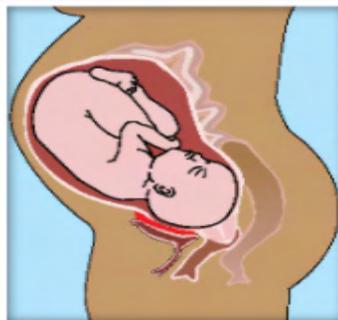




RESEARCH AND GRANT INSTITUTE OF GHANA (ReGIG)



WATER, SANITATION AND HYGIENE (WASH) PROGRAMMING FOR WOMEN WITH OBSTETRIC FISTULA-INDUCED INCONTINENCE IN GHANA

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WELCOME ADDRESS FROM

Project lead (Principal Investigator) Executive Director, ReGIG



Often, things of the unknown bring us anxiety because of the uncertainties associated with the unknown. For the Research and Grant Institute of Ghana (ReGIG), we see this uncertainty as an opportunity to understand the unknown and develop a solution towards the future. With funding from ELRHA-Humanitarian Innovation Fund, ReGIG, undertook a study to understand water, sanitation, and hygiene (WASH) programming for women with incontinence resulting from obstetric fistula.



Dr. Samuel Adjorlolo
Project lead (Principal Investigator)
Executive Director, ReGIG.

The project aimed to understand their lived experiences with regards to WASH, how they meet their WASH needs and more importantly to propose culturally sensitive innovative programs to enhance their WASH experiences. The project partners were CONIWAS and Fistula Foundation Ghana.

We are glad to report that after close to two years of data collection and analysis, it is time to come back to the Fistula Centre of Mercy Women's Catholic Hospital to hold a dissemination and stakeholder engagement workshop. Holding on the belief that the communities and stakeholders are integral part of research, we are here to share the findings of the study with you.

These findings are not sacrosanct. As the Akan proverb says “Tikoro nk agyina”, we invite you to share your views with us which will help us in our final report. We welcome all of you to this important dissemination workshop and hope you make contributions on the way of addressing these challenges facing our women and girls. We are particularly grateful for taking time off your busy schedule to join us. Akwaaba!!!

Executive Summary

Obstetric fistula is a birth-related injury that results in incontinence which refers to involuntary discharge of feces and/or urine through the vagina. Incontinence is associated with urine or fecal odor. Women with incontinence have limited opportunities to keep clean particularly in settings where water, sanitation, and hygiene (WASH) services are notably scarce.

However, the WASH needs of these women have not been granted the requisite scholarly attention, globally. The existing knowledge gap is largely hampering efforts to design programs to support women with incontinence resulting from obstetric fistula to meet their WASH needs.

The current study investigated the lived experiences of women with obstetric fistula-induced incontinence, how they meet their WASH needs, the barriers they encounter, existing and new interventions to improve their WASH experience.

Questionnaires were administered to 40 women with obstetric fistula at Mankessim fistula treatment center. Two focus group discussion and individual in-depth interviews involving 30 women were conducted. Data were analyzed using descriptive and thematic analyses strategies.

The main are summarized below.

- The perceived causes of incontinence include delayed labour and underdeveloped birth canal because of young age
- The women experienced uncontrollable urine or faece leakages, causing them to soil their clothes, experience severe pain and skin irritation.
- The incontinence experience, particularly in public, leaves the women stigmatized, miserably shameful, embarrassed, confused, humiliated, isolated, sad/depressed, loss of self-confidence/low self-esteem.
- The women have profound difficulty assessing sanitary and body care products such as diapers, soap, and Dettol.
- The women adopt constipating practices such as using drugs and/or food (i.e., foods that can constipate such as bread).
- The women used diapers produced from traditional and household materials such as used clothes and flour sacks to manage incontinence.
- The women have limited support from family members, neighbors/communities in efforts to manage their incontinence.
- The women are confronted with economic and social barriers such as lack of job, disruption in family ties and social system worsening their plight.



There is the urgent to institute measures to improve the WASH experiences of women with incontinence.

These include

- (1) Production and distribution of reusable sanitary pads/ diapers,
- (2) Establishment/integration of incontinence-psychosocial support units into existing services,
- (3) Economic empowerment opportunities and (4) Public Education, Awareness Creation and Advocacy

The study was conducted by the Research and Grant Institute of Ghana (ReGIG), in collaboration with Coalition of NGOs in Water and Sanitation (CONIWAS) and Fistula Foundation Ghana (FFG) from November 2019- November 2020. Technical support was provided by UNFPA, Ghana.

- The Water, Sanitation and Hygiene Programming for women with Obstetric-Fistula-Induced Incontinence in Ghana project is funded and supported by Elrha's Humanitarian Innovation Fund (HIF) programme, a grant making facility which improves outcomes for people affected by humanitarian crises by identifying, nurturing and sharing more effective, innovative and scalable solutions.
- Elrha's HIF is funded by aid from the Netherlands Ministry of Foreign Affairs (MFA).
- Elrha is a global charity that finds solutions to complex humanitarian problems through research and innovation. Visit www.elrha.org to find out more.

SECTION A

1.1: Introduction

- Water, sanitation, and hygiene (WASH) needs are universal for every human, including children, women, adolescents, youth, and adults. For example, water is useful for many activities such as washing, cleaning, cooking, and mopping.
- WASH needs and services are in high demand among women who have developed incontinence because of delivery. These women leak urine, feces or both involuntarily.
- Research and Grant Institute of Ghana (ReGIG) conducted a study on WASH experiences and needs of women with incontinence that result from birth injury-obstetric fistula.
- The study was funded by ELRHA's Humanitarian Innovation Fund (HIF with donation from the Netherlands Ministry of Foreign Affairs (MFA).
- The project partners are Coalition of NGOs in Water and Sanitation (CONIWAS) and Fistula Foundation Ghana (FFG). The United Nations Population Fund Agency (UNFPA) provided technical support.

1.2: What Is Obstetric Fistula Incontinence?

Obstetric fistula is a birth-related injury that results in involuntary discharge of feces and/or urine through the vagina.

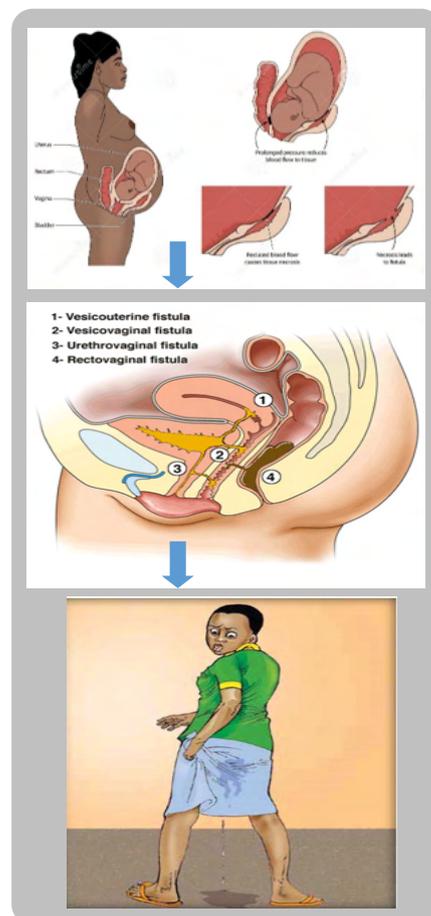
It usually occurs when a woman has an obstructed labour and cannot get a caesarean section when needed.

The obstruction can create a hole or an opening between the vaginal, bladder and rectum

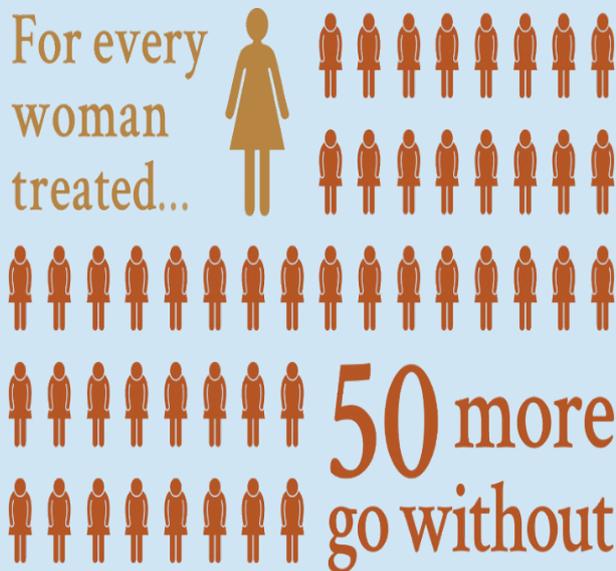
The obstruction occurs when the baby's head is too big, or the baby is badly positioned.

The woman can be in labour for several hours to days without medical help.

The baby usually dies. If the mother survives, she is left with extensive tissue damage to her birth canal that renders her incontinent: leaking urine, faeces or both



1.3: Why Was The Study Conducted?



The WHO estimates that between 50 000 to 100 000 women are affected by obstetric fistula each year.

More than 2 million young women in Asia and sub-Saharan Africa live with incontinence resulting from untreated obstetric fistula

In Ghana, about 7000 women have incontinence resulting from obstetric fistula

Majority of obstetric fistula patients in Ghana come from humanitarian settings, such as Northern region and Buduburam camp.

WASH services are needed most by women with incontinence in humanitarian settings

There is no research exploring the WASH experiences and needs of women with incontinence in humanitarian settings in Ghana.

The existing knowledge gap on the WASH experiences and needs is largely hampering efforts to design programs to meet the WASH needs of obstetric fistula patients in Ghana.

1.4: Who Participated in the Study?

Women with incontinence resulting from obstetric fistula in the Central region (e.g., Buduburam, Mankessim areas).

A total of 40 women with incontinence answered questionnaires on their WASH experiences and needs

A total of 30 women living with obstetric fistula induced incontinence participated in individual in-depth interviews and focus group discussions.

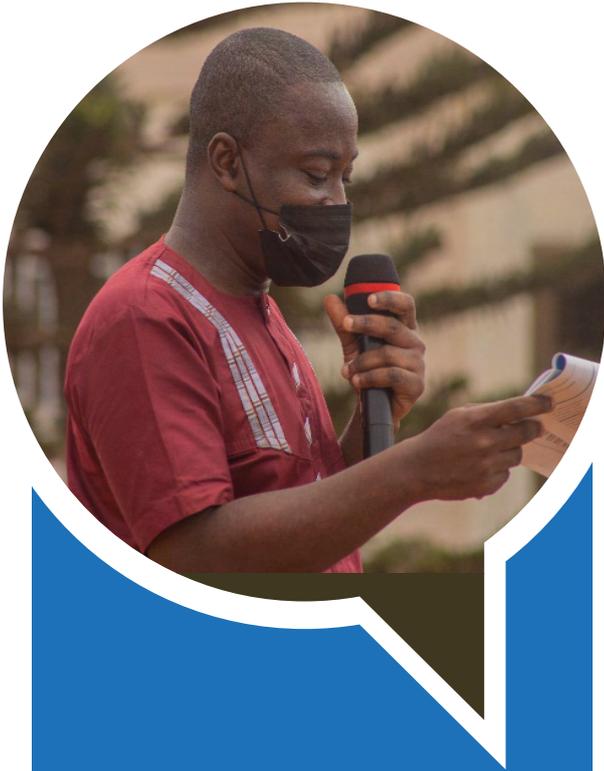
RESULTS DISSEMINATION AND STAKEHOLDER ENGAGEMENT



A cross-section of Stakeholders at the Dissemination and Engagement Workshop.

A dissemination and stakeholder engagement workshop was held on the 2nd March 2022 at the forecourt of the Fistula Unit of Mercy Women Hospital in Mankessim, Central Region, Ghana. The workshop was attended by 65 stakeholders, including representatives of the Ministry of Gender, Children and Social Protection (Mrs. Richlove Amamoo, who double as a queen mother with the stool name Mama Awotsu Adzagba II), United Nations Population Fund (UNFPA; Dr. Claudia Donkor) and Mfantseman Municipal Assembly (Mr. Daniel Tetteh).

In attendance was also the Medical Superintendent of Mercy Women's Catholic hospital (Dr. Silas Amponsah), Ghana's obstetric fistula focal person (Rose Mantey) and other health professionals, community members, women with obstetric fistula and religious leaders. The Paramount Queen Mother of Mankessim Traditional Council, H.R.M. Nana Dr. Ama Amissah III, was the special guest of honor and chairperson for the workshop.



**Mr. Obed Asamoah,
Program manager;
Obstetric Fistula-
Induced Incontinence
and WASH program**

Purpose and Expectations of Workshop

The project manager, Mr. Obed Asamoah, explained that the objective of the stakeholder engagement effort to include;

Bring to the attention of stakeholders, policy makers, humanitarian practitioners and academics the WASH experiences of women with incontinence induced by obstetric fistula.

Promote public understanding of the challenges faced by women with incontinence caused by obstetric fistula.

Raise public awareness about incontinence and WASH needs of women with incontinence resulting from obstetric fistula.

Discuss measures to enhance the WASH experiences of women with incontinence resulting from obstetric fistula.

Remarks by Chairperson



**H.R.M. Nana Dr. Ama Amissah III,
the Nanahenemaa of Mankessim
Traditional Council**

H.R.M. Nana Dr. Ama Amissah III, the Nanahenemaa of Mankessim Traditional Council recounted many instances of disruptions in family ties and negative experiences by women diagnosed with obstetric fistula.

Nanahenemaa educated participants, inspired and encouraged them to see their conditions as normal health problem that is manageable, and which is curable.

Among others, she has commissioned each patient and participant to be a mbassadors of obstetric fistula. She admonished that the only way to eliminate this health problem is to create awareness about it.

Nanahenma stated that it's her fervent belief there are many women out there who do not know that there's a health management and recovery system in place to care for people going through this condition.

She reiterated the need for women living with this condition to speak out and seek assistance since it's through no fault of theirs that they found theselves in this condition She appealed to government, and all stakeholders to join and support in the advocacy and treatment of this unfortunate condition women go through. She requested support for her advocacy activities which she noted have been yielding results.

Address by United Nations Population Fund (UNFPA)



**Dr. Claudia Donkor, Programme Analyst:
Reproductive Health and Humanitarian
Assistance, UNFPA**

Dr. Claudia Donkor, the programme Analyst for the Reproductive Health and Humanitarian Assistance from the UNFPA, addressed the stakeholders on the involvement of UNFPA in ending obstetric fistula in Ghana. She stated that the mission of UNFPA's is to ensure that every childbirth is safe, encompassing the health of both the mother and child, as well as the prevention of obstetric morbidities such as obstetric fistula.

Dr. Donkor intimated that research into the WASH needs of women with obstetric fistula provides up-to-date, evidence-based and relevant data for advocacy, policy dialogue, designing and implementing interventions with best outcomes. She further reiterated that existing research on obstetric fistula in Ghana do not incorporate WASH elements, thus the study by ReGIG has filled an important void in the literature.

According to Dr. Donkor, UNFPA will continue to provide strategic and technical guidance and support, medical supplies and equipment, training and capacity building, as well as support for fistula prevention, treatment and social reintegration and advocacy programming.

Additionally, UNFPA will continue to support Ghana's vision to achieve Universal Health Coverage in key areas, including midwifery, emergency obstetric and newborn care, adolescent and maternal health, she stated.

Address by Ministry of Gender, Children and Social Protection



Mrs. Richlove Amamoo (Mama Awotsu Adzagba II), Deputy Central Regional Director of Ministry of Gender, Children and Social Protection.

Mrs. Richlove Amamoo (Mama Awotsu Adzagba II), the Deputy Central Regional director of the Ministry of Gender, Children and Social Protection, represented the sector minister. She underscored the ministry's preparedness in supporting the course of women in Ghana.

Mrs. Amamoo indicated that the ministry is aware of the increasing reported cases of obstetric fistula condition among Ghanaian women and are working assiduously towards setting up effective social intervention programs that would meet the immediate needs of these women. She entreated the women to, in the meantime, take advantage of the existing programs and also seek support from the ministry when they are in need.

She further noted that it's the ministry's determination to empower women through policy formulation, coordination and monitoring and evaluation of particularly women, Children and social protection issues within the context of the national development agenda. This will lead to the achievement of gender equality, equity, the empowerment of women and girls, promoting the survival and development of children, thus ensuring their rights. It will also ensure harmonizing social protection interventions to better target the vulnerable, excluded and persons with disability and integrate fulfilment of their rights, empowerment and full participation into national development.

Mrs. Amamoo entreated the project team to share the final report of the study with the ministry so that it can factor the findings into government's policy and programs in order to ameliorate the sufferings of women who through no fault of theirs are living with this unfortunate medical abnormality.

Address by Medical Superintendent of Mercy Women's Catholic Hospital
Dr Silas Amponsah, the Medical Superintendent of Mercy Women's Catholic Hospital shared few statistics and concluded by appealing to stakeholders including UNFPA, Government and other non-governmental organizations to support the hospital with funds, logistics and equipment for the efficient operation of the hospital.

The medical superintendent indicated that since 2009 till date, the hospital has performed a successful surgical operation to correct the fistula abnormalities among some 580 patients who have recovered from the condition.

He noted that each medical procedure requires Ghc4500 to complete. On average, 100 patients living with the medical abnormality report to the facility for treatment on yearly basis. The figure requires GHc450, 000 annually to be able to carry out these medical operations on these women.

According to the medical superintendent, most of the victims are economically poor and vulnerable women who cannot pay for the services rendered to them. It is in view of this that he made a passionate appeal to donor community to support their efforts in this regard.



**Dr. Silas Amponsah,
Medical Superintendent of Mercy
Women's Catholic Hospital, Mankessim.**

Remarks by the Obstetric Fistula Nurse: Rose Mantey

Mrs. Rose Mantey (aka Maa Rose), has earned the nickname the “obstetric fistula nurse” owing to her unflinching support for patients with obstetric fistula. She played instrumental in recruiting participants for the study, as well as mobilizing participants for the dissemination and stakeholder engagement.

Maa Rose has called for support for women with obstetric fistula to meet their WASH needs. She noted that most of these women have difficulty assessing WASH services because of their poor economic background. She also lamented the poor support the women receive from their communities. This she noted has contributed to their emotional and psychological disturbances.

Relatedly, she argued that there's a surge in the cases of obstetric fistula induced incontinence because of surgical operation to cure fibroid. Maa Rose observed that surgical operation to remove fibroid from some women is now increasing the chance of having obstetric fistula hence incontinence.

She charged the research community and appealed to Executive Director of ReGIG to consider looking for resources to conduct a study into these new cases and a detailed study into the causes and lived experiences of this patients. She also appealed for material and logistics support for the Fistula Unit to provide economic and psychosocial support for victims.



**Rose Mantey, Nurse at Fistula Unit,
Mercy Women's Catholic Hospital,
Mankessim.**

SECTION B: DISSEMINATION OF FINDINGS



Dissemination was led by Maame Esi Paintsiwaa Nyame, the founder and Executive Director of Fistula Foundation Ghana and a member of the project team.

Discussed the findings based on the following themes:

1. Demographics
2. Lived experiences
3. WASH access and experiences
4. Improving participants WASH experiences
5. Policy implications

1.0: Demographic Characteristics of Study Participants

The demographic characteristics of the participants are summarized in Table 1. As can be seen, more than half of the participants were aged 33-43 years (51.28%), followed by 44 years and above (35.90%). In terms of education, 23 out the 40 participants completed primary/junior high school, whereas 7 had no formal education. More than half of the participants were married (54.3%), while 22.9% (n = 8) were single. With respect to the number of children, 27 (67.5%) had 1 to 3 children. 7 of the participants had no children and 6 of the participants had from 4 to 6 children.

Demographics	Frequency	Percentage
Age of participants		
22- 32yrs	5	12.82
33-43yrs	20	51.28
44yrs and above	14	35.90
Educational level		
No Education	7	17.5
Primary/Junior High	23	57.5
Senior High School	5	12.5
Tertiary	5	12.5
Marital status		
Single	8	22.9
Married	19	54.3
Divorced	3	8.6
Widowed	5	14.3
Number of children		
None	7	17.5
1 to 3	27	67.5
4 to 6	6	15

2.0: Risk Factors/Perceived Causes of Obstetric Fistula-Induced Incontinence

The risk factors or perceived causes of the obstetric fistula mentioned by the participants include young maternal age, and delayed labour and “evil forces”. Others include, big baby causing vaginal tears and failed caesarean section.

2.1: Underage Pregnancy or Young Maternal Age

Some women recounted that they got pregnant at a young age and they may not have had well developed birth canal to support child delivery.

Quotes from participants

“I was very young when I got pregnant...That time I was just 20 years (Akua).

“It’s been long. I was 18 when it started.”. (Koa)



2.2: Delayed Labour



Some women experienced delayed labour which limited their access to professional medical care at a qualified health facility. The delay resulted from several factors including lack of transportation

Quotes from participants

“When I was in labour, I was delayed at home. When I managed to get to the health facility, my vagina was torn in the process of delivery-delayed labour”. (Koa)

2.3: Evil Forces/Demons;

Some women attributed their conditions to spiritual forces. They believe their conditions could be as a result of some spiritual machinations against them.

Quotes from participants

“I even thought that some evil person had a hand in this, I have never heard of this condition before”(Akua)

“My grandmother said it was something spiritual so we should go and consult one man of God.....” (Suzzie)

3.0: Physical Experiences Relating Obstetric Fistula-Induced Incontinence

The physical experiences enumerated by the women include incontinence, changing of soiled clothes and skin irritations.

3.1: Incontinence

The women experienced urine incontinence, faecal incontinence, or both.

Urine incontinence means the women passed urine uncontrollably.

Quote from participant

“I do get the feeling of urinating but when I sleep, I do not get such feeling. All I see is that I am soaked in urine on my bed..... (Adwoa)



Faecal incontinence means the women passed stool or toilet uncontrollably.

Quote from participant

“After childbirth, whenever I went to toilet, some of the toilet leaked through my vagina- faecal incontinence. (Abena) (fafa)”

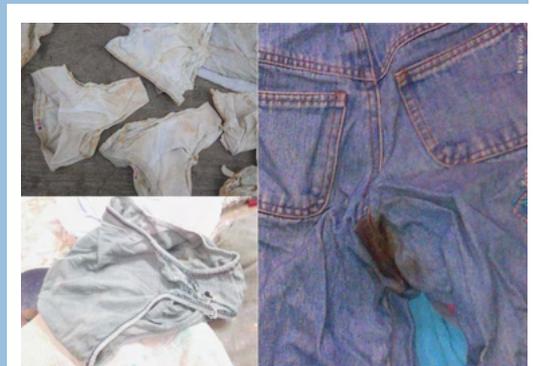
3.2: Changing of Soiled Clothes

The incontinence caused the clothes of the women to be soiled with urine, toilets or both at frequent intervals.

The women are forced to change the soiled clothes frequently to avoid discomfort and other issues.

For those without enough clothes, washing must occur very often.

Depending on the location of women, changing soiled clothes is difficult.



3.3: Skin Irritations

The constant leaking of urine and feaces cause the women to experience skin irritation problems such as

1. Burns
2. Sores at perineal area
3. Boils

Quote from participant

"I have really been through a lot, I noticed that the whole perineum is sored, I cannot even put the cloth there. There would be so much sores and when the urine gets into the sore it would be burning. I cry so much (Mansa)"



4.0: Health Experiences Relating to Obstetric Fistula-Induced Incontinence

The women who participated in the study experienced several health issues. Predominant among them are pain, discomfort resulting from wearing catheter and outcomes of surgeries to repair their fistula.



4.1: Pain

Pain is a major issue experienced by women with obstetric fistula.

Quote from participant

“The pains are unbearable”- Atia

The pain interferes with their performance of activities of daily living such as cooking, bathing, washing etc



4.2: Catheter Discomfort

Quote from participant

“After every two weeks, I had to travel to the hospital and have my catheter change. Even with the catheter, my urine always leaked sideways. Life was very difficult” – catheter care (Akua).

washing etc

4.3: Surgical Repair of Fistula

Some women underwent surgeries to repair the fistula. For these women, the surgery has brought additional burden or suffering to their health system, including

- Damage to urinary system
- Referral to hospitals
- Multiple surgeries

Quotes from participants

“When I was on admission, I sometimes see that my urine spill over to wet my bed. So I enquired from the doctor why I experienced that. He explained that I have developed a problem with my urinary system” – (Akua)

“I have done 7 surgeries since I developed the problem. Now, things are better after the repairs. I am able to control my urine whenever I get the urge”. (Atia)



5.0: Psychological Experiences Relating to Obstetric Fistula-Induced Incontinence

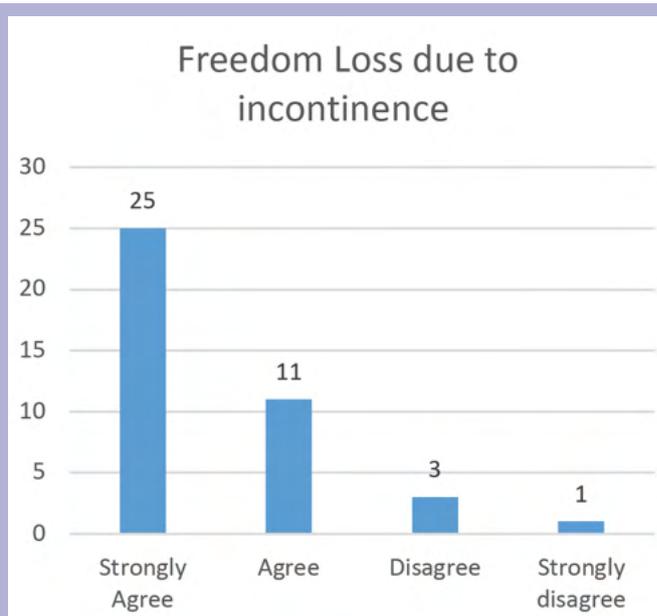
The women who participated in the study reported experiencing a myriad of psychological problems. These include:

- Loss of freedom
- Stigma
- Depressive tendency
- Fear and anxiety
- Isolation and loneliness
- Suicidal ideation
- Low self-confidence and esteem
- Confusion

5.1: Incontinence-Induced Freedom Loss

Out of the 39 women who responded to this item, 36 (90%) indicated that the incontinence has deprived them of their freedom.

This could be attributed to the demands of incontinence such as frequent changes of clothes, washing and fear-to-go-out.

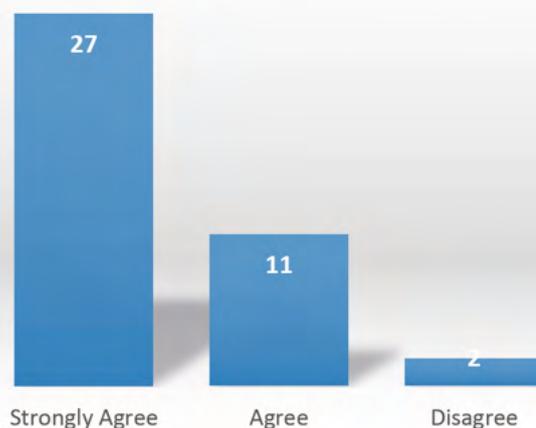


5.2: Incontinence-Induced Emotional Discomfort

Out of the 40 women who responded to this item, 38 (95%) indicated that the incontinence has affected their emotional states negatively.

That is, the women experienced emotional distress because of the incontinence condition.

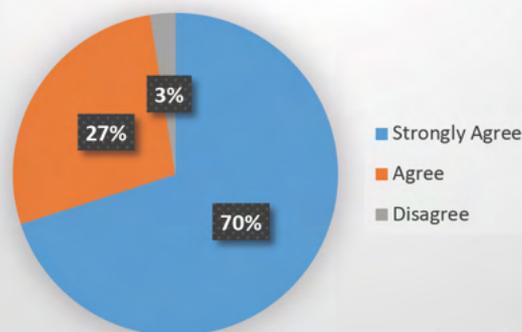
Emotional Discomfort



5.3: Feeling of Sadness

A total of 70% (n = 28) and 27% (n = 11) of the women respectively strongly agreed and agreed that they experienced sadness almost all the times.

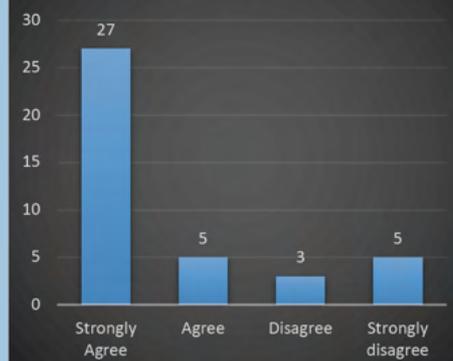
Feeling of sadness



5.4: Incontinence-Induced Poor Sleep

The women indicated that they have poor sleep because of the incontinence condition. Precisely, 8 out every 10 women reported that they do not get good sleep.

Poor Sleep



Quotes from participants on psychological experiences

“I was shattered. I felt confused. I had just finished learning to sew, about to open my own business and this thing just happened to me. Life has been very difficult from that moment” – confusion (Akua)

“As a young woman who had even opened a shop to start business and this thing happened to me, I felt my world was crumbling on me. The bad scent on me made me feel demeaned” - humiliation. (Akua)

“It is very tiring and very sad”
(Maggie)

“It is by God’s grace I am here; else I would have poisoned myself by now. Because the thing worries me. If a man comes to me, they leave me”.
(Koa)

6.0: Socioeconomic Experiences Relating to Obstetric Fistula-Induced Incontinence

The women experienced issues relating to social and economic standing. These experiences mostly center on

- Career challenges, including inability to work and loss of job
- Family challenges such as marital issues and spousal neglect)
- Poor social support
- Challenges associated with attending social functions (e.g, travelling anxiety)
- Self-social isolation

6.1: Financial and Economic Constraints

The women reported that they have limited sources of income. As a result, they live in poverty, making it difficult for them to buy sanitary and hygiene needs necessary for the management of incontinence.

Quotes from participants

“I can change pampers about ten times in a day. When my money gets finished that I had to divide my cloths to use as a pad... I used to buy Dettol, but I was tired of buying so I stopped”
(Mansa)

“I stopped using the catheter after sometime and started using disposable diapers. But getting the diapers was extremely difficult. I struggled to get money to purchase them”
(Akua)

“This condition has affected me because I did not have money. Our entire households depend on my mother’s little pension pay. It came with its own demands. Every week I had to buy diapers for the baby and I. It was challenging”
(Atia).

6.2: Loss of Jobs

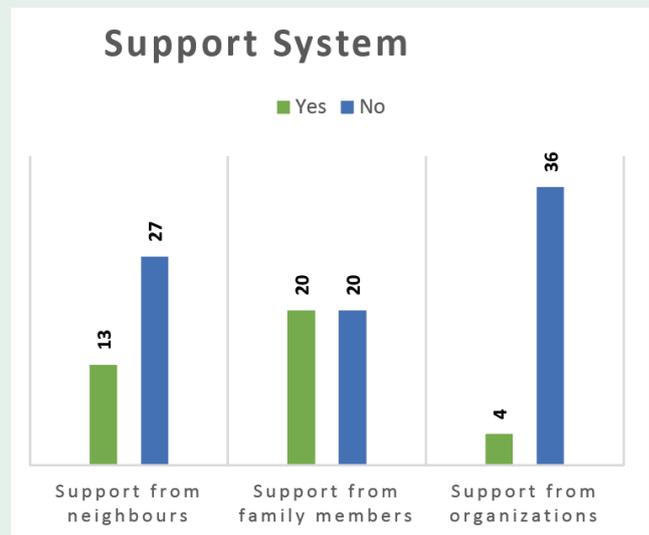
The incontinence condition has made some victims to lose their economic livelihoods because their employers didn't want to work with them or people who know their condition would not transact business or buy from them.

“Sometimes too when incontinence is unbearable and I tell my employer about my experiences, I am told that if this is what I'm having then we cannot work with you” (Ekua).

6.3: Limited Support System

The data show poor availability of support system for women with incontinence.

About 7 out of every 10 participants did not receive support from their neighbors, 5 out of every 10 participants did not receive support from family members and 9 out of every 10 participants did not receive support from community organizations such as NGOs.



Quote from participants

“No family member assisted me. There was no support from anywhere. The only support I had was my children helping me as they grew up” (maame)

“There was no support from any government agency|” (Araba)

“Even in your family you will find someone who will still make you feel.....” (Suzzie)

7.0: WASH Services to Manage Incontinence

Managing incontinence has resulted in increased demand for WASH services. This was echoed by one of the participants: “Had it not been for this condition I would not have used so much water” (Diana)

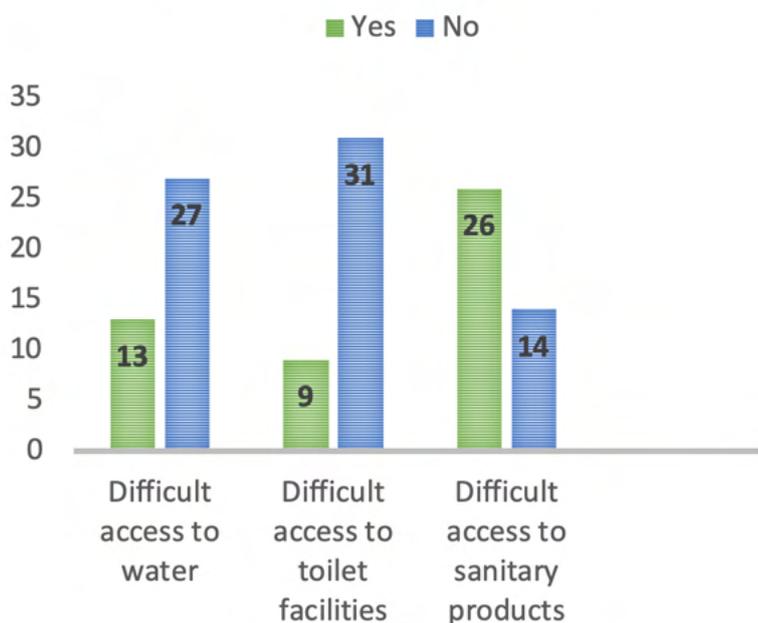


7.1: Access to WASH Needs

The women reported varying experiences regarding access to WASH needs.

For example, 3 out of 10 women reported difficulty accessing water, whereas 2 out of 10 expressed difficulty accessing toilet facilities. Access to sanitary products emerged as the most pressing issue. Out of every 10 women, about 7 reported difficulty accessing sanitary products.

Access to WASH Needs



Quotes from participants

“This increased my water usage at home. It again brought some financial demands because I was buying the water, sometimes in a day I buy five or six buckets and then the next day I go and buy again. I cannot tell how much I spent on water a day but I was buying much water” (Mansa)

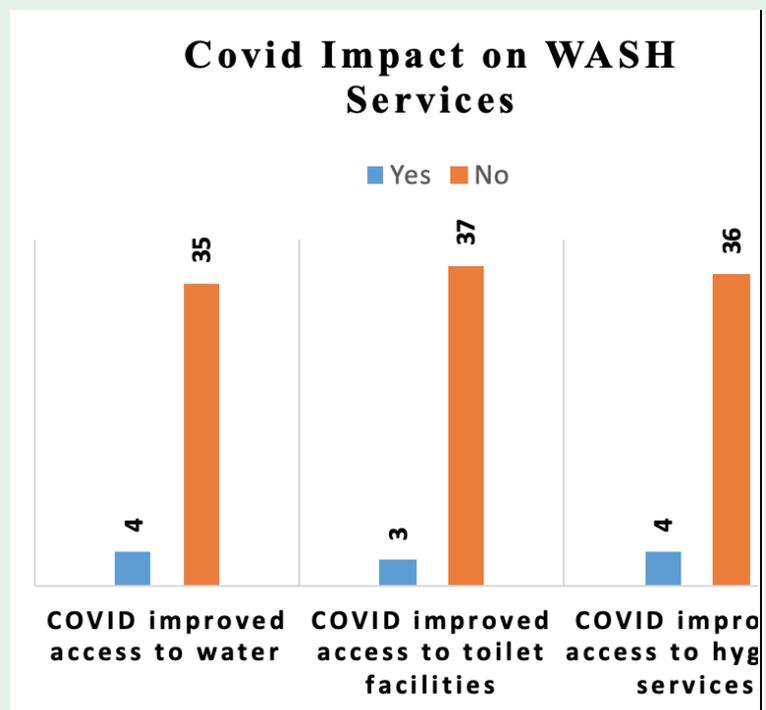
“When the illness started, in my community, we had no water. The tap was always off. So access to water was a major challenge... So in fact, water was a major issue”. (Atia).

“When in school, I had no access to toilet. I had to go to the house. Getting access to the toilet was a bit difficult” (Nana Aba)

“My children fetch water from a well closer to my house, for use. Therefore, water hasn't been a problem... It hasn't really impacted me. Except that you cannot tell whether the water from the well is clean or not” (Adwoa)

7.2: Impact of COVID-19 on Access to WASH Services

The data showed that COVID-19 has not changed the WASH conditions of participants. About 9 out every 10 women reported that COVID did not improve their access to water, toilet facilities and hygiene services



8.0: Existing Non-surgical Interventions to Manage Incontinence

To manage incontinence, the women have used several strategies. These have been categorized into broad approaches:

- Body care products
- Use of absorbents
- Constipating practices

8.1: Body Care Products

The women have used different body care products to manage their incontinence. These products include

- Bleach-power zone
- Detergents (e.g., scented soap and dettol)
- Camphor

Quotes from participants

“We bought diapers, Dettol and Power zone. You always have to buy when they get finished because you cannot wash the soiled old clothes with only water, you have to add soap, if not when someone comes close to you he/she will say you smell” (Araba).

“I used nice scented soap when I go to the bathroom and wash my perineum too before I pick new cloths” (Maame).



Aloe Vera & Honey
Bathing Bar
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8.2: Use of absorbents

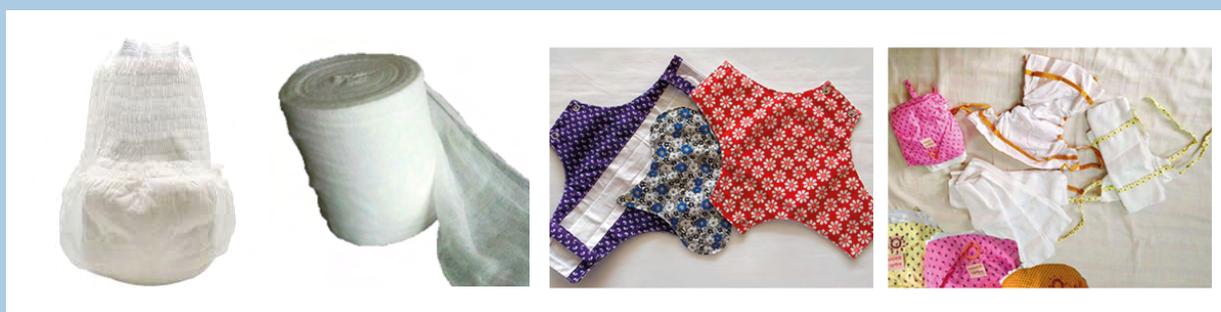
The women have used several materials to manage their incontinence. Some of materials are locally made by the women themselves. These include

- Old clothes
- Diaper
- Sack cloth
- Gauze

Quotes from participants

“One of my aunts used to bake bread, so I used the flour sack as pad. I washed it with Dettol and power zone. When it dries, I folded them into a bag. That was what I was using till I received diapers in the form of a pant from some white visitors who came to the Tema harbour” (Maggie)

“..... I put on a pad from folded clothes and put in in my panty. I can change for about four times in a day before bed time” (Maame)



8.3: Constipating practices

The women have devised means to reduce the impact of the incontinence by constipating themselves. They do so by

- Dietary habit change which involves eating “constipating” foods-bread and hardened food)
- The use of drug to suppress toileting (e.g., Imodium)



8.4: Self-Assistance

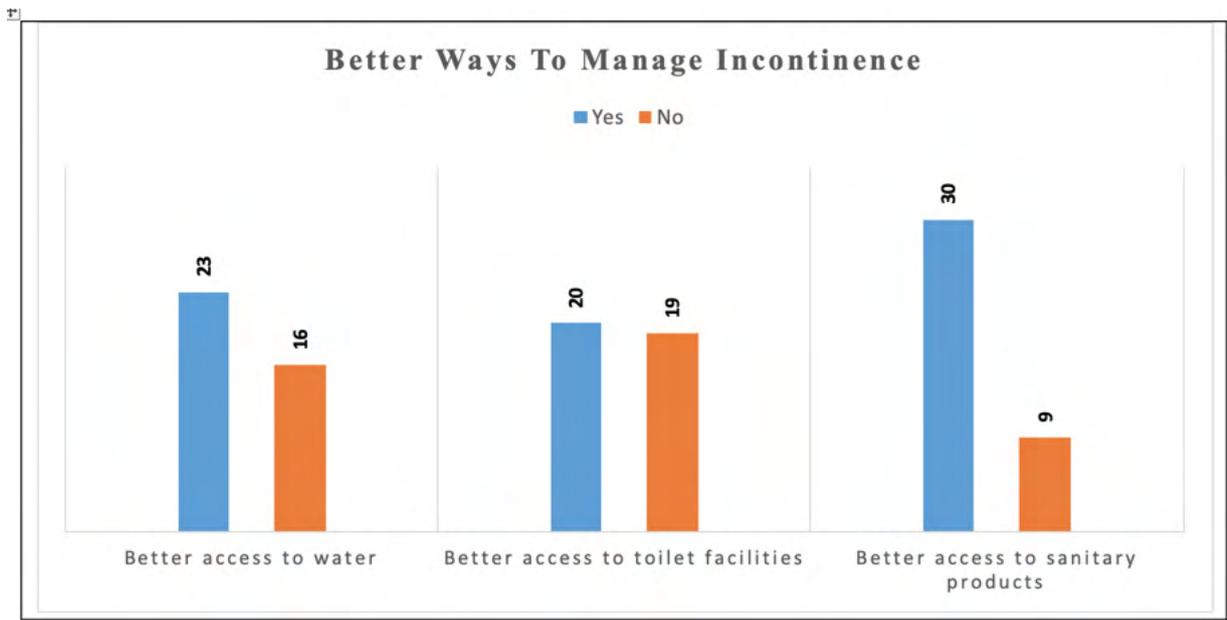
The women have endeavoured to be innovative in meeting their WASH needs. Some of the self-care assistance include devising local technologies including improvising for clean sanitary pads with old cloths.

Quotes from participants

“One of my aunts used to bake bread, so I used the flour sack as pad. I washed it with Dettol and power zone. When it dries, I folded them into a bag. That was what I was using till I received diapers in the form of a pant from some white visitors who came to the Tema harbour” (Maggie)

9.0: Looking for Better Ways to Manage Incontinence

The participants reported that they are looking for better ways to manage incontinence. About 6 out of every 10 participants are looking for better access to water. About 5 out of every 10 participants are looking for better access to toilet facilities. About 8 out of every 10 participants are looking for better access to sanitary products.

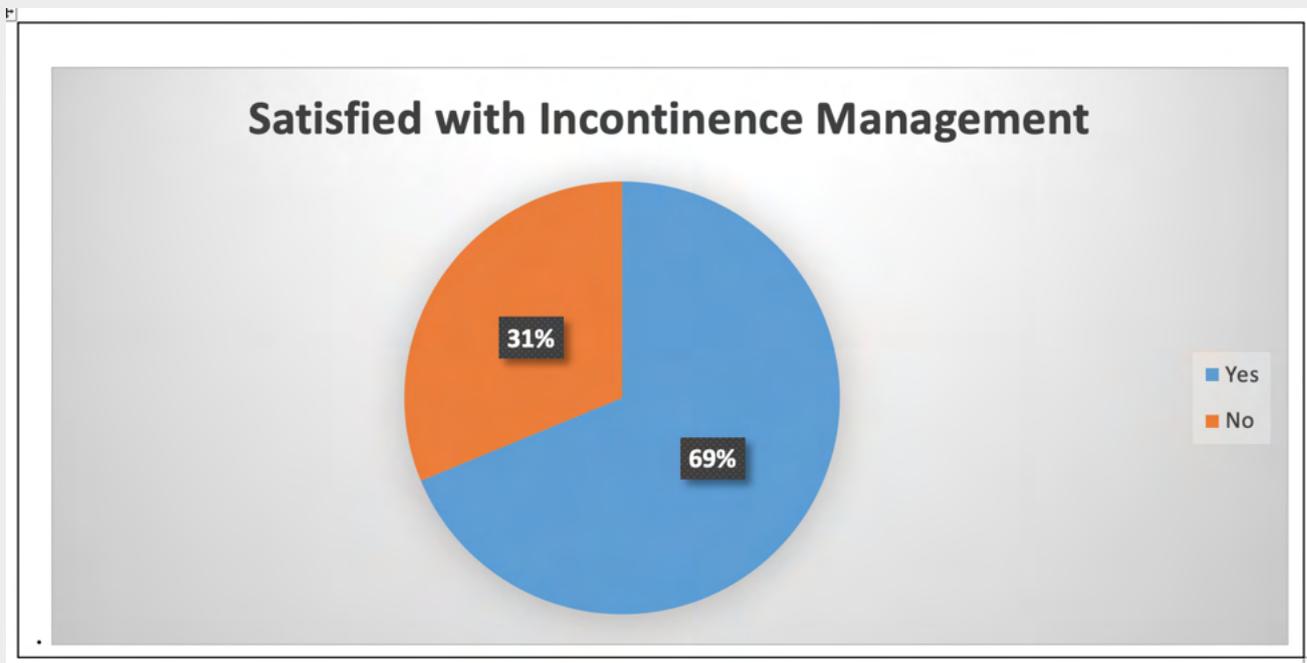


10. Satisfaction with Incontinence Management

About 3 out of every 10 participants were not satisfied with how they manage their incontinence

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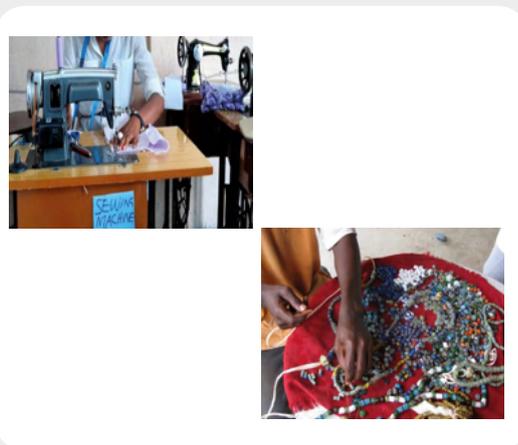


10.0: Suggestions to Improve Incontinence Management Experience

As stated previously, the women have expressed the need for better ways to help them manage their incontinence and the issues associated with the management process. This section essentially highlights some of the suggestions by the women on measures that can support them manage their incontinence.

10.1: Employment and skills training

The women demanded an improvement in their economic and financial challenges through technical and vocational skills support. They mentioned training in dress-making, bead making, and hairdressing and resourcing them with starter packs to establish their own businesses.



Quotes from participants

I needed things to help me manage my situation. I didn't have money so if I had gotten money, buying of diapers would not be an issue. I also needed money to sustain myself and buy basic needs such as food and clothing. (Akua)
"After surgery, we should be given some skills training to help us earn a living when we return to our families". (Suzzie)

10.2: Improving Access to WASH Services

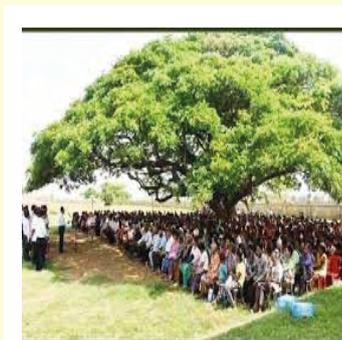
The women want improved access to sanitary products such as detergents, scented soaps, diapers and pads is extremely important. Since most of these individuals are poor women, a program by government and NGOs to supply them with sanitary products would be timely. Support for water services is also needed.

Quote of participants

“Presently, if someone is in such situation money, food, water, Dettol, diapers and all other items will be helpful. (Araba)



10.3: Public Education and Awareness creation



The women called for public education and awareness creation to reduce the stigmatization and other negative experiences.

Quote from participant.

“Public education has to be thorough because there are some persons with the fistula but because of the embarrassment that comes with it, take mine for example, I had to hide it until the surgery.” (Nana Aba)

10.4: Psychosocial Support services

The women suggested the provision of psychological services to help victims cope effectively with the psychosocial issues associated with obstetric fistula and incontinence. Currently, the women do not have access to psychological services at their respective communities or at the hospital.



10.5: Repair of fistula

The women requested for prompt repair of the fistula. They believe that when the repair facilities are many, it would reduce the waiting time for surgery.

Those who undergone surgery for fistula repair also mentioned inadequate logistics and human resource as a challenge.

Quote from participant.

“The government set up a committee to look into problems of women with fistula for them to know our needs and so support us.”

“The government should again increase the training of doctors so that there will be more doctors to the fistula for women” (suzzie).

“The government should support the hospital with logistics so that the surgeries can be done at all times for us to recover” (Diana)

SECTION D: SUMMARY AND RECOMMENDATIONS

1.1: Summary of Main Findings

Women with obstetric fistula experience urine and/or fecal incontinence, excruciating pain, skin irritation and catheter discomfort

The incontinence experience leaves the poor victims miserably shameful, embarrassed, confused, humiliated, isolated, sad/depressed, loss of self-confidence/low self-esteem.

The women have challenges managing their incontinence because of restricted access to WASH services. While access to water and toilet facilities is not particularly challenging, the women have profound difficulty assessing sanitary and body care products such as diapers, soap and Dettol.

The challenges relating to access to WASH services have compelled the women to devise innovative means to manage their incontinence. Prominent is the adoption of constipating practices for urine and fecal retention such as the use of drugs and/or food (i.e., foods that can constipate such as bread), restricted travelling.

The production of diapers from traditional and household materials such as used clothes and flour sacks to manage incontinence could expose the women to infection.

The limited support women with incontinence obtain from family members, neighbors/communities and organizations further worsens their access to WASH services. This has contributed to the difficulty in managing incontinence effectively.

The women are also faced with economic and social barriers such as lack of job, disruption in family ties and social system. This has further worsened their resolve to manage incontinence satisfactorily.

1.2: Recommendations to Improve WASH Experiences of Women with Incontinence

Below are the recommendations and actions that are needed to be taken to improve the WASH experience of women with incontinence.

Production and distribution of reusable sanitary pads/ diapers

A dedicated scheme to produce and distribute reusable diapers/sanitary pads to help women manage their incontinence would be timely.

The insight gleaned from the production, certification and distribution of reusable nose masks during the COVID-19 pandemic should be harnessed to deliver similar resources for women with incontinence.

Establishment/integration of incontinence-psychosocial support units into existing services:

A unit dedicated to providing psychosocial services such as counselling and psychotherapy. This will help lessen the psychological burden on women with incontinence.

The unit should also provide community support services such as linking women with incontinence to job opportunities and intervention programs introduced by governmental and non-governmental organizations, as well as supporting community reintegration of women with incontinence.

The incontinence-psychosocial unit can be a standalone unit in the community and health centers or integrated into the existing services provided at these centers. Economic empowerment opportunities: The following empowerment opportunities will greatly support women with incontinence.

Equip women with incontinence with vocational and technical skills and support them with starter pack to engage in their own businesses to earn income for a living. This will enable them obtain WASH services to effectively manage their incontinence.

Facilitate the inclusion of women with fistula induced incontinence into the Livelihood Empowerment Against poverty (LEAP) program implemented by the Government of Ghana. The program, targeted at the vulnerable and aged should be extended to this unique population of women who live in abject poverty.

Establishment of National Fistula Fund to support patients diagnosed with this condition to receive medical and surgical interventions to manage their incontinence.

Public Education, Awareness Creation and Advocacy

Public education and awareness creation on fistula and its products such as incontinence should be carried out at strategic locations.

This will help community members to be well informed well-informed to appreciate the suffering and challenges of women with incontinence.

This public education is expected to reduce the psychological challenges experienced by women with incontinence, while increasing the sources of support in the family and community settings.

Supporting Participants with Obstetric Fistula Incontinence.



In view of the burden imposed on women with obstetric fistula with respect to access to WASH services, the project team sought support from cooperate organizations. The project team secured WASH products, including sanitary products and detergents that were distributed to the participants. The products were distributed in a customized dissemination bag. The participants were supported with reusable nose masks and alcohol-based hand sanitizer as part of measures to mitigate the spread of COVID-19. The dissemination and COVID-19 mitigation measures were financed by the ELRHA-Humanitarian Innovation Fund.

Monitoring and Evaluation of Obstetric Fistula Incontinence and WASH program

Monitoring and evaluation is an integral component of the project, and it is designed to support the project team to understand core issues relating to the implementation of the project as well as to uncover areas that needs to be strengthened for future endeavors. It was designed to enable the project implementation team gain insights into issues relating to the data collection process, dissemination, and uptake as well as partnerships. A summary of the monitoring and evaluation focusing on the aforementioned areas can be found below.

Project Planning and Implementation: The project implementation commenced well, mainly because of the project workshop organized by ELRHA for grantees. It was observed that the project implementation in general was guided by the discussions that ensued at the workshop that was attended by the project lead and one of the project team members. The team members have unique expertise that supports project implementation, including advanced research skills, community engagement and stakeholder workshop.

The study design was implemented according to the approved protocol, with the incorporation of COVID-19 mitigation measures. Ethics approval was sought from two institutions: Ghana Health Service and Christian Health Association of Ghana. The development of questionnaire and interviews followed the recommended process of literature review and expert-engagement. The recruitment of participants followed laid down rules and procedures by the ethics review committees. Efforts were made to uphold all ethical principles associated with research with human participants, namely confidentiality, protection from harm and anonymity. The decision to recruit the participants with the help of hospital staff whom the participants trust and respect ensure the availability of participants for data collection. Given the sensitivity of the topic under consideration, the research team would have encountered enormous difficulty attempting to recruit the participants without the involvement of nurses at the study sites.

The data collection process was done in accordance with research ethics. Informed consent was sought from participations after the study was explained to them. Participants were granted the opportunity to ask questions to allay any fear of participation. Those who exhibited emotional difficulty during the data collection were made to take some rest and continue with the process if they feel they can continue. Others were referred to the hospital for additional psychological and emotional support. The participants were given pseudonymous to protect confidentiality and ensure anonymity. Data storage and processing were done appropriately. Data were stored on computers encrypted with password that is known to the project lead to prevent unauthorized access. Any person working on the data was made to sign a confidentiality clause. The data analytic strategies used both qualitative and quantitative data were appropriate, guaranteeing that the results is valid and can be trusted. ReGIG handled the study design, data collection and analyses largely because it has the requisite expertise. The partner organizations could have benefited by learning the research process. This did not happen as expected as they had other engagements that limited their availability to learn. Thus, their involvement is limited. Although a review of the project implementation plan submitted to the funding agency shows that ReGIG is responsible for the conduct of the study, it is recommended that project partners learn from each other as much as possible.

Dissemination and Stakeholder Workshop: The workshop was organized to share the findings of the study to stakeholders as well as to engage them on the implications of the study findings. The workshop was well organized, with representatives from UNFPA, Ministry of Gender, Children and Social Protection, local assembly, traditional council, community members, religious leaders, health professionals and women living with obstetric fistula. Following the discussion of the purpose of the workshop, the invited guests were given the opportunity to address the audience. This was followed by the discussion of the findings, led by one of the team members. The stakeholders, including the participants who took part in the study, made input into the findings as well as examining the implications for improving the WASH experiences of women with obstetric fistula. The processes generally validate the findings presented as the participants noted that their views were adequately and properly illustrated.

The participants were given snacks and water during the workshop. When the workshop ended, the participants were given a parcel that include a customized, sack woven dissemination bag. Inside the bag are a pack of sanitary pad, a bottle of bleach, sanitizer, fragrance liquid detergents and nose mask. The participants and other stakeholders were presented a pack of variety of food to choose from as lunch. The participants were also offered a token to be used to defray the cost of transportation. After sharing, the remaining items, namely tissue and soap were donated to the hospital through the coordinating nurse for the obstetric fistula project.

In future events, the project team should consider that possibility some individuals will show up uninvited and must budget for such persons as unforeseen circumstances. Indeed, some people who live nearby the venue for the dissemination came for food, but they could not get any.

Project Partnership: It was observed that the project partners are working together for the first. There were enormous efforts to ensure successful project partnership to pave way for future collaborative effort. There was evidence of mutual respect and collegiality. The expertise of each team member was duly acknowledged and respected. The led organization strived to promote functional division of labour designating roles to individual organizations and team members based on their unique expertise. The project team members were relatively young and full of energy, ideas and experiences pertinent to the successful implementation of the project.

As a known problem in project partnership, effective communication was as the major problem. The communication problems take various forms, but predominantly delayed communication and no communication. The delay in communication can be blamed on largely all partners. This was evident during the preparations for the dissemination and stakeholder engagement work. The lead organization in some instances did not appear proactive as it did not relay information regularly and timely. Sometimes, information is communicated two days prior to an action being taken. This makes it difficult for project partners to plan, knowing that they have other engagement. In the similar manner, the implementing partners sometimes delayed in responding to the suggestions shared on the common WhatsApp platform created for project partners to share information and make decision. This affected prompt and timely project planning and implementation. Some project team members show up for meetings late or do not show up at all, without any communication with the project led or manager. As a result, meetings have been postponed or scheduled to use online platform.

It was observed that some project partners appeared occupied with other projects been undertaken by their parent organization. This limited their full availability and commitment towards the implementation of the obstetric fistula incontinence WASH project. The led organization did excellently well by providing leadership and direction throughout the various phases of the project. This was crucial to the overall success of the project implementation.

1.3: Conclusions

- A concerted effort by government of Ghana, development partners, NGOs, local communities and institutions is needed to improve the WASH experiences of women with obstetric fistula-induced incontinence.



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