members that carried a heavy emotional burden during the reintegration period. The consequences of OF may cause physical or biological changes that affect family relationships and plans for 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 her husband a child. We are very much disappointed but that is how it is.

Some husbands felt emotionally detached from their wives since they were unable to have sexual intercourse with them for three to six months after surgery. Husbands noted that their lack of understanding about abstinence led to misunderstandings.

> 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, as a husband stated, "once bitten twice shy."

Economic. Economic hardship and financial strain occur when a woman is reintegrating to her family and community due to 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 family member 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 due to the loss of an income, decisions must be made about how to prioritize needs. This may mean that commodities such as a child's schooling are not possible either because the family cannot afford the school fees or uniforms, or because the children are needed as income earners in place of their mother. A husband 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.

Family Caregivers Perceptions of Available Supports

Services to caregivers for others are not always available in northern Ghana because they are believed to be a part of an informal system of care (Sanuade & Boatemaa, 2014). Avenues of support commonly mentioned by participants were Ghana's National Health Insurance Scheme (NHIS), UNFPA and the Ministry of Gender Children and Social Protection's skills training program, and HCPs.

It was suggested by many family caregivers that Ghana's NHIS has helped to offset the medical costs associated with OF treatment and care. One family member stated:

> After the surgery, my daughter came home and fell. She broke the sutures and she started leaking again. We waited for some time thinking it would get better but we had to go to the clinic. She needed more surgery and medicines. It was serious, we had no money… but the national health insurance paid for us.

Although most family caregivers acknowledged the NHIS, they reported being unclear about the types of medical resources and supports that are available and covered under the NHIS guidelines. A husband spoke of how his wife developed foot drop, a common consequence of OF. This resulted in weakness in the muscles of her foot, impairing her gait and causing her to be more dependent on her family. Her family had no knowledge that physiotherapy was possible and available through the NHIS so they were unable to utilize it. The husband stated:

> She [woman with OF] has this foot drop and because there is numbness, that was after she was discharged, she walks a little and the leg becomes very stiff. As far as physio is concerned we had nothing like that, no exercises. Nobody helped, nobody told us oh, you should do this, you can get this here... Health workers should know the kind of help we need and help us to get it.

UNFPA and the Ministry of Gender, Children and Social Protection provided a two-week training program after OF repair for women to acquire skills in an income generating activity.

This program was initiated to support women and has benefited families in assisting their relatives in generating income. A husband stated the positive effect this program had for him and his family:

> My wife has been taught soap making. The money she gets from it helps to buy those small things for herself. Sometimes I don't have money to give her but now she can manage and that is better for me.

Less positive reviews of skill training programs placed an added burden on family resources. This emphasizes the need for family input in skill selection. A husband stated:

> My wife was taught to make these dough loafs but it was not working. She was not able to sell and her health was not good. We were losing capital so I told her to stop. Some people came around, an NGO or something, a few months back and told her she must keep trying because they gave money to train her. It was causing a whole lot of stress on me, buying flour, buying oil and finally I had to tell her just to stop.

HCPs were frequent sources of support in providing counselling and information about a woman's care post-OF. A husband stated:

> I consented to the hysterectomy but my wife didn't know and I said not to tell her until she gets better. Keeping the secret was really worrying me and I did not know how to say it. We had to visit the hospital for follow-up and I told them [HCPs] she still does not know what really happened in the theater. The nurse spoke to me and said we will sit her down and break the news to her together, that she no longer can give birth. That's the kind of support we had, just to be counselled was good for me and my wife.

Although families indicated the benefit of counselling, HCPs in the community acknowledged feeling unprepared to provide such support. A CHN stated:

> I haven't really had any special training on fistula. I don't know much about fistula. We talk to them [families and women with OF]… but specifically on fistula no because I really feel not comfortable. I haven't had any training on it.

In a few cases, families reported receiving no follow-up support after OF surgery excluding their three month recheck at the fistula clinic. A family member stated:

> …It would be a big help to have someone [health professional] come to this house to give some small encouragement but no one like that has come to this village. No one has

> come to this house like that to see how we are faring until today. We had follow-up with the nurse after the operation in Tamale but it [is] finished.

A HCP confirmed that community follow-up support was fragmented since there is no formal and consistent community referral system. A HCP in a leadership position shared:

> We don't have any formal referral system or anything. We just inform our public health team that a woman from village A came and had fistula repair and she has gone home so anytime you get to that area just try and find out how she is doing. So somebody probably gets there with the motorbike …but I can't say for sure.

Furthermore, many family members conceded that all forms of government support were political. A family member stated, "support that comes from the government they will ask which party do you belong to, there is kind of politics in it. You must belong to my party before I can support you". Additionally, many family members noted how monetary support in particular never reaches the individuals it was meant to assist. A family member stated:

> Even when they [a donor] give twenty Cedi to [women with OF], the DCE [District Chief Executive] will take small and the assembly man will also take small and before it will get to [a woman with OF], fifteen Cedi will go, leaving her with only five.

Coping Strategies Identified By Family Caregivers After Fistula Repair

Family caregivers rely on both problem and emotion-focused coping strategies to help them support women reintegrating after OF repair. Problem-focused strategies used by participants in this study consisted of trying to find solutions to alleviate the family's economic burdens, seeking health information, and actively trying to ease or share the physical burden of providing care to a woman after OF.

A husband spoke about how the family endeavored to use their family resources to improve their economic situation. He shared that his wife's business was incompatible with the post-OF instructions they had received. The family used their children to assist their mother with the more strenuous tasks of selling goods allowing her to earn a small income. The husband stated:

> …money was a big problem for us when [wife] came home. …She had some small training…but she could not walk around all those villages over there so we got some [her] children to be helping her. [She] makes dough loafs and the children are selling making business and some small profit.

Similarly, a husband explained how he sought information from the nurses at the fistula clinic after hearing from a friend about the skills training program offered to women post-OF repair.

> I heard from this one woman in that village down there [pointing] about this program that helps women after the urine sickness…when [wife] went for follow-up at the clinic I asked the nurses about it, that is how we came to know about it.

Primary family caregivers tried to decrease the amount of physical and emotional burden, which was placed on them by asking other family members to provide assistance. A husband stated how the support of his mother was vital to the care and wellbeing of the family after repair.

> It is my mother that has been helping us since [wife] came home. She [the mother] comes and cooks for us, washing our things… she cares for our small boy. My mother gives small money to help us support ourselves. …it is my mother who sits with [wife] when I am gone to the farm and tells her to have faith that God is the giver of good things.

Emotion-focused strategies used to regulate the stress of care giving included seeking understanding and moral support from others and having faith in God to assist them through the difficult times of providing care to a woman post-OF repair. Many family members mentioned feelings of loneliness in managing the everyday tasks. Talking with and sharing recreational and social activities with a friend helped to ease the emotional, physical and financial stressors of supporting a family member post-repair. A family member commented:

> I use to farm with this man in the village. He would come and talk with me, help me keep a clear mind. He would encourage me to give everything to God. …he asked me to go to the river close to our community to fish. It was nice, we talked and talked. I felt like he understood my situation. At the end of the day, he sold the fish and came and gave me the money. I really appreciated his friendship when I was deeply troubled.

Likewise, the use of prayer to manage difficult times was frequently a coping strategy for families who cared for women post-OF repair. A family member noted:

> When she came home she could not do anything for herself. We prayed to God to help us, to give her strength, to go back to her normal life and normal activities before the operation. We prayed that God would guide our family through this hard time and …to have the wisdom to manage it well.

Discussion

The experiences of family caregivers living in northern Ghana was highlighted. Family members who identified themselves as primary caregivers were predominately male. Common emerging themes focused on the physical, emotional and economic burden of care related to the process of reintegration in rural Ghana. Although some formal supports are provided, family members perceive it to be limited and must often compensate by sourcing support from other family members or by having faith in God. Through exploring the experiences, values, beliefs, and practices of family caregivers, insights gained lead to recommendations to assist family caregivers of women reintegrating post-OF repair in northern Ghana.

Although family members in this study described their joy in having their relatives return home after their surgical repair, they admitted that the high degree of care-giving 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 socio-economic wellbeing of the individual reintegrating as well as 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 such as 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 may be the time when family support and education is most needed to minimize family difficulties.

Traditionally in Ghana, women are obliged to spend time working in the family business, typically farming in the north, raising children, and tending to household chores (i.e. fetching water, gathering firewood, cooking) (Tengey, n.d.). During the OF healing and reintegration period, a woman requires rehabilitation, which seriously impacts 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. As 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 in this study 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 while junior wives enjoy preferential status (Slonim-Nevo & Al-Krenawi, 2006). While most polygamous families interviewed were supportive of each other, feelings of resentment are not unusual when the care-giving role is imposed upon an individual. The role may 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 some male family members often indicated that they were unable to express their fears. The norms for emotional expression are culturally determined (Kuo, 2011). Many male family members in this study believed they were expected to be emotionally strong. This is depicted in the common saying "Barima nsu", translated as "a man does not weep" (Boaky, 2010). Ghanaian men choose to withhold their feelings or to speak metaphorically, creating vagueness and ambiguity in what is being communicated in order 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, as family members recalled a previous time when they had dishonoured their family member for having OF. It was important for caregivers to be aware of and to validate these feelings since the role of care giving 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 in order 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 labour 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 as "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).

Additionally, family caregivers who were husbands or partners commented that they felt emotionally disconnected from their wives since HCP 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 wellbeing. 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 (P. Boakye, personal communication, May 15, 2015) but HCPs 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 towards 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).

The economic challenges for families caring for relatives post-OF repair have been 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, as well as the loss of an income earner within the family. The loss of income and productivity may 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. UNFPA and the Ministry of Gender, Children and Social Protection provide a two week training program for women post-OF repair, with the aim of helping them to acquire income generating skills. This program, however, has been met with mixed reviews from family caregivers. Many family members vehemently believe that financial support should directly benefit the family as opposed to the individual woman who experienced the OF repair.

Family members in this study acknowledged Ghana's NHIS, implemented in 2003 by the National Health Insurance Act, as a health resource. The mandate of the NHIS is "…to ensure access to basic health care services to all residents" (p.7) at minimal cost to subscribers (Government of Ghana, 2003). However, there were a number of instances where families reported not having supports or not being aware that support services were available. Legislatively, Ghana's welfare programs assist in the care of the sick, aged, or injured but they are available only to individuals employed in the formal sector of the economy (Kumado & Gockel, 2003; La Verle, 1994; National Pensions Regulatory, 2010). With approximately 85% of Ghanaians working in the informal sector (Ghana Statistical Service, 2012) the reliance on traditional family care-providing structures is essential to care for women post-OF repair.

It was suggested by many family caregivers that formal support networks are political. Ghana's health sector has been perceived to be susceptible to corruption because of the "uncertainties around the demands for services as seen in many developing countries and particularly in formed centrally-planned economies, where bribery in the form of informal payments from patients to HCPs is common" (Agbenorku, 2012, p.623). In 2010 the World Bank reported that 95% of Ghana's health care resources were "being pocketed" by individuals. This placed Ghana as the second most corrupt country in Africa when it came to managing health care resources, suggesting that officials are failing to deliver health services to the people (Owusu-Bempah, Amoako, Frempong, & Assampong, 2013).

Family caregivers of a woman reintegrating after OF repair engaged in various strategies to manage the physical, emotional and financial consequences of her care. Coping strategies employed to master, tolerate, or reduce the burden of care were often problem or emotion focused. Family caregivers sought health information from HCPs to better support their relatives. As well, they explored alternative support methods, such as prayer, to reduce their burden of care. The belief in a Supreme Being is important in the lives of Ghanaians where God is ever present, providing spiritual support and strength during troubling times (Gyekye, 2003; Gyekye, 2013). Petitions for healing and good health are one of the most common subjects of prayer among Ghanaians (Gyekye, 2003). Studies suggest that prayer does help family caregivers to deal with the burden of care (Aziato & Adejumo, 2014; Papastavrou, Charalambous, & Tsangari, 2012). Being part of a spiritual or religious community also provides a sense of encouragement and social solidarity when people are experiencing hardships.

In the Ghanaian tradition, family members rely on each other to provide physical, emotional, and financial support when required (Gyekye, 2003). Research has shown that caregiving is a shared experience with many family members providing additional support to help offset the burden of care (Barbosa, Figueiredo, Sousa, & Demain, 2011; Gaugler, Mendiondo, Smith, & Schmitt, 2003; Penrod, Kane, Kane, & Finch, 1995; Tennstedt, McKinlay, & Sullivan, 1989). It is important for caregivers to spend time away from their care-giving responsibilities, so to maintain their own wellbeing and self-care (Barbosa et al., 2011).

Urbanization and migration are intruding into Ghana's traditional family structure. Family heads and elders no longer have control over the economic lives of their members; "religious beliefs, which use to motivate people in the area of social control are now viewed with skepticism" (p.152); migration has taken people away from their families; and family policy has given preference to the nuclear family at the expense of extended kinship ties (Nukunya, 2011). It is evident that without the assistance of extended family members, primary caregivers in this study would be overwhelmed. Given the evolving role of family and the lack of available and adequate community resources, the need for formal care-giving support is enormous. Opinion leaders, HCPs, and the community are encouraged to lobby government for more and improved formalized support by speaking with and inviting political leaders to OF led initiatives. This has the potential not only to assist families who care for women post-OF repair but all Ghanaian families in need of care-giving support and services.

Recommendations

Recommendations to help support family members who care for women post-OF repair in Ghana should be directed towards 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 when they are available since 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. In order to accomplish this, HCPs must be able to assess the home environment and the availability and accessibility of support systems for both the woman and her family. HCPs 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 HCPs are competent in their role as family health educators and OF care advocates. Professional continuing educational courses and mentorship programs regulated through professional associations may be one method of achieving these competencies. Families also need to be given a safe and reassuring environment to ask questions in order 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. CHNs need to be formally made aware of and responsible for families in their district who are caring for women post-OF. Technical strategies such as the Mobile Technology for Community Health (MOTECH) have been successfully implemented in Ghana since 2010 for the purpose of improving maternal health care. Similarly, mobile phones could be utilized to provide support (health information, counselling) 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 not-for-profit organization, Net Organization for Youth Empowerment and Development (NOYED) (2016) Ghana. This program utilizes community volunteers to disseminate health information about how to prevent and treat OF. There are many not-for-profit 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 as well as expanding their initiatives to include community awareness about how to support families and women returning home post-OF repair. This may be initiated through the Fistula Task Force, established in 2014, consisting of a group of government and community stakeholders interested in OF care. Males 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 in order to support other families and to validate the need for formal family supports.

Economic difficulties continue to be an issue. UNFPA 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. An approach is required to ensure that all women post-OF repair and their families are presented with opportunities to participate in training programs. 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 world view "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 first-hand 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 since many family members are the primary caregivers and the decisions made about OF impacts their wellbeing as well as 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 family have traditionally played an important role in care giving, but recent social change has weakened these kinship ties and has placed an additional strain 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 types of supports accessed, and the coping techniques used to manage the burden. It is suggested that more and improved formal supports are needed to assist family caregivers. The recommendations made highlight the areas requiring government, nongovernmental, and community attention as identified by family caregivers and HCPs.

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Chapter 6: Reintegration Post-Obstetric Fistula in Northern Ghana: Recommendations and Implications for Policy Development and Nursing Practice [9]

Although obstetric fistula (OF) is highly prevalent in sub-Saharan Africa, OF care, particularly the aspect of social reintegration post-surgical repair, is an understudied phenomenon (Wall, 2012a). After conducting a study exploring a culture of reintegration with women who have experienced OF repair in northern Ghana, West Africa three manuscripts were prepared for publication. This paper builds on those manuscripts that examine the equalities /inequalities in post-OF reintegration programs in northern Ghana (Jarvis et.al, 2016a in review), the needs and challenges of women reintegrating home after an OF repair (Jarvis et.al, 2016b in review) and the perspective of Ghanaian family caregivers of women post-OF repair (Jarvis et.al, 2016c in review), for the purpose of identifying policy and nursing practice recommendations related to reintegration post-OF in northern Ghana.

Background

OF is defined as a "hole" between the vagina and the bladder (vesico-vaginal fistula) and/or between the vagina and the rectum (recto-vaginal fistula) (Bangser, 2006). OF most typically occurs in low or low-middle income countries as a result of prolonged obstructed labour when emergency maternity care is unavailable, inadequate, underutilized, or inaccessible (Donnay & Ramsey, 2006; World Health Organization [WHO] Report, 2005). Women who develop an OF experience a multitude of physical and psychosocial injuries as a result of the unremitting and uncontrollable leakage of urine and/or feces through the vagina (Wall, 2012b). A range of physical injuries known as the "obstructed labour injury complex", include urological, gynecological, neurological, dermatological, and musculoskeletal injuries

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[9] Jarvis et al., (2016). Reintegration Post-Obstetric Fistula in Northern Ghana: Recommendations and Implications for Policy Development and Nursing Practice. *International Nursing Review.* This chapter has been prepared for publication.

(Arrowsmith, Hamlin, & Wall, 1996). Additionally, women who experience OF also encounter social and economic problems such as being ostracized from their family and community, leading to divorce, abandonment, isolation and exclusion from social and religious activities. When OF is stigmatized, a woman’s level of poverty and associated malnutrition increases while her self-esteem decreases; creating feelings of depression, disappointment, anxiety, anger, and sometimes ideations of suicide (Ahmed & Holtz, 2007).

The WHO (2014) estimates that globally more than two million young women live with untreated fistula, and estimates that between 50,000 and 100,000 new cases of OF affect women annually. Statistical data are obtained from countries’ needs assessments, as well as provider and institutional reports; it is possible that numbers from population-based epidemiological studies would be even higher (Adler, Ronsmans, Calvert, & Filippi, 2013). It is challenging to determine the true magnitude of OF because of its hidden nature which affects the most marginalized people in society—those who are young, poor, illiterate girls and women. In a recent study where the burden of OF within Ghana was explored 1,538 OF cases were reported in women between January, 2011and July, 2014 (Ghana Health Service, 2015). The majority were reported in the northern region (Ghana Health Service, 2015), an area known to be exceedingly rural and economically deprived (Lomotey, 2015; Osei-Assibey, 2014). It is critical to be aware of society’s acknowledgement of and actions in addressing OF as an international public health concern. Failure to do so violates a woman’s human right to reproductive health care (Cook, Dicken, & Syed, 2004).

The main social determinants contributing to OF are poverty, early marriage, early pregnancy and childbirth, inadequate childbirth spacing, a lack of or inadequate access to maternal health care, and harmful traditional practices such as female genital cutting (Tollosa &

Kibret, 2013). Prevention is the key to eradicating OF; however, providing care for those women who experience OF is also critically important as this allows women to reclaim their lives and be respected as members of society. It is difficult to quantify the economic worth of human life because of the morality, homogeneity, subjectivity and complexity the issue holds (Rice & Cooper, 1967). However, the scientific evidence illustrates the economic burden of chronic illnesses and disabilities for society and how equipping policy makers to act against such burdens promptly leads to improved societal outcomes for all (Hammond & Levine, 2010; WHO, 2003; WHO, 2015; Wolf, 1998).

There are three components of OF care: awareness, treatment, and reintegration (Fistula Care, 2012). These components are intertwined and difficult to discuss independently since a change in one has implications for the other two components. "Understanding that one must treat the "whole person" with a fistula – and not just the injured bladder or rectum is the single most important concept in fistula care" (Wall, Arrowsmith, Briggs, Browning, & Lassey, n.d, p.1417).

Reintegration is broadly defined as restoring an individual to a state of unity; to return to well-adjusted functioning following a medical condition. Mselle, Evjen-Olsen, Moland, Mvungi and Kohi (2012) state that reintegration:

> ...is a process of helping women affected by OF return to the life they lived before they developed a fistula. This includes how women adjust and reconnect to employment, families, communities, and social life in order to restore their lost dignity and respect and to increase their self-esteem (p.928).

Women's health organizations and researchers have argued the importance of reintegration, particularly social reintegration in OF care (Capes, Ascher-Walsh, Abdoulaye, & Brodman, 2011; Muleta, Fantahun, Tafesse, Hamlin, & Kennedy, 2007; Women's Dignity Project & EngenderHealth, 2006). OF reintegration activities and programs typically focus on patient education and counselling, skills training and income generation, access to maternity and medical care and follow-up, family and community support, and OF awareness (de Bernis, 2007). Women who experienced OF surgical repair in northern Ghana, their family members, health care providers (HCP) employed in the area report that OF treatment frequently ends with surgery with minimal reintegration activities. An OF health care leader and study participant reported:

> On paper, they will say we [government] are mobilizing and treating and reintegrating, but in reality, nobody is doing that, nobody is reintegrating. It all ends at successful surgery, who will fund to follow them up after surgery? The government? You go there [government offices] and they talk about reintegration but it simply is not happening.

This sentiment is also heard among family members. As one husband states:

> You ask about supports to help women return home to their families after the sickness but there is nothing. You need to find your own supports. Government will not help. If they [government] are given money to support the women it will never come. There has been no support since the white man [North American physician] cured her [his wife].

To progress towards reducing maternal mortality and ending fistula, maternal and reproductive health must be a country-owned and country-driven process. According to a government stakeholder, a Fistula Task Force was initiated in 2014 under the leadership of the Director General of Ghana Health Service (GHS) with the aim of establishing the true burden of OF in Ghana and its socio-cultural determinants (Ghana Health Service, 2015). However, no deliberate plan to address reintegration was found.

Methods

Design

A critical ethnography was utilized to explore a culture of reintegration for women who experienced an OF repair in northern Ghana. The design allowed for a dialectical approach, probing below the surface to expose an understanding that goes beyond the surface appearance and identifies the nature of fundamental relationships concerning a culture of reintegration post-OF repair. Ethics approval was obtained from the Human Research Ethics Review Board at the

University of Alberta, Canada, and at the Navrongo Health Research Center Institutional Review Board, Ghana. Participation was voluntary. Participants were informed of their rights as well as the risks of participating before obtaining consent. Participants were given the option to communicate in English or in their mother tongue via a translator.

Data Collection and Fieldwork

Fieldwork was carried out in northern Ghana. Ninety-nine participants were recruited using convenience, purposive, and snowball sampling. The main recruitment site was the Tamale Fistula Clinic (TFC) along with 24 rural communities in the north. Participants consisted of women who had an OF repair (n=41), their family members (n=24), HCPs (n=17) and stakeholders (n=17) who worked with and had knowledge about OF care and reintegration programs. Data were collected over two time periods from March to June, 2014 and April to May, 2015. Semi-structure interviews, observations, and a review of relevant documents related to OF care were the data collection instruments used. Interviews were conducted in English as well as seven additional languages with the aid of translators. Interviews lasted between 30 to 90 minutes and explored a range of topics about OF care, family and community reintegration post-OF repair, and ways that policy could be implemented to create a positive change in OF care. Field notes were written after each interview or observed event to capture nonverbal cues and the social situation or context in which the event occurred.

Data Analysis

Data were analysed according to Hammersley and Atkinson's (2007) approach to ethnographic analysis. Interviews were audio recorded and transcribed verbatim. Transcripts were forward and backward translated for accuracy. A subset of the data was used to construct a coding framework consisting of ten categories and was verified using randomly selected interviews from the main data set. Once the coding framework was considered appropriate it was applied to all remaining data. The data were coded independently by two members of the research team and then compared to ensure accuracy and consistency. Reflexivity was employed through note taking and journaling throughout the research process. Nvivo 10.0 software was used for data management.

Overview of the Research Findings

Study findings (Jarvis et al., 2016a in review; Jarvis et al., 2016b in review) indicated that women who had experienced an OF repair and returned home emphasized the importance of OF teaching, skills training, community follow-up, community awareness, family support, and existing health policies to their reintegration process. There were economic, societal, systemic and cultural constraints that affected a woman's ability to reintegrate. Women typically did not have the decision-making authority to comply with the post-OF treatment recommendations; nor did they consistently have the financial means to partake in follow-up care. Skills training programs were beneficial for some women and a burden for others. The activities related to the skills were often not suited to the woman's physical capabilities or profitable for the local economy.

Many women believed they had to prove themselves "worthy" to be accepted back into their communities, and some continued to be stigmatized post-repair (Jarvis et al., 2016b in review). Family and community support varied among women post-OF and while some women integrated well, others did not (Jarvis et al., 2016b in review; Jarvis et al., 2016c in review). Family members, who identified themselves as "caregivers" of women post-OF repair, suggested that reintegration not only affected those women who received a repair but the family and the community in which women resided (Jarvis et al., 2016c in review).

HCPs identified limitations to their ability to provide adequate follow-up care to women after OF repair. Inadequate infrastructure and issues around personal safety often prevented community health nurses (CHNs) from providing adequate follow-up in the community. As well, nurses described feeling unprepared to provide the complex and multidimensional support needed by these women (Jarvis et al., 2016c in review).

Women described how health policies, particularly the National Health Insurance Scheme (NHIS), had assisted them in their OF care, but they were challenged to articulate how the Ghanaian government could advance OF care beyond surgery. However, along with their family members, HCPs, and stakeholders, they were able to provide meaningful information regarding improvement of reintegration post-OF. A participant makes a powerful statement when she remarks:

> As I sit here I do not know book [illiterate] and I do not know who the government is but I tell you my story so you can write about it and tell the world, I tell you to make a change for the good.

The suggestions made by participants and presented in detail elsewhere (Jarvis et al., 2016a in review; Jarvis et al., 2016b in review; Jarvis et al., 2016c in review) may be valuable for government officials, opinion leaders and those in OF and nursing leadership positions to initiate positive and effective improvements and policy in reintegration to the community following OF treatment and care.

Recommendations

The study results indicate vital concerns for the wellbeing of women reintegrating post-OF repair, categorized broadly as education, skills training and income generation, follow-up care, community awareness, support networks, and collaborative partnerships. Recommendations for policy development and nursing practice related to these categories are discussed below.

Education

Health education and post-OF instruction are important elements of OF care, not just for the woman who undergoes surgery but also for family members. It is essential that OF care takes a family-centered approach, recognizing each family's unique needs and strengths. A true family-centered approach would consider and incorporate teaching directed at the woman and her family's cultural traditions, values and living situation. For instance, males in northern Ghana are typically the family decision-makers and have much influence and authority in how post-OF care will be managed or carried out within the household. It is important, therefore, to identify family authority figures and decision-makers and include them in health teaching. Smooth reintegration depends on this person's ability to understand the reasons behind physical restrictions or limitations, which have been placed on a woman when she returns home.

Health education needs to begin as soon as a woman is diagnosed with OF and continue throughout the reintegration period. Extended and co-ordinated OF care and instructions are important beyond the hospital or OF clinic to reinforce what has been taught and to provide support and counselling for women, their families, and their communities. Nurses are instrumental in facilitating a smooth transition from the OF clinic to home. This requires effective communication and a clear understanding of the expectations of the reintegration process from all parties: a woman and her family, her community, and HCP. Nurses are in a position to coordinate such health care encounters and to assess the need for additional educational support.

In the context of northern Ghana, nurses require appropriate ongoing education and training to practice competently within their scope of practice. This is especially important for maternal and reproductive health including OF care. To ensure best practice, nurses working with OF clients must be given opportunities to learn how to provide accurate and consistent health information that is professionally and culturally appropriate as well as address the needs of women and their families. Providing health education along with appropriate levels of written pictorial and oral material about the importance of nutrition, pelvic floor exercises, exercises to manage limb contractures, foot drop or nerve damage, potential incontinence and bladder training, follow-up and community supports, and sexual health matters after OF is an important extended role for nurses in OF care.

Nurses must be skilful in facilitating a trusting and respectful rapport with women and their families that is required when counselling them about sensitive issues related to abstaining from sexual intercourse, family planning and the need to return to the OF clinic/hospital should sequential pregnancies occur in order to prevent a reoccurring OF. As they advocate for quiet private areas to discuss these confidential issues and attend to the particular social situation and environment of each woman and her family, nurses set the ground-work for further follow-up in the community, and for a smoother reintegration process.

National nursing associations have a responsibility to support nurses, ensuring they have an acceptable standard of knowledge and skill to practice. In order to achieve this, nurses providing care for OF clients and their family must be supported to attend scientific conferences, to partake in continuing education courses and be mentored by world leaders in OF care. It is important that nursing education is nationally regulated to ensure that the nursing curriculum of Ghana includes a minimally acceptable context-specific level of maternal and reproductive health content, including maternal complications such as OF.

Skills Training and Income Generation

Skills training and income generating activities are an important initiative in social reintegration after OF repair since these assist women to rebuild their lives. In northern Ghana, skill training has been offered through United Nations Population Fund (UNFPA) and Ministry of Gender, Children and Social Protection. Skills training programs currently consist of learning new skills in batik tie-dye, soap and pomade making, bread making, and shea butter processing. Women are provided with approximately 100 Ghana Cedis to aid them in setting up a business. However, to date, no formal evaluation regarding the effectiveness of the skills training program has been found. Findings by Jarvis et al. (2016a in review) indicate the need for such an evaluation to occur. Women and family members suggest that skills training and income generating activities do not always comply with a woman's physical capability or the economic environment in which they find themselves. Collaboration with women and families on skills training and income generating activities would ensure that the program meets their needs and capabilities. Programs such as these must also be tailored to match the economic climate in the woman's home community to provide for more long-term profitability. Nurses have a role in urging stakeholders to evaluate skills training activities so that women receive the maximum benefit since it has been shown that women who are employed and able to provide for themselves are able to restore their personal and community value as a woman and to reintegrate more effectively. Nurses spend more time with patients and families more than any other HCP; ideally, they coordinate care and services and share information to all who participate in a patient's care. Nurses, therefore, must be considered an essential part of the process of assessing, referring, and having knowledge about initiatives that maximize success and minimize the chance of women being excluded from opportunities such as skill training. Improvement of women's education levels (literacy workshops for basic reading and writing skills) help to build confidence and increase opportunities for employment, and must also be considered part of the reintegration process.

Follow-up Care

Follow-up care post-OF must, first of all, be accessible. Transportation restrictions, inadequate client referral systems, limited human resources, safety concerns and inadequate infrastructure were identified as barriers to post-OF follow-up care in the community (Jarvis et al., 2016a in review).

Approximately 44% of Ghanaians live on less than 2 dollars per day (United Nations Development Programme, 2015), with the poverty rate in the three northern regions noted to be higher than the national average (International Fund for Agricultural Development, 2013). This contributes to why those living in the north consider transportation from rural northern villages to the OF clinic that is centralized in the northern region too expensive. Nurses are in a position to lobby government and nongovernmental stakeholders to implement a cash reimbursement program for women needing OF follow-up care. Combined with readily available technology, programs such as this could be feasible in even the most remote regions of northern Ghana. As an example, women identified by the CHN as not being able to afford a bus ticket to travel to an OF clinic for assessment or follow-up could qualify to have bus fare transferred to the CHN using mobile technology. A similar program was initiated in Tanzania to encourage women to attend the OF clinic for surgery. Reports indicate that this program surpassed the initial target set for OF referrals within the first year of being implemented (Fiander & Vanneste, 2012).

Currently, a paper-based documentation system is used in the OF clinic in northern Ghana. The utilization of an electronic health record (EHR) would enhance the opportunity for the OF clinic to improve the delivery and co-ordination of OF care (Akanbi et al., 2012). The relevance and feasibility of employing an EHR in rural Ghana were demonstrated in a study conducted by Ohemeng-Dapaah, Pronyk, Akosa, Nemser, and Kanter, (2010). In spite of the challenges such as poor existing infrastructure, frequent power outages and network failure, which could require parallel entries on paper it is believed that facilities that use an EHR have greater data accuracy, improved timelines and availability of routine reports, as well as improved coverage with essential maternal child health services (Akanbi et al., 2012). Other technologies have been shown to assist CHNs and nurse-midwives to improve maternal and women's health care in the community. For example, Mobile Technology for Community Health (MOTECH) is used in the Upper East region of Ghana to provide follow-up for pregnant women (Ghana Health Service, 2012). Likewise, this technology could be adapted to remind women post-OF about follow-up visits at the OF clinic, or to answer questions about post-OF care via text messaging.

The physician and nurse population ratios in northern Ghana are quoted to be the lowest in the country (Singh et al., 2015). More educated nurses and nurse-midwives are needed in order to provide improved and accessible maternal and reproductive care, including post-OF follow-up. Recruitment and retention of nurses in rural areas such as northern Ghana are challenging since there are few opportunities for professional advancement or mentorship and working conditions are typically poor in that nurses most often lack support and appropriate medications and supplies. Nurses who practice in rural areas convey frustration of having low wages, high workloads, and a high cost of living in comparison to those who live in urban areas (Kwansah et al., 2012). For nurses who agree to work in the north, there is a lack of information and disappointment with the positions and posting system. Frequently there is inadequate transparency about the expected terms of employment as well as the procedures for transfer and promotions. These issues affect post-OF care in the north since nurses who work under these conditions express job dissatisfaction (Kwansah et al., 2012) leading to poor patient care and subsequent poor outcomes (Jibril, Aliyu, Umar, Nadett, & Ibraheem, 2014).The nursing profession must come together as one voice, verbalizing their employment challenges, needs, and expectations and collaborating with health care facilities and the Ministry of Health (MoH) to devise interventions to promote rural nursing recruitment and retention. Strategies might consist of more transparent and reliable positions and postings, improved opportunities for education and career advancement, and financial incentives.

Poor road networks and safety concerns for HCPs are other issues impacting upon post-OF follow-up. MoH adopted a transport management system in 1993 that provided health clinics with two motorbikes, fuel and maintenance (Porter, 2002) to aid with follow-up care. Nurses can organize within their districts to document the effectiveness and challenges of the transport management system and its impact on patient outcomes and follow-up care in order to provide authority and support for the continuation of programs. Furthermore, the use of fleet management software and global positioning system (GPS) to track motorbikes, motorbike maintenance, and user safety could be a long-term initiative if the transport management systems are shown to result in positive health outcomes. Finally, nurses must lobby government to allocate resources to improve and maintain infrastructure (i.e. road network, electricity, internet, and telecommunications) in the three northern regions by communicating and reminding politicians about national and international initiative such as the Sustainable Development Goals (SDG).

Community Awareness

While some communities have invested in outstanding community awareness campaigns, others have lagged behind. OF awareness in northern Ghana is essential to inform the community about the condition, and the available treatment and its effectiveness. In many Ghanaian communities, OF is regarded as a curse or punishment from God. A survey conducted in northern Ghana found that awareness about the condition was low. This was attributed to the low literacy rate and a lack of OF awareness programs in the area (Saeed, Alhassan, Opare-Asamoah, & Kuubiere, 2014). Nurses employed in northern Ghana can be encouraged to collaborate with UNFPA, a long-time supporter of OF community awareness, to create opportunities for communities who have excelled at OF awareness to mentor other communities and community leaders by sharing their experiences. Children's theatre arts performances that dispel the myths about OF and reinforce the impact of adequate maternal and reproductive health care have had a positive impact in one rural northern Ghanaian community (Jarvis et al., 2016b in review). Community nurses have created innovative ways for community involvement aimed at creating OF awareness and reducing the potential stigma associated with the condition. Similar findings were noted in Uganda where theatrical performances designed to alter the misconceptions of OF led to success with social reintegration post-OF at the community and national level (Emasu, 2015). There is a need for nurses to take a leadership role in motivating communities to act in order to learn about and overcome the stigma associated with OF and to build healthy and respectful communities.

Women who successfully reintegrated into their communities post-OF can be strong advocates for OF awareness campaigns. Although nurses must have realistic expectations of OF survivors and respect their decisions to decline participation in awareness activities should they choose, nurses can regard them as partners and valuable resources. Nurses can support OF survivors to inform community members as well as traditional and political leaders about OF preventative measures, treatment options, and the importance of successfully reintegrating into society. These personal insights are fundamental to supporting women who are living with OF or returning to their communities post-OF repair.

Additionally, public service announcements about OF should be broadcast via radio in the local languages of the people. Health education in the form of pictures can be posted in regional hospitals, community-based health planning and services (CHPS) compounds, and other community buildings (schools, churches, mosques). Community gatherings providing OF education by CHNs or midwives should be mandated by the MoH to occur annually. May 23, International Day to End Obstetric Fistulas should be more visible, and used to emphasize the plight of women experiencing OF. OF advocates and leaders can take this opportunity to educate the community and policy leaders within the country, and to gain political support for OF care.

Support Networks

Support for OF survivors and their family is an important aspect of care post-OF. Research has indicated that women who have support networks reintegrate more successfully (Ahmed & Holt, 2007; Donnelly, Oliveras, Tilahun, Belachew, & Asnake, 2015). Women post-OF need to feel accepted by both their families and their communities (Jarvis et al. 2016b in review). Bringing together women who have experienced OF to talk about their experiences in either formal or informal settings can be therapeutic. Nurses can collaborate with masiears, the women leaders in their communities, to facilitate the bringing together of OF survivors and to encourage their participation in community life. The use of mobile technology and software such as Text4Mood implemented in northern Alberta, Canada to support individuals experiencing mood disorders (Laferriere, 2016) could be adapted to a Ghanaian context to support OF survivors and family members living in remote areas by linking OF survivors to nurses and others as a means of support. Connecting OF survivors and family members can create a supportive and positive environment for healing post-OF. Additionally, nurses can counsel OF survivors in the benefits of dialogue with family and community members about what they have experienced, as well as locating and providing a source of spiritual support.

Policies and Collaborative Partnerships

It is essential that nurses are aware of and be encouraged to participate in political discussions regarding the nature and direction of OF care. Nurses have the practical insight and information to influence decisions regarding health insurance, coordination of health services, and the transparency and accountability of health priorities and expenditures. Existing policies such as the NHIS, which allows for universal maternal health care without personal cost in Ghana, including OF repair and rehabilitation must be protected. OF support and services need to be more co-ordinated, with partnerships forged to prevent duplication and maximize resources dedicated to OF care. For example, the nongovernmental organization, Net Organization for Youth Empowerment and Development-Ghana (NOYED), has partnered with UNFPA and the only government run OF clinic located in northern Ghana to initiate a program for a “Fistula Free Northern Ghana”. Transparency in and coordination of the selection and funding for OF programs by interest groups such as the National Fistula Task Force, as well as government and nongovernmental agencies, is essential.

Nurses are mandated to take every opportunity to partner with and to improve the health and wellbeing of their patients. This can range from running for political office to writing commentaries for local newspapers such as Joynews or GhanaWeb to lobbying government officials, and/or to being actively involved in Ghana Registered Nurses Association (GRNA). As the category of HCP most likely to have consistent close contact with women post-OF repair, nurses must be mentored and prepared to view themselves as advocates for women post-OF repair and to take action to facilitate optimal health outcomes for them.

Implications for Nursing Practice

Nurses can affect change in the care and reintegration of women post-OF through acquiring and promoting health education and community awareness, coordination of services, and advocating at the grass roots level. Nurses are the HCPs with the most interpersonal contact with women who have experienced an OF repair and their families and are responsible for assessing, plan, implement, coordinate and evaluate post-OF and follow-up care. The perspective held by nurses as a result of such consistent contact and collaboration with families and communities can effectively inform educational, awareness and service programs to provide better health outcomes for those in need.

Advocacy may encompass speaking out against inequities and inequalities as well as supporting individuals, families, and communities to promote maternal and reproductive wellbeing. The International Council of Nurses (ICN) recognizes advocacy as one of the core values of nursing practice (Benton, 2012). Though successful reintegration is heavily influenced by the level of national commitment to OF prevention and treatment nurses play an important role in the trajectory of OF care. OF is a complex condition requiring a multi-strategy approach and issues pertaining to reintegration do not occur in isolation of OF prevention and treatment. Nurses at a grass root level must advocate for a holistic approach which includes all three aspects of OF care.

Nurses are core participants in delivering health care globally and are essential to building safe and healthy communities. They have a role in policy making and participating in political advocacy orienting humanitarian effects and demanding human rights and dignity for all people. OF is a preventable condition that rarely occurs in high resource countries but continues to affect millions of women in low resource countries and is "the result of gross societal and institutional neglect of women by any standard" (Cook et al., 2004, p.73).

The ICN recommends that nurses have a key political role to play in the SDG with 17 targets, one of which vows to improve health, including women's maternal and reproductive health, by 2030 (ICN, 2015). Additionally, the Canadian Nurses Association (CNA) (2009) indicates that Canadian nurses have a responsibility to advocate for:

- Elimination of social injustices locally, nationally and internationally,
- Raised awareness about inequalities in global health such as OF and to participate in finding viable solutions, and
- Conducting global health research which will provide evidence to guide policy makers, researchers and health care professionals committed to advancing global health initiatives such as exploring a culture of reintegration post-OF; providing evidence for effective public policy related to maternal and reproductive injustices.

Ghanaian nurses and nurse-midwives must be supported by the global nursing community so that they are able to provide high quality OF care and to advocate for improved public policy. Benton (2012) suggests the most significant factor in influencing health policy is solidarity within the nursing profession. Nurses globally must speak out with one voice and with clarity about maternal and reproductive injustices to improve the lives of those who greatly depend on them.

Conclusion

A critical ethnographic study pointed to public health policy recommendations on the reintegration of northern Ghanaian women post-OF repair. Implications for nursing practice at the local, national and international level were also discussed. Nurses are key players in influencing strong public health policy, and in implementing practices that produce the best possible health outcomes for women post-OF repair.

Nurses are in a privileged position to share in the experiences of women and family members who are affected by OF. These women and their families are the experts on the condition and can provide great insight into how to propel forward OF care and post-treatment reintegration in Ghana. Nurses create positive change in OF care and reintegration by supporting women affected by OF and their families to find their voices and advocating for them to improve public policy in the political area.

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Chapter 7: Limitations and Future Research

This chapter highlights study limitations and suggestions for future research. I conclude that a culture of reintegration for women post-OF is neither singular nor static, but instead is dynamic and complex. It is embedded into family and societal values, traditional practices, and beliefs, and is influenced by language and metaphors, religion, and social, political, economic, environmental and historical factors.

Limitations to the Research

Community Partnership

Conducting global cross-cultural research brings significant challenges such as issues with language comprehension, cultural interpretation, and physical access to participants. Navigating the logistical and cultural pitfalls requires community partnership and research collaboration. Kim (2006) notes,

> …research collaboration is often regarded as an effective way to get to the developed scientific knowledge and technologies for the developing country. From this prospect, the collaboration is not an indicator of research quality as such but a means to reach the quality (p. 231).

In this study, collaboration with community partners for the purpose of conducting research in northern Ghana opened doors, but also presented a potential limitation to the research. Community partners were gate openers who facilitated access to the community, provided advice and functioned as cultural brokers. All partnerships were built on trust and respect and community partners were fully informed that this study was part of my doctoral research. However, while I was able to offer mentorship about conducting research, I was unable to reciprocate in terms of providing authorship on publications or allowing access to the data.

This potentially set-up a power imbalance between me and my community partners, and might have limited the quality of the data collected.

Recruitment

I had not visited northern Ghana prior to conducting this study. Plans for recruiting participants were based on a study conducted by a nursing colleague three months prior to this research which explored the sources of informal supports for women who experienced an OF (Sullivan, 2014) and used on-the-ground knowledge provided by community partners. It was anticipated that accessing participants who met the inclusion criteria would be challenging. The recruitment area was therefore expanded to include northern Ghana composed of Upper East, Upper West and Northern Regions. These three regions account for 44.9% of the country's total landmass, and are culturally diverse (Government of Ghana, 2016). This study provides an overview of a culture of reintegration in northern Ghana but cannot draw inferences about specific northern communities.

Quantitative Data

The study employed only qualitative data. Although demographic data was collected, it was not consistently collected among each participant. A survey collecting demographic data (participant's age, religion, tribe, marital status, number of children, number of years living with OF, number of OF surgeries) would have provided more accurate statistics to assist in analysis.

Language, Translation, and Transcription

Interviews were conducted in seven different languages with the aid of many translators/interpreters. Translation required more than simply stating verbatim, and translators had to take on a dual role of translating and interpreting to explain the meaning of particular phrases. For example, one woman spoke about the joy she felt after having her OF repaired surgically in terms of having a “white heart”. This provided the first level of data analysis and might have created bias within the data set. Additionally, a local transcriptionist was used to translate the local language, including understanding the intonations and local expressions. The local transcriptionist presented some challenges in terms of ensuring accuracy since words or phrases deemed “unimportant” by the transcriptionist were occasionally deleted.

Insider or Outsider to a Culture

“Location and positionality should not be conceived as one-dimensional or static but as multiple and with varying degrees of mobility" (Alcoff, 1995, p.106). It is agreed among scholars that there are pros and cons to being an insider or an outsider to the research (Asselin, 2003; Giwa, 2015; Merriam et al., 2001). Throughout the research process, I frequently move between being an insider and an outsider. Despite reflecting before the start of the study about where I stood with respect to power and privilege there were many occasions early in the research where I was enlightened to my Western privilege. This led me to question my potential bias about how I was interpreting the data. Fay (1996) asked, “do you have to be one to know one?” (p.9) to which he replies, knowing is more than just experiencing something, it entails identifying, describing and explaining it. I reflected on these experiences in my journal and debriefed with my supervisor.

Time in the Field

Ethnographers immerse themselves in the world of their participants (Roper & Shapira, 2000). They engage in participant-observer or observer-participant roles, participating in, observing to varying degrees, and being respectfully critical of local daily life in order to attain a deeper understanding or perspective. Ethnographers spend months to years in the field collecting data to inform their inquiry. I spent seven months collecting data in the field in northern Ghana.

While my data were rich, I do acknowledge that my time in the field was brief considering that I was a non-native conducting a critical ethnography in rural Ghana. This potentially limits the breadth and depth of this study.

Future Research

This study provides insight into a culture of reintegration for women who experience OF repair in northern Ghana, but does not draw inferences about specific northern communities. Conducting further research in smaller communities, for example in the eastern corridor (i.e. Bimbilla, Saboba, Chereponi, Yendi, Gushiegu, Salaga and Nanumba South and North) where the incidence of OF and OF repair are high, could provide in-depth insight into a culture of reintegration and offer the basis for making comparisons among northern communities.

Further research into the effect of OF on family members and the community is needed as well as research into the supports and resources they require to unconditionally welcome home women who have had OF repair and to assist them with their reintegration process. It is important to consider that women are one part of a larger entity (i.e. family, village, district, region) that has indirectly experienced OF. Understanding the needs, challenges, hopes and fears of families and communities could provide insight for improving an OF transitional model of care.

Additionally, the skills training income generation activities implemented in northern Ghana must be evaluated to determine if program goals and objectives are effectively meeting the requirements of women reintegrating post-OF repair. Alternatively, a multiple intervention study to explore ways to enhance the synergies between the components (health teaching/counselling, skills training, follow-up care/access to health care, community sensitization/awareness) of an OF reintegration program and to monitor the sustainability of their impact ought to be proposed.

Conclusion

The purpose of this study was to develop insight and knowledge into a culture of reintegration for women who experience OF repair in northern Ghana. Based on the strength of my findings, I conclude that a culture of reintegration for women post-OF is neither singular nor static, but instead is dynamic and complex. A culture of reintegration is embedded into family and societal values, traditional practices, and beliefs, and is influenced by language and metaphors, religion, and social, political, economic, environmental and historical factors. The three finding papers written for this dissertation document capture only a small portion of the whole story of a culture of reintegration. Future manuscripts from this research will focus on: the challenging context in which these women live and how this context influences reintegration; the significant role played by spirituality and superstition in the reintegration process; the consequences of internal and external stigma post-OF; supports provided by and for health-care providers (HCP) to assist with reintegration; and the influence of power and gender roles on reintegration. As well, a case study of a community where members are actively involved in OF care/reintegration and are making a positive difference in the lives of women returning home is under preparation. The findings from this study give voice to women, their families, HCPs and communities supplying them and OF stakeholders with the evidence needed to call for effective public policy related to OF care. Reintegration is a neglected but important component in that care and must be implemented in Ghana's national strategy to improve maternal and reproductive health. No woman who experiences an OF repair should believe that care ends at surgery.

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Appendix A: Systematized Review

Review	Purpose	Design	Sample Size	Sample Methods	Analysis	Findings/Conclusions
Donnelly, Oliveras, Tilahun, Belachew, & Asnake, (2015)	To examine the experiences of 51 Ethiopian women after fistula repair surgery to identify priority post-repair interventions that could maximise their quality of life	Mixed methods *This paper focuses only on the analysis and results of the qualitative data	Purposive sample (n=51)	Semi-structured community based in-depth interviews Facility-based survey	Narrative thematic analysis	The results showed that the majority of women felt a dramatic sensation of relief and happiness following repair, yet some continued to experience mental anguish, stigma, and physical problems regardless of the outcome of the procedure **Physical health recovery and gaps** 82% no longer suffered from urinary or faecal incontinence following OF repair 40% complained of physical health problems **Mental health relief and ongoing desperation** Women felt feelings of happiness, hope and gratitude after successful OF repair Women reported feeling eager and capable of reintegrating; participating in social events. A small group of women experienced residual distress and feelings of desperation **Fear of fistula recurrence** Most women report fear of relapse from sex, pregnancy, physical task/physical movement **Marital status** Several women were considering divorce since their husband were placing unreasonable demands on them to farm or have sex 18 out 51 women reported their husbands were supportive and assumed more responsibility to promote their recovery. Women abandoned by their husbands harbored

						negative perceptions of men and were not interested in remarrying **Perspectives on childbearing and sex** Among women of reproductive years there is a strong need to have children; fertility before and after fistula repair is important in sustaining their marriage Women feel frustrated with men (partners) who felt entitled to have sex with them post-repair; husband who respected their wives wish had a positive sexual relationship. Four out of 51 participants had children post-repair **Returning to work** Women were infrequently able to return to the job they had pre fistula. Most women tried to do household chores (i.e. fetch water) and their husband's tried to compensate. Many unmarried women depended on relatives to support them financially. Loss of income exacerbated women's economic hardship; many were limited by a scarcity of start-up capital **Communication gap with fistula care providers** Language barriers created problem with health care workers. Participants had variable recollections of their post-repair teaching/counselling **Reintegration support** Women expressed gratitude for assistance received upon hospital departure post-OF repair. Majority of women returned home to live with their husband or family members. Women did not receive support from their community (money, food, help with household duties, invitations to social events) **Fistula advocacy** Most women were willing to be involved in fistula related advocacy activities (i.e. awareness creation); support

						women who had OF treatment; or provide general maternal health education
Gebresilase, (2014)	To explore the evolution of survivors' perception of their social relationships and health since the developing of OF	Qualitative, explorative study	Purposive &snowball sampling (n=8)	In-depth interviews Two interviews conducted 4-6 days apart at the OF clinic Interview1 questions focused on situation and setting leading to OF Interview 2 focused on participants describing difficulties encountered and strategies to help them cope. Participants were asked to provide meaning to their experiences of OF	Thematic and content analysis	**Understanding factors predisposing to OF** Most participants described a change in their knowledge about OF after visiting health facilities **Challenges encountered by OF survivors** Participants reported the powerlessness experienced in childhood and in their marriages Prolonged and obstructed labour as a traumatic event. None of the participants had antenatal care; all participants reported being in labour for a minimum of 4 days and were assisted by family and friends during this time. All participants reported being subjected to traditional practices used by the community to minimize pain in labour **Emotional challenges associated with OF** Participants described physical changes (i.e. weight loss, pain around pelvis, exhaustion, inability to work or walk) which led to feelings of dependency. All participants reports changes in their relationships and a loss of control over daily routines. Participants experienced anger, shame and sadness associated with the loss of a child, the loss of ability to work and loss of support of their husband. Six of the participants recall mistreatment when experiencing OF Participants reported fear about the future and reintegrating back into their communities; having partners, marriage or sex and becoming pregnant or giving birth **Coping mechanisms** Pre OF repair most participants had one family member to provide emotional and financial support The OF clinic where the repair was done provided support and was a source of social recovery. Participants describe how discussion among other OF patients provided strength and pleasure All had the opportunity to participant in skill training at the OF clinic

						Many participants reported coping with OF by isolating themselves or through positive interpretation (i.e. learning through the experiences of others, belief in God**)** None of the participants wanted to return to their communities post-OF repair because their communities did not fit with their health condition **Struggling to keep going** Women experienced joy post-OF repair; they were able to do what they wanted without fear or shame Four participants described OF as an opportunity to live a better life Participants described OF as a motivation to change their perspective on life Two participants described OF as the reason for their loss of identity (i.e. loss of their traditional role as women)
Khisa & Nyamongo, (2012)	To explore the challenges faced by obstetric fistula survivors after corrective surgery in West Pokot, a rural district in northwest Kenya Findings to offer important insight into the design of reintegration programs	Exploratory Study	Convenience sample (n=8)	Semi-structured interviews took place 1-4 years after OF occurred and 3-36 months after the most recent surgery	Thematic Analysis	**Stigma and psychological trauma** Stigma continues after corrective surgery and was directed at the participants and their families (i.e. women were not allowed to cook or serve guests) Participants reported being discredited as women and were believed to be cursed Participants whose surgery was unsuccessful were not accepted back into the community Some participants isolated themselves as a way of coping and all experienced psychological trauma (i.e. memories of OF, loss of child or fertility, afraid of men and sex) **Marital instability** Participants reported that their marriages were in jeopardized because the women had to abstain from sex and because the husband take the condition as a bad omen and abandons their wives Women faced difficulties with post-operative instruction as men did not understand why their wives could not have sex post-repair. Women often stayed with their parents which affected their marriage and reintegration Women struggled not to conceive for two years since their worth as a woman was linked to her ability to have children

						Economic difficulties Lack of economic empowerment was a big challenge after surgery and participants had to rely on their husband or relatives Women were not able to do heavy work and found themselves without the means to generate income and was disconnected from social forms of fundraising (community directed social insurance) **Consequence of unsuccessful repair** Participants who had unsuccessful repairs were not accepted back to their community
Mselle, Evjen-Olsen, Moland, Mvungi, & Kohi, (2012)	To provide information about women's expectation of life after fistula repair To explore their hopes and worries related to reintegration into family and community life To give women experiencing the social and physical consequences of OF a voice and to alert the political community to the need for reintegration and rehabilitation programs	Mixed Methods	Convenience sample Qualitative (n=8) Explored the hopes, dreams, fears and worries about the future Convenience sample Quantitative (n=151) Explored patterns in how women perceived reintegration	Semi-structured interviews (n=1) followed up for six months post-OF repair in community. Closed –ended questionnaire	Thematic Analysis Descriptive Analysis	**Uncertainty about being accepted as a wife** 49.7% believed they would return home to live with their husbands while 51.3% felt their husbands would not accept them regardless of being fully recovered **The need to have children** 55% of women expressed a desire to give birth in the future **Hoping for a social life.** 89% of women believed that their friends would not accept them post-repair **Worrying about survival** 80% of women believed that if cured they would be able to make a living by themselves

Pope, Bangser, & Requejo, (2011)	To explore the relationship between surgical outcomes and women's perceived quality of life (PQoL) To compare affected women's PQoL post- OF repair with non-affected women living in the same community and with those awaiting OF repair	Mix methods	Purposive & snowball sample (n=66) Group 1 (women to receive OF repair): (n=25) Group 2 (non-affected women): (n= 25) Group 3 (women awaiting OF repair): (n=21)	Qualitative Semi-structured interviews Social Map Quantitative PQoL Tool (Patrick 2000). Tool was adapted for the culture Reintegrated to Normal Living (RNLI) (Daneski et al. 2003).	Thematic Analysis Descriptive Analysis	**Resuming responsibilities and social roles** 60% of women in Group 1 reported being able to work was the most important factor in the reintegration process. 68% of women in Group 1 perceived themselves as healed or almost healed one year post-repair **Women's social roles following repair** 32% of women in Group 1 stated a desire to have children and 28% of women in Group 2 wanted to have children. Divorce rates were 56%, 4.3% and 16% consecutively for Groups 1, 2 and 3. 52% of women in Group 1 report physical symptoms compared to the 44% in Group 2 PQoL score was higher in Group 2 (*M* =5.95) than Group 1 (*M*= 1.81) RNLI of Group 2 was higher (*M*=8.82) compared with Group 1 (*M*=7.72) **Long-term consequences of a fistula** 76% of women in Group 1 indicated further medical attention **Access to follow-up** Women in Group 1 wanted more and better access to facilities addressing sexual function & fertility **Family support** 68% of women in Group 1 reported help from a family member to reintegrate; 60% of women lived with their parent; n= 10 were abandoned by their partners/husbands **Time as a key factor in the health process** PQoL scores were the lowest during the period when women were living with a fistula and steadily increased over time after surgical repair **Leaking of urine post-operatively** 8 of 25 women in Group 1 did not consider themselves healed (5 women had stress urinary incontinence, 2 had an unsuccessful repairs, and 1 a gynecological problem)

						Social stigma and community awareness Only 1 women in Group 3 experienced community mistreatment while living with OF Since 1999 or later no women were shunned (all received services within one year)
Umoiyoho, Inyang-Etoh, Abah, Abasiattai, & Akaiso, (2011)	To discover the effect of successful vesicovaginal repair on affected women's quality of life	Cross-sectional, prospective study	Purposive &convenience sampling (n= 265) recruited (n=150) returned for follow-up and comprised the sample	World Health Organization Quality of Life (WHOQOF)-BREF Questionnaire Two part WHOQOF-BREF Questionnaire Subjective assessment Four domains of health: Physical Mental Social Environment	Descriptive and inferential statistics	**General health status** 20% of women judged their general health status to be satisfactory before repair 90% after successful OF repair **Physical Health** Mean quality of life score was 67.9 ± 4.4 before and 69.3 ± 3.4 after successful repair and the difference was statistically significant (t = 30.43, df = 1; p<0.01) Significant improvement reported in personal hygiene, healing of perineal excoriation and perineal pain **Mental Health** Mean quality of life score was 32.4 ± 8.7 before and 74.7 ± 3.2 after successful repair, and the difference was highly statistically significant (t= 55.7, df = 1; p<0.005) Significant improvement reported in self-esteem, levels of concentration and sleeping patterns **Social Health** Mean quality of life score was 20.2 ± 2.7 before and 69.7 ± 2.3 after successful repair, an also highly statistically significant difference (t = 165,df = 1; p< 0.001) Significant improvement reported in interpersonal relationships, sexual functions and support from family and friends **Environment** Mean quality of life score was 60.3 ± 4.3 before and 59.7 ± 2.7 after successful repair but the difference was not statistically significant (t = 1.46, df = 1; p< 0.2)

						No significant improvement reported in women’s income, ability to carry out their daily chores, and level of participation in leisure activities
Yeakey, Chipeta, Rijken, Taulo, & Tsui, (2011)	To understand how women who experiences OF repair rebuild their lives in their home communities and resume relationships with partners, family and community members To report the experiences of women, their spouses and their immediate female relatives while burdened with the fistula condition and when repaired	Qualitative	Purposive & snowball sampling Initial interviews (n=45) living with OF (n=5) post-OF repair participants (n=30) family members (n=80) total Post-OF follow-up interviews (4 months later) (n=18) post-OF repair participants (same 5 original participants plus 13 new participants) (n=11) family members (n=29) total	In-depth, semi-structured interviews	Thematic Analysis	**Being relieved of the burden of fistula** Pre repair: women reported physical burdens, painful blisters, wetness and friction Post-repair: improvement in or cessation of OF symptoms; even when partial repaired improvement reported **health care and surgery experiences** Pre repair: receiving medical treatment for OF is challenging (i.e. wait times, multiple referrals, financial resources); Some women experienced fear of leaving their families and community to have the surgery Post-repair: Participants who had a positive OF repair became advocates for the hospital (women readily shared their experiences) **Families experiences with OF** Pre repair: family members expressed worry, sadness and helplessness over the situation indicating the burden fistula imposed (especially when there was no husband); some women needed family members to travel to the health facility this was another support placed on families Post-repair: family members reported that they also experienced the positive impact of their family member’s repair; social limitation were now removed **Husband’s perspective on OF** Pre repair: Husband expressed concern for their wives. Men discussed their wives condition (smell, isolation) which was also their burden Post-repair: Husband expressed immediate sense of relief and happiness with wives’ recovery. Husbands were supportive of their wives inability not to have sex for 6 month while healing

Turan, Johnson, & Polan, (2007)	To inform or provide guidance for community mobilization and education projects on safe motherhood Improve medical and social services for women suffering from OF	Qualitative	Purposive sample (n=31) First interviews: new women who underwent OF surgery in Nov 2004 (n=11); Five accompanying family members (n=5) Second interviews: Women who underwent OF surgery in Feb 2004 (n=15)	Open-end interviews (new OF patients and their family members) Semi-structured interviews (previous OF patients returning for follow- up 6-10 months later)	Ethnography qualitative analysis & Descriptive analysis	**Labour and delivery experience when fistula occurred** Long labours before help was sought Female relatives, neighbors, and traditional birth attendants often present for home births Older females are often the decision-makers during birth **Transfers to health facilities** Distance from the village to the health facility were often long and difficult to arrange **Discovering the fistula and perceptions of why it occurred** Participants realized they had a problem with urine leakage soon after delivery but was given little information about the problem from HCPs. All participants knew OF was related to delivery and some linked it to not receiving antenatal, assistance from trained health workers during labour and delivery, attendants pulled the baby out using force **Effects on women's lives** Physical discomfort; social isolation; psychological effects; economics, unable to support themselves; divorced/abandoned **Fistula repair** Of the 15 follow-up participant, 1 had undergone one prior unsuccessful repair attempt 5 of the women received no explanation of what would be done during the surgery to attempt to close the fistula. Approximately 50% of women said they were given information about how to care for themselves after returning home Health after the fistula repair: At the time of the follow-up interview reports of urine leakage… 13%- no urine leakage 67%- less urine leakage than before the surgery 13%-urine leakage the same as before surgery

						7%-urine leakage worse than before surgery 53%- continuous leakage Only 2 women reported being sexuality active **Fistula in the community** Some follow-up participants knew other women who had an OF in their community while others learned the problem was widespread at the hospital. The majority of follow-up patients (n=11) said they do not talk with others about their fistula or OF repair. Of the women (n=4) who do talk about it all had experienced improvements in their degree of incontinence **Underlying problems** Problems that negatively influence women's ability to get medical help: war, rape, absent husbands and fathers, patriarchal traditions
Nielsen et al., (2009)	To assess urinary and reproductive health and quality of life (QofL) following surgical repair of OF	Community-based long term follow-up study	Purposive sample (n=37) A total of 44 women had been treated Out of 44 women 38 met the eligibility criteria and one died. 37 women participated	Community-based structured interviews, 14-28 months following OF repair. Using a customised questionnaire addressing urinary health, reproductive health and quality of life	Statistical analysis	**Urinary function** During follow-up 57% of women were completely dry, 35% had degrees of incontinence; and 8% had fistula **Quality of life** Was significantly lower during the time living with a fistula than before developing the fistula OF surgery improved women's QofL and social reintegration to a level comparable to that before OF development **Marital status and reproductive** 71% of women reported remaining married and sexually active; 33% became pregnant; 59% recalled receiving advice for future delivery **Understanding of fistula and knowledge of others with fistula in the community** 27% stated that OF could be prevented and 16% shared this knowledge

						Occupation 75% of women stated returning to their former occupation
Browning & Menber, (2008)	To quantify surgical and quality of life outcomes six months after obstetric fistula repair	Prospective study	Purposive & convenience sample (n=240)	Standardized questionnaire using a 10 point Likert scale used to assess overall impact of fistula repair on quality of life Physical examination	Statistical analysis	**Urinary function** Continent status at discharge was maintained at six months. Many women discharged with incontinent improved and a few women cured at discharged had later become incontinent **Reproductive Status** Six women were pregnant at the time of their six month follow-up One third of women had resumed sexual activity, 90% without pain **Quality of life** 82% of women reported their life had at least moderately improved post-OF repair
Women's Dignity Project & EngenderHealth, (2006)	To understand the many dimensions of fistula and its related social vulnerability through the experiences and views of girls and women living with fistula, members of their families and communities, and local HCPs To explore participants' recommendations	Qualitative Descriptive & exploratory Study	Purposive & convenience sample (n=194) Women with OF/repair (W) (n=61) Family members (FM) (n=42) Community members (CM) (n=68) Health-care providers (HCP) (n=23)	Data collected July 2003- Sept 2005 at 3 sites in Tanzania Focused Interviews (W),(FM),(CM) ,(HCP) Group discussion (CM),(HCP) Problem Tree (W),(FM), (CM) Free listing & ranking exercises (CM)	Thematic Analysis	**OF affects women of all ages, both at first and later pregnancies** Public education, policies, and interventions to reduce the risks of fistula must address the full reproductive life-cycle of girls and women. **Inadequate/inconsistent antenatal care services** Providers need adequate training, supplies and equipment, as well as supportive supervision, to implement high quality and consistent antenatal care services **Lack of birth preparedness (information on childbirth and "delays")** Concrete information on birth preparedness, that is understood and acted upon, is critical to avoid delays in time of emergency **Lack of emergency caesarean section** Girls and women, particularly in rural areas, urgently need access to emergency obstetric care

						(EmOC) provided by trained health workers. The financial and logistical barriers to EmOC services must be eliminated **The inaccessibility of high-quality fistula repair presents a barrier to care** High quality fistula repair services must be made available and accessible to women, and at highly subsidized or no cost **The cost and inaccessibility of high quality fistula repair services are barriers to care for many girls and women substantial for women and their families** Advocacy support and reintegration efforts should be instituted to reduce the emotional and economic impacts of OF
Young-Lin, Namugunga, Lussy, & Benfield, (2015)	To understand perspectives of local health providers on the social reintegration of patients who have undergone fistula repair in the eastern Democratic Republic of Congo	Qualitative study	Purposive sample (n=41) Patient-care professionals working with women with fistula were interviewed	Semi-structured interviews	Thematic analysis	**Surgical repair- Normal life** Successful surgical repair was reported to be the most important factor contributing to patients 'ability to lead a normal life by all providers post-repair **Acceptance** Family acceptance—especially from the husband—was deemed crucial for reintegration by 39 (95%) providers, and 29 (71%) believed this acceptance was more important than the ability to work Forty (98%) providers felt that, on the basis of African values, future childbearing was key for family acceptance **Reproductive** Because of poor access and the high cost of Cesarean deliveries, 28 (68%) providers were concerned about fistula recurrence **Resources, service and follow-up** 21 (51%) of providers mentioned that psychotherapy in addition to capacity building through vocational training as an invaluable service for their patients

						Some providers stated that community education about genital fistula was helpful for women's reintegration Providers, 17 (41%), noted closer community-based follow-up is needed post-repair to understand a woman's physical and psychosocial conditions after she returns to her village Providers emphasized that it is the husband who needs to accept the woman and be counseled on her condition and the steps to full recovery after her surgery
Johnson, Turan, Hailemariam, Mengsteab, Jena, & Polan, (2010)	To evaluate the first formal counselling program for obstetric fistula patients in Eritrea	Mixed methods	Convenience & purposive sample (n=47) quantitative (n=19) qualitative	Interviews (n=47) interviewed pre and post counselling (intervention) Two focus group (explored patients experience with counselling) (n=19)	Questionnaires were analyzed using SPSS 12.0 Windows, Version 12. McNemar's Test was used to compare before and after responses for paired observations Focus group, Thematic analysis	**Self-worth** There was a statistically significant increase in women's self-esteem scores, from an average score of 13.6 out of 30 before preoperative counselling to 27.9 after post-operative counselling. 71.4% of women strongly believed that they were not worthy of being around others because of their fistulas; this number decreased to 28.3% following counselling. Only 15.2% of women strongly agreed that they were a person of worth before receiving counselling. After counselling, this percentage increased to 71.4%. **Health behaviours** Post-counselling responses to questions regarding behavioral intentions after surgical repair revealed that women were significantly more likely to state intentions to practice positive health behaviors (i.e. large increases in the percentage of women who intended to use family planning and improve their nutritional intake). **Need to connect with others** Following counselling, the majority of women expressed intentions to talk with family members (91%) and other community members (77%) about fistula and fistula prevention, compared to 26% and 34% respectively of women prior to counselling **Family needs for counselling**

						Counselling program could be improved, a number of women stated that they wished their family members could also be counseled on fistula and fistula prevention.
Nathan, Rochat, Grigorescu, & Banks, (2009)	The objective of this study is to gain insight into the nature of obstetric fistulae in Africa through patient perspectives	Quantitative	Purposive sample (n=37)	Open-ended questionnaires (descriptive data) Structured interviews (perspectives about fistula cause, obstacles to medical care, prevention, and reintegration)	Descriptive statistical analysis	**Perceived causes** Perceived fistula causes were delivery trauma (43%), financial (49%) lack of prenatal care (38%), lack of knowledge (22%). Despite that some women lived less than 20 km from a health care clinic, more than three quarters laboured between 1 and 3 days before they either delivered at home or were transported to a clinic **Reintegration needs** 49% of the participants requested no further reintegration assistance aside from surgery. Participants, who did desire reintegration assistance, predominantly sought economic self-sufficiency through financial assistance to start small businesses or employment. Some participants also requested education for family and friends about the nature and cause of fistulae. Specifically, they wanted their village to understand they were not cursed.
Castille, Avocetien, Zaongo, Colas, Peabody, & Rochat, (2015)	To investigate whether the positive impact of a program of physiotherapy and health education on the outcome of obstetric fistula surgery was maintained after 1 year	Quantitative	Purposive sample (n=84) Initial group (n=108), 24 participants dropped out or were lost in follow-up one year later	Follow-up analysis at 3, 6, and 12months post-OF surgery. The Ditrovie scale was used to measure quality of life (QofL), and continence and performance of the physiotherapy exercises	Statistical analysis	**Quality of life** QofL score was 36.9 (range 16.0–49.0) before surgery and after one year their mean QofL score had improved significantly to 18.5 (range 10.0–47.0; P b 0.001) **Health improvements** Between hospital discharge and 1 year, the number of women with a closed fistula increased from 48 (57.1%) to 53 (63.1%) and the number with urinary stress incontinence reduced from 11 (13.1%) to 9 (10.7%)

Muleta, Hamlin, Fantahun, Kennedy, & Tafesse, (2008)	To assess health, social, and psychological problems encountered by women with treated and untreated obstetric fistula	Cross-sectional study consisting of quantitative & qualitative components	Randomly selected sample Household visited (n=19153) Surveyed (n=52)Interviewed (n=39)of the untreated women and (n=13) of the treated	Surveys In-depth interviews	Statistical analysis	Results for the 13 treated women post-OF surgery **Health improvements and concerns** Four had attained control of leakage on discharge from hospital following surgery, 4 after two to three months, and another 4 after four to five months; 1was still leaking continuously Amenorrhea, leg pain, and difficulty with walking were some of the health problems mentioned, but no foot drop or contractures were seen in these women **Reproduction and Sexuality** Three of the women with fistula repair reported that sexual intercourse was painful and could not be tolerated; 4 did not have any difficulty, and the remaining 6 said they did not try to have sexual intercourse after the operation (because of fear of fistula recurrence in 5, and because of incontinence in 1) Two of the treated women had given birth, by Caesarean section, since treatment **Follow-up** Four women reported they had visited the hospital for follow-up when they felt unwell
Lombard, de St. Jorre, Geddes, El Ayadi, & Grant, (2015)	To synthesise evidence on women's experiences surrounding rehabilitation and reintegration after obstetric fistula repair in sub-Saharan Africa and explore recommendations from	Systemic Review	Purposive sample (n=10)	Cochrane Qualitative Research Methods Group guidance (to retrieve articles) Critical appraisal skills programme assessment tool to capture essential issues	Thematic analysis	The most important rehabilitating factor for women was fulfilment of social roles. Health service perspectives were more frequent than women's perspectives. Counselling and health education were the most common recommendations from both perspectives

	women and health service providers			of quality appraisal		
Velez, Ramsey, & Tell, (2007)	To expand knowledge on the issue related to causes and impact, country capacity to manage the problem and clinical and programmatic gaps	Qualitative and Quantitative	25 countries in Africa and Asia Unknown the sample size of individual projects	Focus group discussions; in-depth interviews/narratives; key informant interviews; and review of medical records	Not Specified	Analysis of 20 of these assessments provides insight into the capacities, gaps, and perspectives specific to each country regarding fistula prevention and treatment and the social reintegration of treated women. **Reintegration needs** Patients are in great need of counselling during the preoperative and postoperative periods. The assessments found great shortfalls in the provision of reintegration services, including family planning, psychosocial counselling, and capacity-building activities. In most cases rehabilitation care was not available in any consistent manner, nor was follow-up undertaken after discharge.
Fistula Care, (2010)	To understand more about the women's social situation and needs who had received fistula repair services	Program evaluation Components The Market Town Approach, to increase the use of local government funds for fistula services Safe motherhood committees, to address fistula prevention and the referral of fistula patients for treatment A waiting home, to provide short-term convalescence	Unknown Program began in the Kissidougou District Hospital	Semi-structured in-depth interviews	Not Specified	**Democratic local governance** The Market Town Approach has facilitated a level of trust and transparency among stakeholders and has promoted local ownership of the program **Prevention** The safe motherhood committees are the critical link between the community, local health centers, and Kissidougou District Hospital and are a major contributor to prevention efforts. According to hospital reports, patients referred by committee volunteers have fewer complications, spend less time at the facility, and have higher recovery rates because they seek treatment sooner and are more likely to adhere to treatment regimens **Reintegration** Waiting home and host families facilitate reintegration of patients into society. They provide transitional experiences that support women before they return home. The program needs more work to address the psychosocial needs of patients and to improve the knowledge of the host families and communities volunteer

		for women after repair surgery and a place where women can begin to reintegrate into society Social immersion with host families to support reintegration of fistula patients				
Mohammad, (2007)	To strengthen existing community-based health provision and delivery services; to improve the socio-economic status of women by strengthening adult literacy services, with a high component of vocational training to develop and build skills for income generating activities; and to create community awareness through culturally	Program Review Components Provides a safe environment for women living with OF Creates a tie with other women who have experienced OF Income generating activities, provides vocational skills. Clients	Project location, Dambatta area of Kano State, Nigeria From 1999/00 to 2005/06 (n=145) at the Center	Not Specified	FORWARD approach, which addresses prevention, treatment, rehabilitation, and community reintegration for women who have experienced the trauma of living with fistula. Project activities are carried out at a residential rehabilitation center	**Reintegration Success** All women reported to have successfully reintegrated into their communities. With a good intervention package and a suitable environment, it is possible to turn around the lives of women with fistula—from hopelessness to good mental and physical health The project has strong built-in health components, such as raising awareness and increasing knowledge on issues concerning reproductive health and sexual rights, which are necessary for the eradication of fistula. The project also focuses on the importance of the women's reintegration into their communities following the rehabilitation period. They gain empowerment and socio-economic status from being involved in the project, and many are setting up women's cooperatives and businesses The project can be seen as an example of a holistic approach, with community participation, to address a problem whose causes are multidimensional **Recommendations**

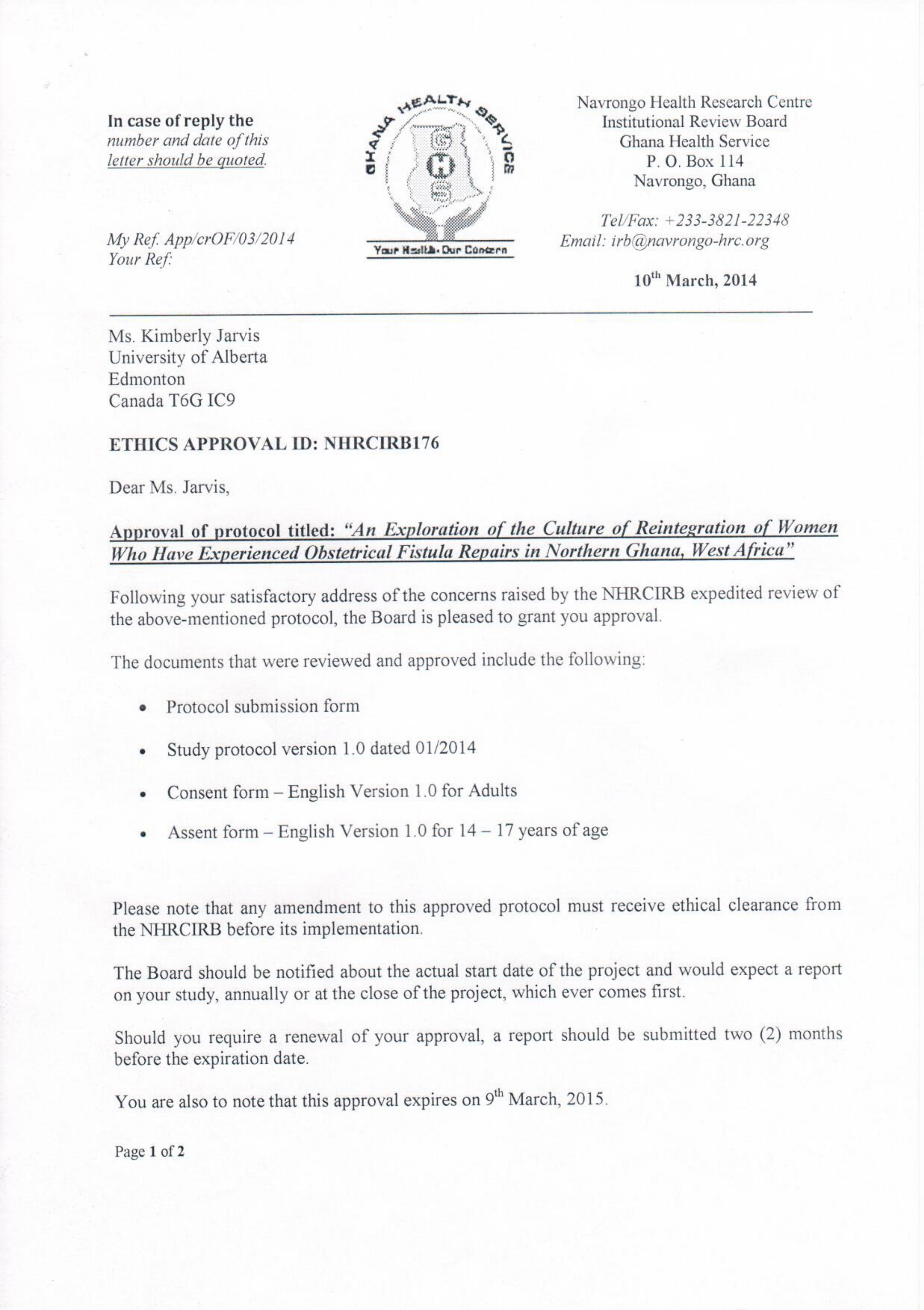
	sensitive information, education, and communication for behavioral changes	are given a loan in kind to start a business Provides community follow-up to former clients				Involve local expertise, as a home-grown solution will be less expensive and more sustainable The objectives of Safe Motherhood must be achieved Government must be a principal stakeholder in addressing issues of OF Maternal and child nutrition is very important to improve the psychological and physical health of women and children
Wilson et al., (2011)	To assess fertility and pregnancy experiences pre and post-OF repair	Qualitative	Purposive and snowball sample (n=58) Women (n=32) Family members (n=26)	In-depth interviews	Thematic analysis	**Fertility** 26 out of 32 women had an OF repair 6 out 26 women had conceived post-OF repair 20 out of 26 women had not conceived but 9 were attempting to conceive post-OF 5 out of 20 women wanted information to help with fertility 2 out of 20 women blamed there infertility on the OF repair 6 out of 3 women had conceived more than once for a total of 10 pregnancies 7 out of 10 pregnancies ended in spontaneous abortion 1 woman redeveloped OF during delivery

Appendix B: Ethics Approval Forms

Ethics Application has been Approved

ID:	Pro00044305
Title:	An Exploration of a Culture of Reintegration of Women Who Have Experienced Obstetrical Fistula Repair in Rural Ghana, West Africa.
Study Investigator:	Kimberly Jarvis
Description:	This is to inform you that the above study has been approved. Click on the link(s) above to navigate to the HERO workspace. Note: Please be reminded that the REMO system works best with Internet Explorer or Firefox. Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1



In case of reply the
number and date of this
letter should be quoted.

Navrongo Health Research Centre
Institutional Review Board
Ghana Health Service
P. O. Box 114
Navrongo, Ghana

Tel/Fax: +233-3821-22348
Email: irb@navrongo-hrc.org

My Ref. App/crOF/03/2014
Your Ref:

10th March, 2014

Ms. Kimberly Jarvis
University of Alberta
Edmonton
Canada T6G IC9

ETHICS APPROVAL ID: NHRCIRB176

Dear Ms. Jarvis,

Approval of protocol titled: ***"An Exploration of the Culture of Reintegration of Women Who Have Experienced Obstetrical Fistula Repairs in Northern Ghana, West Africa"***

Following your satisfactory address of the concerns raised by the NHRCIRB expedited review of the above-mentioned protocol, the Board is pleased to grant you approval.

The documents that were reviewed and approved include the following:

- Protocol submission form
- Study protocol version 1.0 dated 01/2014
- Consent form – English Version 1.0 for Adults
- Assent form – English Version 1.0 for 14 – 17 years of age

Please note that any amendment to this approved protocol must receive ethical clearance from the NHRCIRB before its implementation.

The Board should be notified about the actual start date of the project and would expect a report on your study, annually or at the close of the project, which ever comes first.

Should you require a renewal of your approval, a report should be submitted two (2) months before the expiration date.

You are also to note that this approval expires on 9th March, 2015.

The Board wishes you the best in this study.

Sincerely,

Dr. (Mrs.) Nana Akosua Ansah
(Vice Chair, NHRCIRB)

Cc: The Director
NHRC, Navrongo

Amendment/Renewal to Study has been Approved

Amendment/Renewal ID:	Pro00044305_REN1
Study ID:	MS1_Pro00044305
Study Title:	An Exploration of a Culture of Reintegration of Women Who Have Experienced Obstetrical Fistula Repair in Rural Ghana, West Africa.
Study Investigator:	Kimberly Jarvis
Description:	The amendment/renewal to the above study has been approved. Click on the link(s) above to navigate to the HERO workspace. Important: Please be reminded that the REMO system works best with Internet Explorer or Firefox. Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1

In case of reply the
number and date of this
letter should be quoted.

My Ref. AppEx/crOF/02/2015
Your Ref:

Your Health - Our Concern

Navrongo Health Research Centre
Institutional Review Board
Ghana Health Service
P. O. Box 114
Navrongo, Ghana

Tel/Fax: +233-3821-22380
Email: irb@navrongo-hrc.org

20th February, 2015

Ms. Kimberly Jarvis
University of Alberta
Edmonton
Canada T6G IC9

ETHICS APPROVAL ID: NHRCIRB176

Dear Ms. Jarvis,

Approval for Extension of study titled *An Exploration of the Culture of Reintegration of Women Who Have Experienced Obstetrical Fistula Repairs in Northern Ghana, West Africa*

The Navrongo Health Research Centre Institutional Review Board (NHRCIRB) has reviewed the documents submitted for extension of ethical approval for the above-mentioned study and finds that it is relevant and the extension will be pertinent to rehabilitation and reintegration of women with obstetric fistula repair in society. The Board is therefore pleased to grant you an extension.

The documents that were reviewed and approved include the following:

- Completed Continuing Review submission form
- Summary of study protocol
- Progress reports

Please note that any amendment to this approved extension must receive ethical clearance from the NHRCIRB before its implementation.

Should you require a second renewal of your approval, which expires on **19th February, 2016**, a progress report should be submitted two (2) months before the expiration date.

Please you are required to submit a final report to the NHRCIRB at the end of the study.

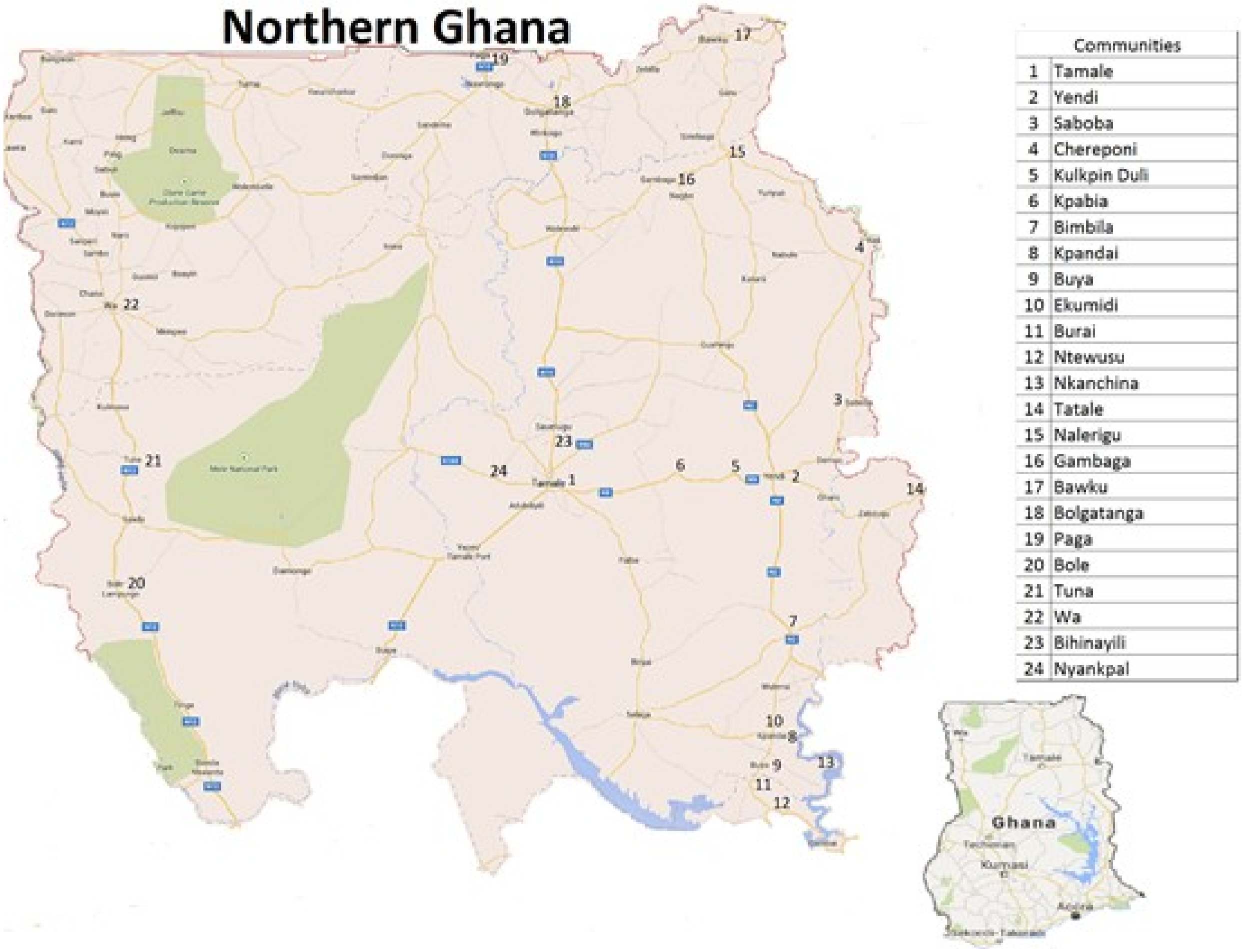
The Board wishes you all the best in the rest of the study.

Sincerely,

Dr. (Mrs.) Nana Akosua Ansah
(Vice Chair, NHRCIRB)

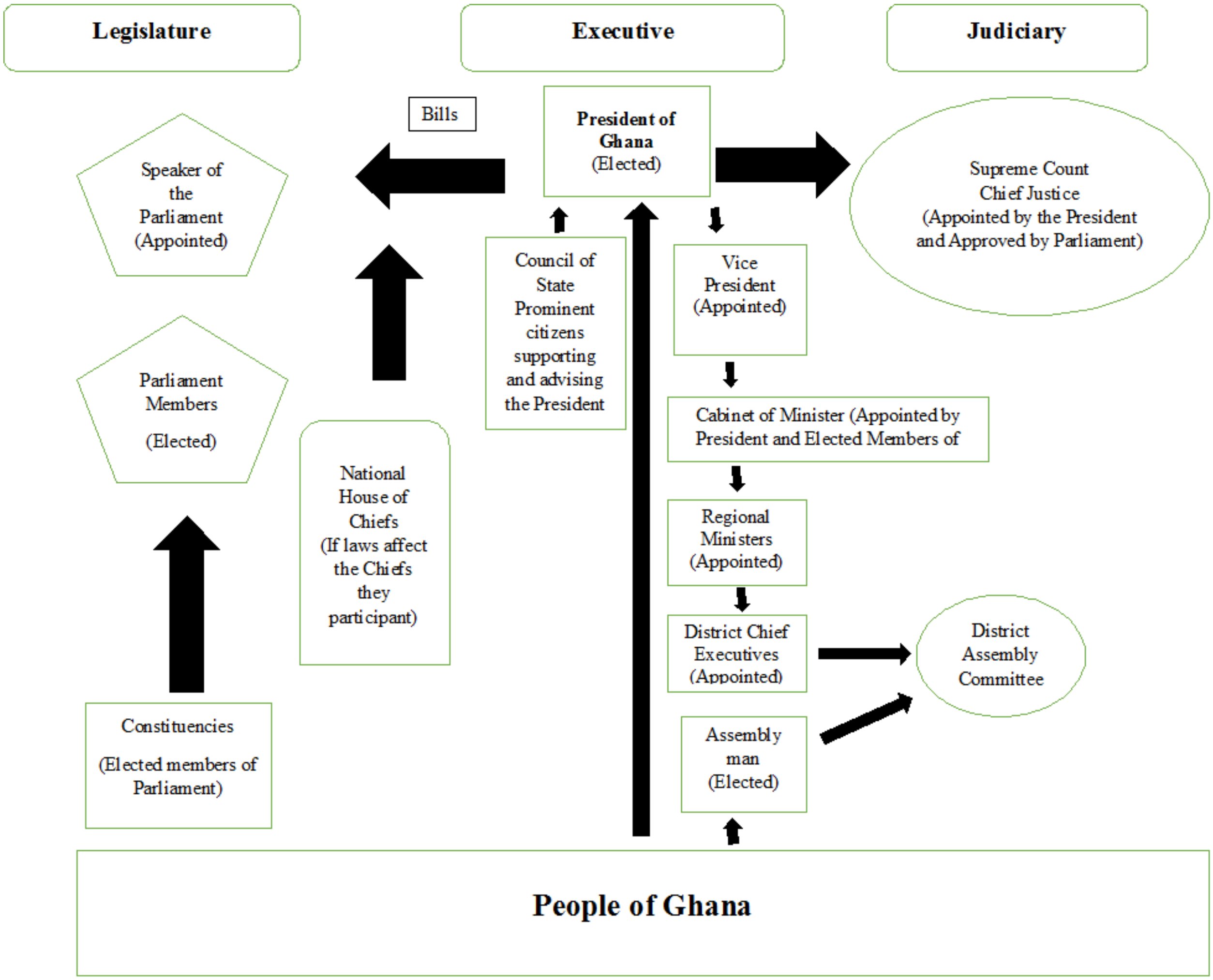
Cc: The Director
NHRC, Navrongo

Appendix C: Ghana Map - Communities Visited

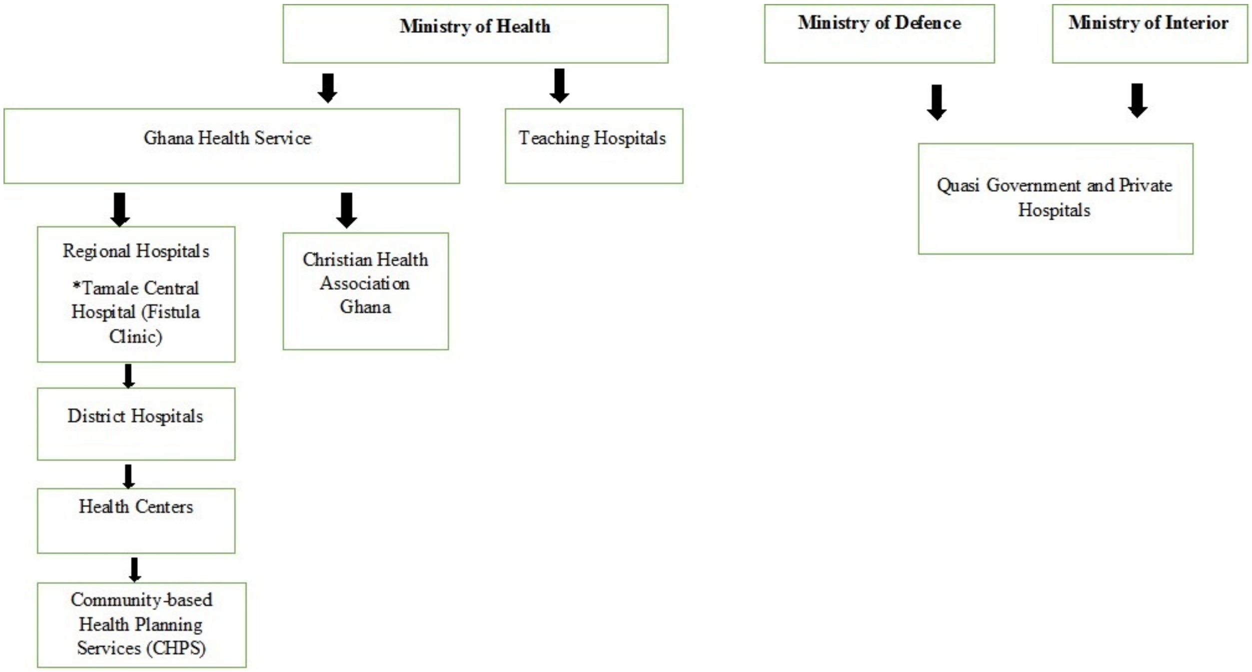


	Communities
1	Tamale
2	Yendi
3	Saboba
4	Chereponi
5	Kulkpin Duli
6	Kpabia
7	Bimbila
8	Kpandai
9	Buya
10	Ekumidi
11	Burai
12	Ntewusu
13	Nkanchina
14	Tatale
15	Nalerigu
16	Gambaga
17	Bawku
18	Bolgatanga
19	Paga
20	Bole
21	Tuna
22	Wa
23	Bihinayili
24	Nyankpal

Appendix D: Ghana - Government Structure



Appendix E: Ghana – Health Care System



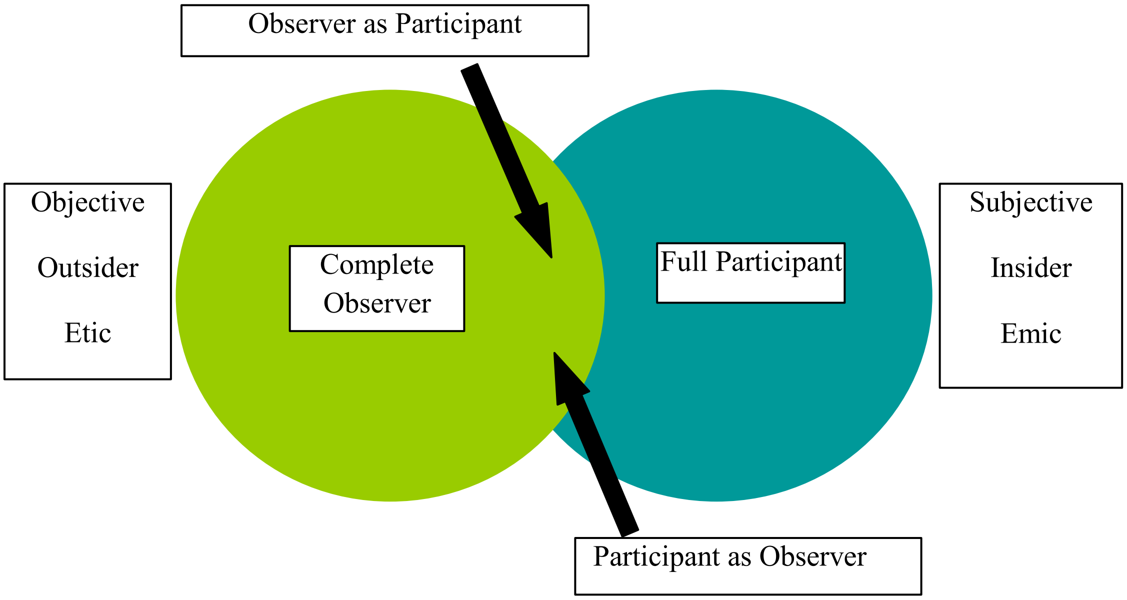
Appendix F: Sample/Recruitment Table

Participant Configuration	Recruitment 1 : March – June 2014	Recruitment 2: April – May 2015	Number of Follow-up Interviews
Women	40	1	9
Family Members	24	0	1
Health-care Providers	17	0	2
Stakeholders	14	3	2
Total	**95**	**4**	**14**

Appendix G: Demographics of Obstetric Fistula Women

Age	**Marital Status**	**Religion**	**Place of Residence**	**Number of children**	**Employment**	**Years living with OF**	**Number of OF surgery**	**Number of years post-OF**
18-52 years Most stated unknown	Married-19 Divorced-11 Widowed-3 Single-2 Unknown-7	Muslim- 16 Christian-8 Traditionist-3 Unknown-14	Urban-15 Rural-26	None-8 1 to 3-14 >3-5 Unknown-14	Professionals-2 Farming-6 Petty Trade-18 Unknown-15	<1 year-1 1 to 3 years- 6 >3 years-15 Unknown-19	1 surgery-3 2 surgeries-16 >2 surgeries- 5 Unknown-17	<1 year-6 1 to 2 years-16 >2 years- 2 Unknown-17

Appendix H: An Ethnographer's Position within the Research



Appendix I: Ethnographic Observation Tool [10]

Instructions for observation: Use a separate observation tool form for each observation session.

Physical space: (e.g., include location for action, places where people act, where events are held)

People involved: (e.g. includes anything that might indicate membership in groups or in sub-populations of interest to the study, such as roles, social status, socioeconomic class, religion, or ethnicity)

Activities: (When you are unsure what to attend to, look to see what is calling your attention and why you have been drawn to it)

Actions/Behaviors: (e.g., includes nonverbal behavior/nuances and outcomes/results of actions. How people use their bodies and voices to communicate different emotions; what individuals 'behaviors indicate about their feelings toward one another.)

Objects: (e.g. information/resources and include function/uses for the object)

Events: (e.g. formal and informal, sequencing of event)

Time: (e.g. day, date, time)

Goals people are trying to accomplish: (and rationale)

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[10] Adapted from: Spradley, J. (1980). *Participants' observation*. NY: Holt Reinheart & Winston

Appendix J: Sample Interview Guides

Women who experienced an obstetrical fistula /repair.

1. Can you briefly tell me about yourself?

   Probes: What is your name? How old are you? Where do you live? Are you married? Do you have children and if so how many? What is the age of your child(ren)?

2. Can you tell me about your experience(s) during pregnancy and/or delivery?

   Probes: Where did you labour? How long were you in labour? Who was with you? How many pre- natal visits did you have?

3. Can you tell me about your experience living with an obstetric fistula?

   Probes: What does your ideal world look like? What does your real world look like? Tell me about some of your everyday challenges with your relationships, with your work (economics), with your physical, sexual and psychological health. How did people in your community treat you? How long did you live with an obstetric fistula before seeking treatment? What treatments have you undergone? What caused you to seek treatment?

4. Can you tell me about your experience, returning home to your community, after having an obstetric fistula repair?

   Probes: What were your first thoughts and feelings when returning home post-obstetric fistula repair? Tell me about your everyday challenges with your relationships, with your work (economics), with your physical, sexual and psychological health post fistula repair? How do people in your community treat you post fistula repair? How do you cope within your community? What resources are available to you in the community post fistula repair? What resources would you like to see to help you cope better within the family and the community post fistula repair? Do you talk to other women in your community about obstetric fistula/ repair?

Family members who cared for women with an obstetric fistula /repair.

1. Can you briefly tell me your relationship to the woman you cared for with obstetric fistula/repair?
2. Can you tell me about the types of care you provided for your family member?

   Probe: Provide examples of physical, psychological, social, financial, spiritual care
3. Can to describe the impact of caring/supporting a family member with obstetric fistula/repair had on you and your family physically, emotionally, socially, financially, sexually?
4. Can you describe your experience living with a family member who has had an obstetric fistula repair?

   Probe: Challenges, resources needed.

Health professionals (stakeholders) working directly or indirectly with women who experienced an obstetric fistula /repair.

1. How long have you been working with obstetric fistula patients? And in what capacity (doctor, nurse, counselor, midwife)?
2. Can you tell me the prevalence and incidence of obstetric fistula in the region?
3. Can you comment on what might be contributing to the high rate of obstetric fistula in this region?
4. Can you tell me many women come seeking obstetric fistula treatment/repair? How many obstetric fistula repairs are performed annually?
5. On average how long would women have experienced this condition before seeking treatment?
6. Can you describe the type and how extensive the obstetric fistulas you are seeing?
7. Can you comment on the success rate of obstetrical fistula repair in Ghana?
8. Can you comment on the types of care/teaching/programs provided to a woman who receives obstetric fistula treatment/repair?
9. Tell me about follow-up care/ supports in place in the community for women who are discharged home post- obstetric fistula repairs?
10. Can you tell me about the major challenges and successes for women post obstetric fistula repairs to reintegrate?
11. Can you tell me the impact of caring for women with obstetric fistula/repair has on health-care providers? Do health-care providers have the resources to assist women to reintegrate? Who has a role to play in the success of reintegrate post fistula repair?

Stakeholders involved obstetrical fistula care and rehabilitation.

1. Tell me a little bit about yourself, your role in this community/organization/department?

2. Tell me about the initiatives or involvement your community/ organization/ department is doing with women who have experienced an obstetrical fistula/repair? Tell me thoughts on women's ability to be accepted back into their communities post fistula repair?

3. Describe where your community/ organization/ department view the greatest gaps and successes regarding obstetrical fistula care/rehabilitation/ reintegration?

4. Tell me what your community/ organization/ department would like to see in the future (two, five and ten years) regarding obstetrical fistula care/rehabilitation/ reintegration?

5. Describe how your community/ organization/ department evaluates or measures success in obstetrical fistula care/ rehabilitation/ reintegration?

6. Tell me your thoughts about what the government is doing (things you hear or observe) to assist with the reintegration of women who have experienced an obstetrical fistula/repair?

Appendix K: Coding Framework/Tree Diagram Used in Analysis of Data

1. Demographics

- 1.1 Religion
- 1.2 Age
- 1.3 Marital Status/Years Married
- 1.4 Ethnicity
- 1.5 Work/ Employment
- 1.6 Location/ Village/Community
- 1.7 Position in Family/Status
- 1.8 Number of Children/GTPAL (gravid, term, parity, abortion, living)
- 1.9 Number of Wives
- 1.10 Years Living with Obstetrical Fistula

2. Obstetrical History

- 2.1 Obstetrical Complications/Labour Experiences
- 2.2 Access to Care
  - 2.2.1 Antenatal Care
  - 2.2.2 Intrapartum Care
  - 2.2.3 Postnatal Care
- 2.3 Mode of Delivery

3. Birth Attendance

- 3.1 Registered Nurse and/or Midwife
- 3.2 Traditional Birth Attendant
- 3.3 No Attendance/Family Member

4. Obstetrical Fistula

- 4.1 Understanding Obstetrical Fistula
- 4.2 Causes Obstetrical Fistula
- 4.3 Impact: Living with Obstetrical Fistula
  - 4.3.1 Women
  - 4.3.2 Family Members
  - 4.3.3 Health Care Providers/Stakeholders

5. Culture

- 5.1 Traditional Health Beliefs/Practices (General)
- 5.2 Traditional Health Beliefs about Obstetrical Fistula (Cause, Treatment)
- 5.3 Traditional Treatment
- 5.4 Traditional Role of Women

- 5.5 Traditional Role of Men (Patriarchal Society)
- 5.6 Traditional Role of Family/Community
- 5.7 Metaphors

6. Care

- 6.1 Treatment
  - 6.1.1 Treatment History (Woman's Narrative)
  - 6.1.2 Treatment History (Development of Obstetrical Fistula Programs)
- 6.2 Expense of Care
- 6.3 Seeking Care
- 6.4 Access to Care
- 6.5 Decisions-making Related to Care
- 6.6 Education Related to Obstetrical Fistula Care/Reintegration
- 6.7 Token/Actions of Gratitude and Appreciations
- 6.8 Factors Affecting Success or Failure to Care
- 6.9 Governing of Obstetrical Fistula Care
- 6.10 Desperate for a Cure

7. Relationships

- 7.1 Family: Dynamics Post-Obstetrical Fistula Repair
  - 7.1.1 Rival
  - 7.1.2 Children
  - 7.1.3 Natal family
  - 7.1.4 Husband
- 7.2 Community: Dynamics Post-Obstetrical Fistula Repair
- 7.3 Health Care Providers: Dynamics Post-Obstetrical Fistula Repair

8. Welcome Home

- 8.1 Delay in Returning Home
- 8.2 Concerns Raised
  - 8.2.1 Women
  - 8.2.2 Husband
  - 8.2.3 Family
  - 8.2.4 Health Care Providers
  - 8.2.5 Community/Stakeholders
- 8.3 Needs
  - 8.3.1 Women
  - 8.3.2 Family Members
  - 8.3.3 Health Care Providers/Stakeholders
  - 8.3.4 Community
- 8.4 Accepted Home

9. Challenging Context

- 9.1 Infrastructure (Road Network, Transportation, Electricity, Internet, Telecommunication, Water)
- 9.2 Social Determinants of Health (SDOH) (Child Marriage, Female Genital Cutting, Education, Nutrition)
- 9.3 Distance and Environmental Challenges
- 9.4 Perception of Time
- 9.5 Resources (Equipment, Human Resources, Facilities)
- 9.6 Governing Challenges
- 9.7 Political Issues

10. Keys to Success

- 10.1 Collaborative Partnerships
- 10.2 Follow-up/through
- 10.3 Support
  - 10.3.1 Health Care Providers
  - 10.3.2 Peers
  - 10.3.3 UNFPA (NGO)
  - 10.3.4 Government
  - 10.3.5 Self
  - 10.3.6 Family
  - 10.3.7 Friends/Community/Volunteers
  - 10.3.8 God/Spirituality
- 10.4 Training/Education
- 10.5 Empowerment/Emancipation/Power
- 10.6 Awareness/Knowledge
- 10.7 Professional Accountability
- 10.8 Reintegration

Appendix L: Assent Form

FACULTY OF
NURSING
UNIVERSITY OF ALBERTA

Assent Form

Title: **An Exploration of a Culture of Reintegration with Women Who Have Experienced Obstetrical Fistula Repair in Rural Ghana, West Africa.**

Principal Investigator: Kimberly Jarvis RN; PhD (candidate)
kdjarvis@ualberta.ca
1 (780) 492-7953 or 0261877220
Address: Faculty of Nursing,
Level 3, Edmonton Clinic Health Academy,
11405 87 Avenue, University of Alberta
Edmonton Alberta T6G 1C9

Supervisor: Dr. Solina Richter RN; DCur
solina.richter@ualberta.ca
1 (780) 492-7953
Address: Faculty of Nursing,
Level 3, Edmonton Clinic Health Academy,
11405 87 Avenue, University of Alberta
Edmonton Alberta T6G 1C9

What is a research study?
A research study is a way to find out new information about something. People do not need to be in a research study if they do not want to.

Why are you being asked to be part of this research study?
Sometimes when it is nearly time to give birth, women will have a very slow and painful labour. These pains may last for a long time, even several days. If women are in labour for too long they may develop a serious injury to their birth canal. It is called an obstetric fistula. Many women who have an obstetric fistula will leak urine or feces or both until they are able to get treatment. I am a nurse who wants to learn more about how to help women who have this condition. My way of learning is to do a research study. To do this, I want to learn about what life is like once women return home after having obstetric fistula treatment or repair. I think that your knowledge can help be understand if there are cultural beliefs about obstetric fistula and how to best support and care for women affected by this injury.

If you join the study what will happen to you?
If you decide to take part in this study, you will meet with me; Kimberly Jarvis. I will ask you and/or your family member(s) what it is like to have had or care for a woman with an obstetric fistula/ repair. I will also ask you about the best way nurses and people in the community can care for women who have an obstetric fistula/repair.

The talk will not last for more than 1 hour. What you say will be recorded so that I can remember everything you say. No one else will know what you say, our talk is private. You can decide where the talk will take place in your home or community. If you want to speak in your own language, someone who can speak both English and your language will tell me what you are saying. That person will have to promise that they will not tell anyone what you say.

Will any part of the study hurt?
No harm should come to you if you decide to talk to me. It may cause some people to remember a sad or difficult time. If this happens and you want to talk about it, I will get someone trained in talking about these issues to help you feel better. If you decide that you do not want to say anything more, just tell me and our talk will end.

Will the study help you?
This study gives you a chance to talk about what happened and about the good and bad effects involving treatment/repair, what it feels like to come home or have a family member come home after treatment/repair. You can also tell me what kind of help you think you or your family member should have. Many women have obstetric fistula so what you know may help other women and families in the same situation.

Does your parents/husband/guardian know about this study?
This study was explained to your parents/husband/ guardian and they said that I could ask you if you want to be in it. You can talk this over with them before you decide.

Who will see the information collected about you?
The information collected about you during this study will be kept safely locked up. Nobody will know it except the people doing the research. The study information about you will not be given to your parents/ husband/guardian unless you want to tell him or her. The researchers will not tell your friends or anyone else.

I will write a report to tell people in the Northern Region what I learned by talking to women and to the families of women with a fistula. I will also write a report to tell nurses and others who look after women with obstetric fistula what I learned. This report might be put in a health magazine (journal). If this happens, I will only say that I talked to women, family members or others in a community where there was a woman with obstetric fistula. I will not use anyone's name or the name of the community. What you say could be used in a future study. That will only happen if the researcher gets special permission. After the study is done we still need to store what you say. The information will be securely stored at the University of Alberta, Canada for at least 5 years after the study is over.

What do you get for being in the study?
I value the time you give me in understanding the problem of obstetrical fistula. I will give women and family members in the study a small token (10 Cedi) for helping me. Transportation will be arranged.

Do you have to be in the study?
You do not have to be in the study. No one will be upset if you do not want to be in this study, you just have to tell me. It is up to you.

You can take more time to think about being in the study. It you decide to be in the study and change your mind **before June 30, 2014** you just need to call me and I will remove all that you told me.

What if you have any questions?
You can ask any questions that you may have about the study. If you have a question later you can call or have your parents/husband/guardian call one of the numbers listed above. You will be given a copy of this paper to keep.

Your rights as a Participant
This research has been reviewed and approved by the University of Alberta Health Ethics Review Board and the Navrongo Health Research Centre. If you have any questions about your rights as a research participant you can contact the IRB Office the Navrongo Health Research Centre by email at irb@navrongo-hrc.org or by telephone at (233) 03821 22348/22310 or the Alberta Research Ethics Office at 1(780) 492-2615.

☐ Yes, I will be in this research study. ☐ No, I do not want to do this.

____________________ Participant's name (Print)	____________________ Signature/Thumbprint of Participant	☐	____________ Date
____________________ Legal Guardian (Print)	____________________ Signature/Thumbprint	☐	____________ Date
____________________ Researcher's Signature	____________________ Date		

Appendix M: Information Sheet

FACULTY OF NURSING
UNIVERSITY OF ALBERTA

U of A: Information Letter and General Consent to Participate

Title: **An Exploration of a Culture of Reintegration with Women Who Have Experienced Obstetrical Fistula Repair in Rural Ghana, West Africa.**

Principal Investigator: Kimberly Jarvis RN; PhD (candidate)
kdjarvis@ualberta.ca
1 (780) 492-7953or 0261877220
Address: Faculty of Nursing,
Level 3, Edmonton Clinic Health Academy,
11405 87 Avenue, University of Alberta
Edmonton Alberta T6G 1C9

Supervisor: Dr. Solina Richter RN; DCur
solina.richter@ualberta.ca
1 (780) 492-7953
Address: Faculty of Nursing,
Level 3, Edmonton Clinic Health Academy,
11405 87 Avenue, University of Alberta
Edmonton Alberta T6G 1C9

General Information about Research

Sometimes when it is nearly time to give birth, women will have a very slow and painful labour. These pains may last for a long time, even several days. If women are in labour for too long they may develop a serious injury to their birth canal. It is called an obstetric fistula. Many women who have an obstetric fistula will leak urine or feces or both until they are able to get treatment. I am a nurse who wants to learn more about how to help women who have this condition. My way of learning is to do a research study. To do this, I want to learn about what life is like once women return home after having obstetrical fistula treatment or repair. The reason for doing this research study is to find out if there are cultural beliefs about obstetrical fistula and how to best support and care for women affected by this serious injury.

If you decide to take part in this study, you will meet with me; Kimberly Jarvis. I will ask you and/or your family member(s) what it is like to have had or care for a woman with an obstetrical fistula/ repair. I will also ask you about the best way nurses and people in the community can care for women who have an obstetrical fistula/repair.

The talk will not last for more than 1 hour. What you say will be recorded so I can remember everything you say. No one else will know what you say, our talk is private. You can decide where the talk will take place. If you want to speak in your own language, someone who can speak both English and your language will tell me what you are saying. That person will have to promise that they will not tell anyone what you say.

Possible Risks and Discomforts

No harm should come to you if you decide to talk to me but it may cause some people to remember a sad or difficult time. If this happens and you want to talk about it, I will get someone trained in talking about these issues to help you feel better. If you decide you do not want to say anything more, just tell me and our talk will end.

Possible Benefits

This study gives you a chance to talk about what happened and about the good and bad effects involving treatment/repair, what it feels like to come home or have a family member come home after treatment/repair. You can also tell me what kind of help you think you or your family member should have. Many women have obstetric fistula so what you know may help other women and families in the same situation.

Confidentiality

No one will know that you are in the study unless you want to tell him or her. No one will know what you say to me. Your name will not be put on anything that you tell me. I will write a report to tell people in the Northern Region what I learned by talking to women and to the families of women with a fistula. I will also write a report to tell nurses and others who look after women with obstetric fistula what I learned. This report might be put in a health magazine (journal). If this happens, I will only say that I talked to women, family members or others in a community where there was a woman with obstetric fistula. I will not use anyone's name or the name of the community. What you say could be used in a future study. That will only happen if the researcher gets special permission. After the study is done we still need to store what you say. The information will be securely stored at the University of Alberta, Canada for at least 5 years after the study is over.

Compensation

I value the time you give me in understanding the problem of obstetrical fistula. I will give women and family members in the study a small token (10 Cedi) for helping me. Transportation will be arranged.

Voluntary Participation and Right to Leave the Research

Being in this study is your choice. You do not have to answer any questions you do not want to answer. If you decide to be in the study, you can stop talking to me at any time. No one will know if you decide to quit. You just have to tell me this is what you want to do **before June 30, 2014**.

Statement of Consent

I have read the information in this consent form including risks and possible benefits. I have been given the chance to ask questions. My questions have been answered to my satisfaction, and I agree to be interviewed and have the information used as talked about above. I have been given a copy of this form.

SIGNATURE

____
Name of Participant (Please Print)

____ ____________________
Signature/Thumbprint of Participant Date

____ ____________________
Signature of Witness (if needed) Date

I have explained the research to the participant and answered all his/her questions. I will give a copy of the signed consent form to the participant.

____
Name of Person Obtaining Consent (Please Print)

____ ____________________
Signature of Person Obtaining Consent Date

Your rights as a Participant

This research has been reviewed and approved by the University of Alberta Health Ethics Review Board and the Navrongo Health Research Centre. If you have any questions about your rights as a research participant you can contact the IRB Office the Navrongo Health Research Centre by email at irb@navrongo-hrc.org or by telephone at (233) 03821 22348/22310 or the Alberta Research Ethics Office at 1(780) 492-2615.

Appendix N: Consent Forms

FACULTY OF NURSING
UNIVERSITY OF ALBERTA

CONSENT FORM

Title: An Exploration of a Culture of Reintegration with Women Who Have Experienced Obstetrical Fistula Repair in Northern Ghana, West Africa.

Researcher: Kimberly Jarvis RN; PhD (candidate) Phone Number(s):1 (780) 492-7953or 0261877220
Research Supervisor: Solina Richter RN; DCur Phone Number(s):1 (780) 492-7953

Part 2 (to be completed by the research participant):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without penalty?	☐	☐
Has the issue of confidentiality and anonymity been explained to you?	☐	☐
Do you understand that the conversations will be recorded?	☐	☐
Do you understand that portions of the final research may be published in professional journals or presented at conferences?	☐	☐
**Do you agree that the information collected in this study can be used for future studies?	☐	☐

Who explained this study to you? _______________

I agree to take part in this study: YES ☐ NO ☐

Signature/Thumb print of Research Participant ____________________________________

(Printed Name) ____
Date: ________________________________

Signature of Witness ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee __________________________________ Date __________

Navrongo: Consent to Participate in a Research Study

TITLE OF RESEARCH STUDY:
An Exploration of a Culture of Reintegration of Women Who Have Experienced Obstetrical Fistula Repair in Northern Ghana, West Africa.

Introduction/Purpose of Study
Sometimes when it is nearly time to give birth, women will have a very slow and painful labour. These pains may last for a long time, even several days. If women are in labour for too long they may develop a serious injury to their birth canal. It is called an obstetrical fistula. Many women who have an obstetric fistula will leak urine or feces or both until they are able to get treatment. I am a nurse who wants to learn more about how to help women who have this condition. My way of learning is to do a research study. To do this, I want to learn about what life is like once women return home after having obstetrical fistula treatment or repair. The reason for doing this research study is to find out if there are cultural beliefs about obstetrical fistula and how to best support and care for women affected by this serious injury.

Study Procedure
If you decide to take part in this study, you will meet with me; Kimberly Jarvis. I will ask you as a woman who has experienced an obstetrical fistula/ repair or as a family member, health care professional or community member what it is like to have had or to care for a women with an obstetrical fistula/ repair. I will also ask you about how women with an obstetrical fistula/ repair are received back into their communities and how health-care providers and community leaders can better care for women who have an obstetrical fistula/repair.

The talk will not last for more than 1 hour. What you say will be recorded so that I can remember everything you say. No one else will know what you say, our talk is private. You can decide where the talk will take place. If you want to speak in your own language, someone who can speak both English and your language will tell me what you are saying. That person will have to promise that they will not tell anyone what you say.

Benefits/Risks of the Study
No harm should come to you if you decide to talk to me but it may cause some people to remember a sad or difficult time. If this happens and you want to talk about it, I will get someone trained in talking about these issues to help you feel better. If you decide that you do not want to say anything more, just tell me and our talk will end.

This study gives you a chance to talk about what happened and about the good and bad effects involving treatment/repair, what it feels like to come home or have a family/community member come home after an obstetrical fistulas repair/treatment. You can also tell me what kind of help you think you or your family/community member should have. Many women have obstetrical fistulas so what you know may help other women and families in the same situation.

Confidentiality
No one will know that you are in the study unless you want to tell him or her. No one will know what you say to me. Your name will not be put on anything that you tell me. I will write a report to tell people in the Northern Region what I learned by talking to women and to the families of women with a fistula. I will also write a report to tell nurses and others who look after women with obstetrical fistula what I learned. This report might be put in a health magazine (journal). If this happens, I will only say that I talked to women, family members or others in a community where there was a woman with an obstetrical fistula. I will not use anyone's name or the name of the community. What you say could be used in a

future study. After the study is done we still need to store what you say. The information will be securely stored at the University of Alberta, Canada for at least 5 years after the study is over.

Compensation
I value the time you give me in understanding the problem of obstetrical fistula. I will give women and family members in the study a small token (10 Cedi) for helping me. Transportation will be arranged.

Withdrawal from study
Being in this study is your choice. You do not have to answer any questions that you do not want to answer. If you decide to be in the study, you can stop talking to me at any time and you can take back all that you told me. No one will know if you decide to quit. You just have to tell me that this is what you want to do **before June 30, 2014**.

Questions
If you have any questions about the research now or later, please contact

1. Ms. Kimberly Jarvis RN, PhD (candidate) University of Alberta, Faculty of Nursing, 1(780) 492-7953 or 0261877220
   kdjarvis@ualberta.ca

2. Dr. Solina Richter RN, DCur, Associate Professor, University of Alberta, Faculty of Nursing, 1(780) 492-7953
   solina.richter@ualberta.ca

This research has been reviewed and approved by the University of Alberta Health Ethics Review Board and the Navrongo Health Research Centre. If you have any questions about your rights as a research participant you can contact the IRB Office the Navrongo Health Research Centre by email at irb@navrongo-hrc.org or by telephone at: (233) 03821 22348/22310 or the Alberta Research Ethics Office at 1(780) 492-2615.

VOLUNTEER AGREEMENT

I have read or have had someone read all of the above, asked questions, received answers concerning areas I did not understand, and am willing to give consent for me, my child/ ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records. I agree to participate as a volunteer. I agree that what I say will be tape recorder. The above document describing the benefits, risks and procedures for the research title: ***An Exploration of a Culture of Reintegration of Women Who Have Experienced Obstetrical Fistula Repair in Northern Ghana, West Africa*** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer and understand that I can withdraw my consent to volunteer before **June 30, 2014**.

Name of Participant (Print) Date

Signature / Thumbprint of Participant/His/Her Legal representative ☐

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Name and Signature of Witness Date

I certify that I have explained to the above individual the nature and purpose, the potential benefits, and possible risks associated with the participation in this research project. I have answered any questions that have been raised and have witnessed the above signature on the date indicated below.

Name and Signature of Person Who Obtained Consent Date

FACULTY OF
NURSING
UNIVERSITY OF ALBERTA

Permission to Take Photograph(s)

Consent for Photography

Name of person to be photographed or to have their property photographed:

____
(Please print)

I am the person named above.

I understand that a researcher/ graduate student from the University of Alberta is planning to take photographs of and make captions /headings identifying me and/or my family members and/or my property for the purpose of research.

I understand that:
These images may be used in the researcher's research reports / scholarly publications (including books) and in presentations at academic conferences. Photographs will reveal my identity. In captions/headings and in discussions about the photographs, it is your choice if you want to have your face hidden. Your name will not be identified.

If you wish to have your face hidden to protect your identity please check Yes____ No____

My signature below indicates that I consent to the above-described collection, use and release of photographs and captions/headings.

Name of person consenting: _________________________
(Please print)

____
Signature/Thumbprint of Participant

Date: ____________________

Name of witness: _________________________
(Please print)

____
Signature/Thumbprint of Participant

Date: ____________________

I understand that I may withdraw this consent at any time **before June 30, 2014**

If you have any questions about the research now or later, please contact:
Principal Investigator: Kimberly Jarvis RN; PhD (candidate)
kdjarvis@ualberta.ca
1 (780) 492-7953or 0261877220
Address: Faculty of Nursing,
Level 3, Edmonton Clinic Health Academy,
11405 87 Avenue, University of Alberta
Edmonton Alberta T6G 1C9

Supervisor: Dr. Solina Richter RN; DCur
solina.richter@ualberta.ca
1 (780) 492-7953
Address: Faculty of Nursing,
Level 3, Edmonton Clinic Health Academy,
11405 87 Avenue, University of Alberta
Edmonton Alberta T6G 1C9

This research has been reviewed and approved by the University of Alberta Health Ethics Review Board and the Navrongo Health Research Centre. If you have any questions about your rights as a research participant you can contact the IRB Office the Navrongo Health Research Centre by email at irb@navrongo-hrc.org or by telephone at (233) 03821 22348/22310 or the Alberta Research Ethics Office at 1(780) 492-2615.

Appendix O: Confidential Agreement

FACULTY OF
NURSING
UNIVERSITY OF ALBERTA

QUAECUMQUE VERA

Confidentiality Agreement

An Exploration of a Culture of Reintegration with Women Who Have Experienced Obstetrical Fistula Repair in Rural Ghana, West Africa.

I, ______________________________, the ______________________________ (specific job description, e.g., interpreter/translator) have been hired to______________________________

I agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s)*.
2. Keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.
3. Return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks.
4. After consulting with the *Researcher(s),* erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive).

____________________	____________________	____________________
(Print Name)	(Signature)	(Date)

Researcher(s)

____________________	____________________	____________________
(Print Name)	(Signature)	(Date)

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by Research Ethics Board (Human Research Ethics, REB1*)* at the University of Alberta and the Navrongo Health Research Centre, Ghana. For questions regarding participant rights and ethical conduct of research, contact the Navrongo Health Research Centre by email at irb@navrongo-hrc.org or by telephone at (233) 03821 22348/22310 or the Alberta Research Ethics Office at 1(780) 492-2615.