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Obstetric fistula-induced incontinence and WASH programming in humanitarian settings: agenda for research, innovation, and practice

Samuel Adjorlolo^{1,2*} , Mary Ani-Amponsah³, Emily Hammond⁴ and Maame Esi Pantiwaa Nyame⁵

Abstract

Women living with obstetric fistula-induced incontinence (OFII) have heightened need for water, sanitation and hygiene (WASH) services because they experience involuntary leaking of urine, feces, or both. In humanitarian settings where access to WASH services is notably limited, research and innovation relating to OFII and WASH programming has not been granted the requisite attention, relative to menstrual hygiene management. The paper is intended to bring to the attention of humanitarian researchers and practitioners the research needs of women living with OFII. Three thematic areas that have the propensity to arouse interest in this neglected topical issue and help to set the stage for research and actions are discussed. These are the prevalence of OFII, prevention of OFII, and WASH programming for women living with OFII. Empirical studies dedicated to the above thematic issues will generate the needed evidence base to inform decision-making processes relating to improving the WASH needs of women living with OFII.

Keywords: Obstetric fistula, Incontinence, Humanitarian, Emergency, WASH

Background

Researchers, policy-makers, and practitioners have expressed profound interest in the provision of water, sanitation, and hygiene (WASH) services in humanitarian settings through the development and implementation of several innovative products and services, including care guidelines (Brown et al. 2012; Giles-Hansen 2015; Vujcic et al. 2015). Within the general humanitarian population is a subset of vulnerable women who have heightened need for WASH services because they experience incontinence, referred to as involuntary loss of urine and/or feces. One of the notable causes of incontinence is obstetric fistula (OF), defined as the formation of a hole between the vagina and bladder (vesico-vaginal

fistula), vagina and rectum (recto-vaginal fistula), or both (Lufumpa et al. 2018; Rosato-Scott and Barrington 2018; Tayler-Smith et al. 2013). OF often results from obstructed labor caused by a mismatch between the size of the fetus and birth canal (Wall 2006) and lack of access to emergency care, such as caesarean section. Obstructed labor induces pressure on the tissues of the bladder, vagina and rectum, leading to inadequate blood supply and death of tissues (Bashah et al. 2018). Although OF has been eradicated in high income countries, where 'a mismatch between fetal head and pelvis is rapidly recognized and managed correctly (Lufumpa et al. 2018), it is one of the major challenges facing women in low and resource constrained settings (Rosato-Scott and Barrington 2018; Tayler-Smith et al. 2013). Sexual offenses such as rape against underaged women or pregnant women could contribute to OF. These social vices are very common in humanitarian settlements.

*Correspondence: sadjorlolo@regig.org

¹ Research and Grant Institute of Ghana, Legon Post Office, Agbawe Avenue 22, P.O. Box LG 1004, AdentanAccra, Accra, Ghana
Full list of author information is available at the end of the article

Obstetric fistula-induced incontinence (OFII) results in several complications and health problems, including genital ulceration, pain, infection, secondary infertility, depression, and amenorrhea (Arrowsmith et al. 1996; Wall et al. 2005). Women with OFII reportedly experienced shame, embarrassment, marginalization, social exclusion, and neglect by family relations and community members (Donnay and Weil 2004; Enfield 2018; Siddle et al. 2013). These experiences are not only distressing (Yeakey et al. 2009) but also act as major barriers to seeking early treatment (Lufumpa et al. 2018). Moreover, incontinence is generally associated with significant economic costs. For example, the annual economic burden of urinary incontinence in selected high income countries such as Canada, Germany, Italy, Spain, Sweden, and the UK was estimated at €7 billion. In the USA, the estimated cost was \$66 billion (Milsom et al. 2014).

Evidence suggests that women living with incontinence in non-humanitarian settings have substantial challenges in meeting their WASH needs. These challenges stem from unavailability of WASH services at locations frequented by the women and relatively high cost of incontinence materials (Gjerde et al. 2013; Rosato-Scott and Barrington 2018; Walker and Gunasekera 2011). The aforementioned challenges are more likely to be compounded in humanitarian settings where access to WASH services is notably limited, providing enough impetus for researchers to systematically investigate and assess WASH services at all levels in humanitarian settings, including at the household, personal, and community levels, for women living with OFII. This would guide the research community and innovators in devising optimal strategies to improve the WASH experiences of women living with OFII to achieve the United Nations Sustainable Development Goals 3 (Ensure healthy lives and promote wellbeing), 5 (Achieve gender equality and empower all women and girls) and 10 (Reduce inequalities within and among countries).

However, to date, research in humanitarian settings relating to OFII and WASH programming has not been granted the requisite attention. Issues relating to OF in humanitarian settings and more importantly the WASH needs of women living with incontinence, including OFII are under-researched. The lack of evidence-based guidance on incontinence care in general is concerning (Giles-Hansen 2015). The limited discourse and insight into the WASH programming for women living with OFII has undeniably hampered efforts to improve their WASH services. There is, however, considerable evidence on research conducted on OF and/or incontinence in non-humanitarian environments. These studies may have limited utility in humanitarian settings owing to the observable structural and functional differences.

Humanitarian environments are typically characterized by poor healthcare infrastructure and inadequate healthcare delivery system, resulting in poor maternity care, higher maternal mortalities, and morbidities (Nickerson et al. 2015). Additionally, the general breakdown in social order and high prevalence of violence, specifically gender-based violence and early marriage practices in humanitarian settings provide fertile grounds for maternal health issues to develop, OFII (Marsh, Purdin, and Navani, 2006). In this paper, we used predominantly insights from developments in non-humanitarian settings to unearth salient and critical issues to guide humanitarian research, innovators and practitioners with respect to OFII and WASH programming. Therefore, the overarching aim of this paper was to advance the science of the WASH needs of women living with OFII in humanitarian settings. Specifically, we sought to provide guidance for future research and innovation with respect to improving the WASH experiences of women living with OFII. The current paper discussed issues relating to the prevalence of OF/OFII, measures to prevent women with obstetric fistula and lastly the WASH needs of women living with OFII. Although the above-mentioned thematic areas are not exhaustive; we believe that they are among the most pressing areas that could arouse interest in this neglected topical issue and help set the stage for other elaborate theoretical, conceptual, and practical discussions. More specifically, it is expected that empirical data on the prevalence and burden of OFII would influence and persuade researchers, policymakers, and practitioners in humanitarian settings to invest resources to prevent OF and improve the WASH needs of women living with OFII. Relatedly, the call for studies to devise interventions grounded in empirical evidence to prevent OFII is consistent with calls by international organizations such as UNFPA and Member States of United Nations to end OF (Anastasi et al. 2020). Lastly, the constant and voluntary leaking of urine, feces or both establishes that WASH facilities and services are major considerations for women living with OFII.

The paper was underpinned by a purposive review approach in view of the lack of studies addressing the issue under-consideration in humanitarian settings. This approach offered us the flexibility to discuss the topic by drawing on the findings from related and relevant research as well as creating an opportunity for the experiential knowledge of the authors about WASH practices in humanitarian context to be brought to bear. The purposive research approach, although offer little insight and assurance of a balanced perspective on an issue, has been recognized as a complementary knowledge production tool to systematic reviews (Eva, 2008). As pointed out by Cook (2019), researchers have the obligation to

point out the biases associated with their methodologies to enable interpretation and contextualization of their research. We, therefore, emphasized from the outset that the methodological approach adopted in this paper was not intended to provide a synthesis of existing literature but more importantly to build a case for greater attention to OFII and WASH services in humanitarian context.

Prevalence of obstetric fistula-induced incontinence

The prevalence of OFII has been estimated variously in existing studies. In 2006, the WHO estimated that, more than 2 million young women were living with OF globally, and that between 50,000 and 100,000 new cases of OF occur every year (WHO 2006). These estimates have been criticized on the ground of overreliance on physician report (Adler et al. 2013; Cowgill et al. 2015). In response, Adler et al. (2013) synthesized 19 studies predominantly from sub-Saharan Africa and South Asia, comprising 13 community-based and 6 hospital-based studies. The results showed that, in general, less than 1 out of 1000 women suffer from OFII. When the analysis was restricted to studies from sub-Saharan Africa and South Asia countries, the number increased to 1.57 per 1000 women. The number of new OF cases varied considerably between community-based studies (i.e., 0.09 per 1000 recently pregnant women) and hospital-based studies (i.e., 0.66 per 1000 pregnancies). In a related systematic review of 62 studies, Cowgill et al. (2015) found substantial heterogeneity in the prevalence of OFII, which was estimated to be as high as 4.09 cases per 1000 deliveries in women under 20 years, and 2.11 per 1000 deliveries in women aged 12–49 years. More importantly, it should be noted that the OF prevalence rates noted above could be underestimated as thousands of women with OF have not been accounted for (Lufumpa et al. 2018). This is largely because stigmatization, marginalization and social exclusion and high treatment cost have deterred women with OF from seeking help and/or disclosing their OF status (Adler et al. 2013; Cowgill et al. 2015; Lufumpa et al. 2018).

Nevertheless, the major caveat in the humanitarian literature is the lack of data on the prevalence of OFII. While there is the possibility that existing prevalence estimates from hospital/community settings comprised data from women in humanitarian and non-humanitarian settings, it would be meaningful to develop humanitarian database to advance context-specific discussions and establish context-specific interventions. Therefore, the implications of the above reviewed studies for research in humanitarian settings are critical. Typically, women living with OFII may escape identification in community-based estimates given the serial factors

affecting help-seeking, as noted previously (Giles-Hansen 2015; Vujcic et al. 2015). Meanwhile, community-based studies are important in documenting the prevalence of OFII given the challenges confronting healthcare provision in humanitarian, and the resulting reliance on informal systems for healthcare services in the communities. To proceed in this regard, there is the need for innovative strategies to profile, target and systematically screen childbearing women who have been exposed to OF risk factors such as rape, early marriage, domestic violence or intimate partner violence and/or have delivered at non-health facilities (Berg and Underland 2013; Salim 2012). Women with history of female genital mutilation are also at risk (Browning, Allsworth, and Wall, 2010).

A good understanding of the cultural practices of the various humanitarian communities is important for identifying potentially dangerous practices that increase OF risk. For example, the plights of women in conflict-ridden communities in Northern Ghana are exacerbated by the prevailing cultural beliefs that prohibit women from seeking medical care until their husbands or another man deem it appropriate and approve of same. In these settings, vaginal delivery at home is highly favored while deliveries at health facilities, even for women with obstructed labor, are antithetical to cultural expectations. A woman's ability to give birth at home and in 'silence' is a testament of her pain tolerance level, proof of womanhood and pride of her family. These cultural practices have compelled woman to attempt vaginal delivery, though contra-indicated, leading to OFII in some instances. Detecting cases of OFII would require establishing good rapport with the various households, building and maintaining individual, household and community-level trust that would permit information sharing, collective decision making and supportive programs.

Studies targeting the prevalence of OF in humanitarian settings should address several pertinent issues, including whether the prevalence of OFII differ as a function of the various humanitarian settings (e.g., conflict versus natural disaster environments). It would also be interesting to determine whether the various phases of humanitarian crises (e.g., acute versus recovery) could significantly influence the prevalence of OFII. This would help to expand the scope of existing studies that have tended to focus on the systematic devastation, sexual violence and gynecological fistulae resulting from war (Kinyanda et al. 2010; Salim 2012). Another topical issue relates to the prevalence of the various types of incontinence (e.g., urine, faeces or both) and factors accounting for the variations in the presentation of incontinence across different groups of women in varied settings. Lastly, studies should examine the risk and protective factors for OFII. Although the literature is inundated with risk factors

(Kinyanda et al. 2010; Salim 2012), it is important to note that not all women exposed to the same or similar risk factors develop OFII. This suggests the availability of protective factors, defined broadly as factors that have the propensity to avert or cause a reduction in the experiences of OFII by moderating or mediating the relationship between risk factors and OF, or acting independent of risk factors (De Vries Robbé et al. 2015). Given that protective factors can be harnessed to overcome the impact of risk factors (De Vries Robbé et al. 2015), it will also be insightful to investigate these factors, their mechanism of actions and how they can be maximized to mitigate the debilitating effects of the various risk factors of OFII.

Preventing obstetric fistula-induced incontinence

There are several treatments available for OF, including surgeries (Pope and Beddow 2020). However, the relatively high cost of surgical treatment poses significant challenges to access to healthcare by women in humanitarian settings (Lufumpa et al. 2018). Evidence from high income countries has shown that OF can be prevented. Given the comparative advantage of prevention over treatment, this paper advocates for prevention as the most plausible way to eliminate OF in all settings. This position is also consistent with the resolution adopted by Member States of the United Nations in 2018 to end fistula within a decade (Anastasi et al. 2020). Following a review of existing studies, we categorized prevention frameworks using the ecological models of health promotion (Golden and Earp 2012; Richard et al. 2011) as follows: individual-level, community-level, healthcare system-based, and policy-related consideration.

Because successful prevention can be achieved using context specific data to inform local interventions, studies should examine barriers and enablers of preventing OFII, design and implement preventive measures at the levels specified above. For example, at the individual level, a systematic review has found that women's inability to seek early obstetric care is related to lack of knowledge and awareness of the dangers of unsupervised labor (Lufumpa et al. 2018). More worrying is the observation that among women who are aware of the dangers of unsupervised labor, hierarchical and hegemonic family structures impede their ability to seek timely obstetric care. As illustrated from some Ghanaian cultures, a man must approve for a woman to seek help from health professionals, including the decision to deliver at the hospital. Similarly, actual and vicarious experiences of negative treatment at health centers have adversely influenced care seeking behaviors of women during pregnancy and labor. Granted the above, research focusing on measures to improve healthcare seeking behaviors

among childbearing women in humanitarian settings is needed. Studies are invited to investigate the utility of participatory approaches to strengthening interventions that address negative experiences of women, improving early decision making for facility-based care and addressing aspects of the Three Phase Delay Model (Thaddeus and Maine 1994). Furthermore, measures to improve the knowledge levels of women on the dangers of delivering in silence at home, OFII, and optimal help seeking behaviors should be carried out in the local language and supported by community elders, opinion and religious leaders, and women groups.

At the community level, studies have shown that supporting women to establish viable socioeconomic status strengthened their economic capacity to take decisions about their health (Ngoma 2011). Therefore, potential areas of research must include how women groups and income generating activities could be supportive of preventing OFII. Technical and vocational training opportunities have been instituted for women groups in sub-Saharan African countries to help them earn income. These include beads making, dressmaking, and catering services. The income generated from these activities could support women to be independent and more importantly meet their WASH needs, including buying sanitary products such as diapers, soaps, and detergents. Other areas include community health education programs, organization of transport for pregnant women in need and building the capacity of traditional birth attendants (TBAs). These interventions have proven to be successful in preventing maternal health issues in Nigeria (Ojanuga 1991, 1992). The World Health Organization promoted the training of TBAs as part of the broader measures to reduce maternal and neonatal mortality. An integrated literature review reported that perinatal death, stillbirth, and neonatal death were significantly lower among trained TBAs versus untrained TBAs (Sibley, Sipe, and Barry 2012). It follows that building the capacity of TBAs could contribute to a reduction in the incidence of OFII, particularly given that delayed labor is a risk factor for OF (Wall 2006). As noted previously, understanding the cultural practices of residents in humanitarian settings would aid practitioners to profile of at-risk women based on insights into risk factors of OF.

At the health system level, factors such as skilled staff shortages, lack of healthcare resources, and delays in receiving care have reportedly impede access to timely obstetric care when women finally take the decision to seek facility-based care (Banke-Thomas et al. 2014; Lufumpa et al. 2018; Ngoma 2011). Studies should investigate interventions to improve the quality of care received at healthcare facilities and how to strengthen partnerships between health facilities, governments,

communities, and institutions that provide financial and resource support (Anastasi et al. 2020; Lufumpa et al. 2018). Lastly, research should systematically evaluate existing policies and programs aimed at reducing maternal morbidity and mortality for advocacy and other interventions. Potential areas for consideration include enactment of policies to mobilize recognized experts to empower women, make provision for maternal health gatekeepers and mobile prenatal clinics (Lufumpa et al. 2018). Other policy-level interventions pertinent to preventing OFII included sustained advocacy at governmental and organizational levels, within the framework of Sustainable Development Goals (Anastasi et al. 2020).

In addition to the independent effects of the barriers and enablers, research should also examine the interactive or synergistic effects of interventions across the various levels of health promotion on the prevention of OFII. This is consistent with the view that the determinants of health are multifaceted, drawn from several domains (Bahabadi et al. 2020). Additionally, health promotion models that incorporate the barriers and enablers of OFII prevention and also improve better access to quality healthcare services should be developed and validated to provide guidance and directions for the care of affected women. The models should be detailed and parsimonious, incorporating salient factors in health promotion to maximize their usefulness, in view of the scarce human, logistics, and financial resources. Such models should support consistent approaches to delivering preventative programs, as well as evaluating the effectiveness and addressing inefficiencies of preventative programs to enhance service delivery and optimal use of limited resources (Ah Chee et al. 2016; Golden and Earp 2012; Richard et al. 2011).

Obstetric fistula-induced incontinence and WASH experiences

Women with OFII have high demand for WASH services and facilities before and sometimes after surgical repairs and other treatment modalities. Critical among the pre-treatment factors are poor help seeking behaviors and delay in seeking care. These behavioral practices vary considerably across contexts. For example, in Malawi, the median duration of living with OF before seeking treatment was three years (Kalilani-Phiri et al. 2010) whereas in Ethiopia, the duration was eight years (Muleta et al. 2007). Data from Zambia suggests that some women seek treatment after living with the condition for as long as over 20 years (Holme et al. 2007). This is similar to the trend in Ghana where some women reportedly lived with obstetric fistula for over 30 years (GHS 2015). The weight of the evidence, therefore, appears to support the view that women do live with OFII for years before seeking

treatment (Adler et al. 2013). The high level of stigmatization, marginalization, social exclusion, and high cost of interventions have set women on poor health trajectories and impacted their help seeking behavior on early treatment (Lufumpa et al. 2018). Women living with OFII are unable to financially support the cost of treatment, hence they delay in seeking treatment until funding is available from benevolent organizations.

WASH services are extremely important in the lives of these women prior to seeking any treatment. Of course, the women must keep clean by managing their incontinence before and while seeking treatment. This will require WASH products such as body care products, namely bleach-power zone, detergents (e.g., scented soap and dettol) and camphor. Others include absorbents such as diapers. Access to water facilities to bath and wash soiled clothes and panties is necessary to avoid discomfort, body smell and skin irritations. Lastly, for women with fecal incontinence, access to toilet facilities is non-negotiable. The limited access to WASH services could serve as a major barrier to seeking early treatment. Women are less likely to take the risk of seeking treatment from facilities located several communities away from their residence when doing so will expose them to public shame, ridicule and stigmatization. Therefore, improving and providing access to WASH services should be prioritized as part of measures to support early treatment seeking.

Furthermore, incontinence after repair is the major post-treatment challenge requiring WASH programming for women with OFII. This problem has been widely acknowledged in the scientific community and has been referred to variously as stress incontinence (Holme et al. 2007; Lewis et al. 2009; McFadden et al. 2011), residual incontinence (Browning 2006; Muleta 2006; Tebeu et al. 2010) or 'persistent urinary incontinence (Brook and Tessema 2013). Surgical treatment remains the best option to repair fistula and ultimately to stop incontinence. However, surgical operations are not always successful as envisaged. In some instances, patients who underwent fistula repair still leaks urine or feces, suggesting unsuccessful repair or additional damage to the urinary system. The need for WASH services among women with residual incontinence could be as high as those who are yet to receive or undergoing surgical repairs.

To improve the experience of women in managing their incontinence, we emphasize the need to elucidate the types and sources of incontinence materials needed to manage incontinence in humanitarian settings and conditions pertaining to the use of these materials. Although, anecdotal evidence suggests that some incontinence materials are made from local resources such as sacks, used clothes, issues pertaining to how

and where the resources are obtained from, and their health implications have not been explored. Studies addressing these issues would provide the evidence-base needed to advance discussions on, for instance, re-engineering locally sourced and readily available materials to improve the management of incontinence in humanitarian settings. Moreover, given that 50–70% of the cost of managing incontinence is attributable to routine care, including obtaining incontinence products (Subak et al. 2006), the interesting question in this regard relates to the economic implications for women living with OFII. It is important to understand the extent to which OFII complicate or exacerbate the socioeconomic conditions of affected women. Furthermore, research is needed to explore how incontinence restrict access to food and WASH services and the general atmosphere of support in humanitarian or emergency contexts (Giles-Hansen 2015). For women who have undergone treatment for OF, it would be important to unearth their WASH experiences and how these impact the treatment process, their recovery, wellness living and community reintegration.

Several devices such as handwashing bag, and Bush-Proof Handwashing Containers to promote handwashing behaviors in humanitarian settings exist currently (Brown et al. 2012; ELRHA 2016; Vujcic et al. 2015). However, evidence suggest that some of the devices (e., handwashing bag) are poorly utilized because they are not user-friendly or do not take into account the unique circumstances of users (ELRHA 2016; Ramesh et al. 2015). Unfortunately, the experiences of women living with OFII have not been explored with respect to how they interact with various wash devices in humanitarian settings. This is deserving of research attention to understand the handwashing practices of women living with OFII in order to improve their WASH experiences.

Another important theme that requires research consideration is the indicators of successful fistula treatment/repair. A review, however, found that the indicators of successful fistula treatment have been centered on non-WASH experiences such as ability to conceive (Arrowsmith et al. 2013). Women's WASH experiences should be treated as an important outcome indicator of successful fistula repair or treatment. The general expectation is that successful repair and treatment would significantly improve the WASH experiences of women with OFII. Studies should, therefore, systematically investigate and track the WASH needs and experiences of women who underwent fistula treatment over time to unearth their WASH needs and pattern, comparing same to their counterparts with OF. This would help greatly in determining whether and extent to which treatment for fistula has been successful.

Summary and conclusions

The overarching aim of this paper was to determine the research needs of women living with OFII in humanitarian settings to provide guidance for future research, policy and practice, in accordance with the United Nations vision of “leave no one behind” (Anastasi et al. 2020). Some key research questions for consideration include (1) What are the WASH experiences of women with OFII or how do women with OFII meet their WASH needs? (2) What are the non-surgical interventions adopted by women with OFII used to manage their incontinence? Are the interventions sourced locally? How are the interventions developed? What are the enablers, barriers, challenges, and advantages associated with using these interventions? (3) How can the existing interventions be improved to enhance the WASH experiences of women with OFII? (4) How does pandemics and/or epidemics impact on access to and affordability of WASH services? (5) What are the individual, family, community, governmental, and non-governmental support systems available to improve the WASH experiences of women with OFII? (6) What are the socioeconomic experiences associated with incontinence management or how does socioeconomic status impact on incontinence management?

Additionally, studies should estimate the prevalence, the risk and protective factors of OF in humanitarian settings. The health and social issues related to living with OFII impacts not only maternal morbidity and mortality trends but also neonatal health. Given the devastating nature of OFII, it is important to develop insights into OF prevalence, as well as strategies to prevent it and ways to improve the WASH experiences of women with OFII. This action is important to inform researchers, policy-makers, and practitioners on the burden of OFII as a measure to guide prioritization related to prevention, early identification, and development of robust WASH-sector support systems to promote the overall quality of life and wellbeing of women with OFII.

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Authors' contributions

SA conceptualized the problem statement and drafted the methodology. All the authors reviewed and approved the method. SA searched for literature and prepared the first draft of the manuscript. MAA, EH and MEPN reviewed the first draft. All the authors read and approved the manuscript draft for submission. All the authors worked on subsequent revisions of the manuscript as suggested by the reviewers.

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Declarations**Competing interests**

The authors declare that they have no competing interests.

Author details

¹Research and Grant Institute of Ghana, Legon Post Office, Agbawe Avenue 22, P.O. Box LG 1004, AdentanAccra, Accra, Ghana. ²Department of Mental Health, School of Nursing and Midwifery, University of Ghana, P. O. Box LG 43, Legon, Accra, Ghana. ³Department of Child and Maternal Health, School of Nursing and Midwifery, University of Ghana, P. O. Box LG 43, Legon, Accra, Ghana. ⁴Coalition of NGOs in Water and Sanitation, NO C8243/3, Mango Tree Avenue, Asylum Down, Accra, Ghana. ⁵Fistula Foundation Ghana, Sampa Valley, (Nr Embert Spot) Hse No. SV59, Accra, Ghana.

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