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# Re-Integrating Fistula-Repaired Women into Society in Central Uganda: A Community Participatory and Action Approach

**Joan Kabayambi[1], Sam A Okuonzi[2*]**

[1]Africa Renewal University, Kampala, Uganda

[2]African Centre for Global Health and Social Transformation, Kampala, Uganda

[*]**Corresponding author:** Sam A Okuonzi, African Centre for Global Health and Social Transformation, Kampala, Uganda

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## Abstract

**Introduction:** Women with repaired Obstetric Fistula (OF) are often socially isolated, discriminated and stigmatized. Consequently, they may require support to reintegrate them into communities. We designed and implemented a pilot intervention to integrate women with repaired OF in two districts (Kiboga and Kyankwanzi) in Uganda.

**Methodology:** Prior to the design of the intervention, one hundred key informants were interviewed. Data was collected on the probable local solutions/actions that could be undertaken to reintegrate women with repaired OF and the challenges they would face in getting reintegrated into the community. These findings were used to inform the design of the pilot intervention using a community participatory reflection approach (PRA) model encompassing five steps: 1) Raising community awareness; 2) identification of neighbors of the women with repaired OF; 3) development of an action plan with full participation of the community; 4) implementation of agreed actions; and 5) monitoring and evaluation.

**Results:** Baseline findings from the 100 people interviewed revealed that women with OF were afraid of people and in hiding, they were silent about their condition, they smelled badly and were shunned by others, people were unfriendly to them, and they were sad and uncooperative. Eight women were identified with unrepaired OF and referred to health facilities. Community members visited the families of women with OF and made contributions of basic needs. Community members also encouraged women with OF women to join social groups to uplift their standard of living. The women with OF were encouraged to become advocates for the campaign to end fistula. The free discussions enabled women with OF to speak boldly about their condition which contributed to the reduction of stigma against them. Subsequently 30 more women with OF were identified. The end-line was that their participation and social inclusion in community functions increased, significant stigma mitigation was achieved, poverty reduction was noticed as they resumed income generating work, and the women were accorded equal opportunity in society like everybody else.

**Discussion:** Communities were virtually ignorant of the challenges faced by women with OF but were willing to help once sensitized. Women with OF, when well informed, opened up to the community members. The community responded positively by visiting them and providing them with some basic needs. Through all these actions, women with OF were empowered enough to be included into community groups and programs.

**Conclusion:** The social impact of OF on women can be effectively mitigated by the combined actions on and by the community and OF women sufferers themselves. The awareness raising and comprehensive approach could lead to fistula prevention and pave way for the treatment of OF when they still occur.

**Keywords**: Community participation, Fistula-repaired, Obstetric fistula, Re-integration; Uganda, Women

## Introduction

Obstetric fistula is a crippling maternal childbirth injury that affects approximately three million women worldwide, disproportionately impacting countries with weak health systems and limited resources. It is a hole between the bladder and vagina or vagina and rectum that results from prolonged obstructed labour, associated with delays in seeking and receiving appropriate care. Although reparable through surgery, few women are able to access treatment and many are stigmatised by physical and social consequences [1]. These women are often are shunned, abandoned, stigmatized by their families and communities [2]. They are distressed, disillusioned, dejected and depressed [3,4] and continue to live in fear due to the stigma and discrimination they face from their husbands, family members and the entire community. Little assistance is available for rehabilitation and reintegration of the women into their communities after surgery.

Common re-integration efforts in place for women with obstetric fistula tend to include skills training, tailoring, interior decoration, soap making, tie and dye, pastry baking. This approach is expensive as it involves a lot of investment. Secondly, often the women are not given the opportunity to choose how they would prefer to be re-integrated in community in an easy way that is acceptable to them [5]. Such incomplete social re-integration efforts have been made in Pakistan where women with OF are connected to income generating activities providing a livelihood after treatment [6,7].

This study was aimed at identifying, developing and implementing low-cost, sustainable and community-owned solutions to the challenges women with OF using a community-participatory reflection action approach (PRA) [2]. The objectives of the pilot study were to 1) identify re-integration challenges, 2) develop strategies that are less costly, sustainable and owned by community, and 3) facilitate local communities to implement this approach on women living with OF among them.

### Methods

#### *Study design*

This was conducted as a qualitative participatory reflection action research project. Reflection meetings were held with the two communities in Kiboga and Kyankwanzi districts. A participatory reflection action research approach (PRA) is a structured methodology centered on the principle that participation is a moral right [8]. Multiple views are sought through a process of group inquiry, developed for the specific context, and so using systematic methods to help people organize to bring about changes in problem situations that they see as improvements [9]. The methods are structured into four classes namely those for group and team dynamics, for sampling, for interviewing and dialogue, and visualization and diagramming [10]. It is the collection of these methods into unique approaches, or packages of methods that constitute the systems of inquiry [11-15]. Participatory action research makes research part of a learning process and raising awareness on issues that is unknown to community. Through reflection meetings questions are raised, problems are identified, plans are developed to solve challenges in the community in a participatory manner [16].

Participatory reflection and action research approach supports concerted interventions which empower leaders in the community (village health teams) who take decisions and actions, and then follow up and evaluate them. Within these interventions they look specifically at the questions related to better understanding of the issues inherent in community. The approach encourages bottom up planning.

A participatory inquiry involves eight clearly defined steps [12] as follows:

1. Selection of a location and getting an approval from local administrative officials and community leaders
2. A preliminary visit (steps 1 and 2 include community review and a planning meetings to share the purpose and objectives of the study
3. Collection of secondary and field data
4. Synthesis and analysis of the data
5. Identifying problems and opportunities to resolve them;
6. Ranking opportunities and preparing maps, action plans, reports and costings
7. Adoption and implementation of the plan
8. Follow-up, evaluation and dissemination findings.

The PRA approach as a process cycle begins with community assessment, identification of issues (problem) prioritize the issue and act on them. Then review and reflect on these issues which are again evaluated. At this point new issues come up and the cycle is repeated until the problem in the community is addressed or there are sustainable solutions. Here the cycle is illustrated in the figure below Figure 1:

Community Participatory Reflection Action Model

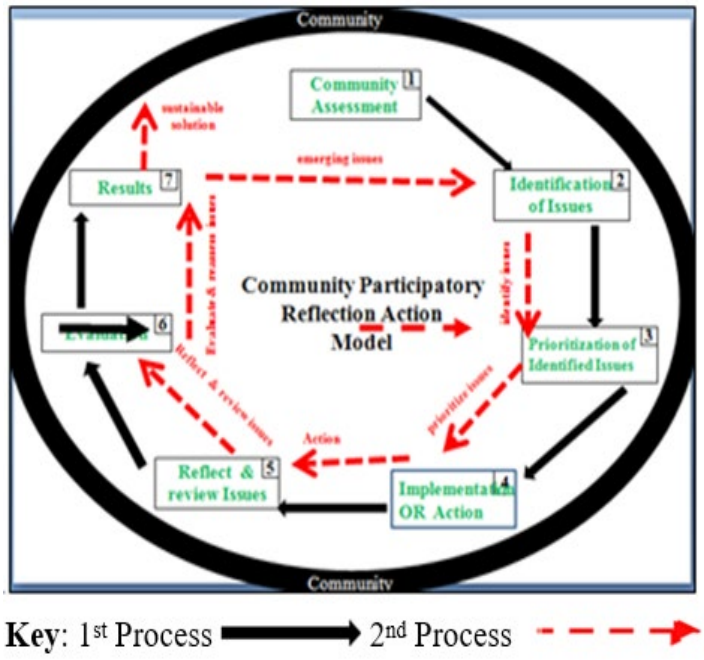


**Figure 1:** Source: Author (JK)

***Study population***

The study targeted 100 community participants and five (5) women who had been repaired of obstetric fistula (OF). Community participants were purposively selected on the basis of their status and knowledge of maternal health issues such as elected community and clan leaders, Village Health Teams (VHTs), Traditional Birth Attendants (TBAs), religious leaders, teachers and close relatives. The five women who participated were head hunt. Participants were from eight parishes in 2 sub- counties. They included 10 community leaders, 8 Religious leaders, 18 VHTs, 6 TBAs, 8 Health workers and 16 teachers. Of the five women three were from Mulagi sub-county in Kyankwazi and two from Kibiga sub-county in Kiboga district. The five women who were repaired of OF, were key informants, and in-depth interviews were held with them.

***Project interventions***

The PRA approach was used to develop and implement the package of interventions. The following steps were followed:

**Step1:** A preliminary meeting to introduce the purpose and objectives of the PRA was held to initiate the dialogue between all parties. Two community awareness meetings on obstetric fistula condition were held in both Kibiga and Mulagi sub-counties.

**Step 2:** Group discussions were given ample time to exhaustively discuss. Each group was given a different question, the questions included: i) challenges surrounding OF condition as viewed by the community, ii) how women with OF can be identified, iii) ways by which the community can mitigate stigma, iv) simple ways by which the community can help women with repaired OF to re-connect back to society. Reports of the discussions were shared in plenary sessions where responses were enriched by participants.

**Step 3:** The research met community members who live near the five women with repaired OF who had been identified for the study. During these phases, strategies were identified that could be used to re-integrate the women into the community. The actions were prioritized using the criteria: simple, low cost, easy to implement, feasible and acceptable to both the women and men in the community.

**Step 4:** The next step was developing an action plan. The different roles were played by close family members, friends, neighbors, as well as social groups – churches, women groups, NGOs and local leaders.

**Step 5:** The community implemented their action plan for a period of eight weeks. Implementation, data collection and documentation were done at the same time.

**Step 6:** This step was to evaluate the interventions. Women agreed to join the bigger group (community) to carry out this process. It was done for a whole day in different sessions. The women were evaluated alone using a questionnaire, while the other participants went into groups. Then later all the participants came together in the last session for validation of information. The evaluation centered on what was done, what was not done and why. Each group discussed the challenges that hindered them to take action. New issues that emerged were noted for follow up.

***Data collection***

Head hunting sampling was used to select 5 women who had OF during childbirth. Potential research participants were recruited from 8 parishes in Kibiga and Mulagi sub-counties (Kiboga and Kyankwanzi districts respectively), at which time they were requested to participate in an ongoing study. Telephone contacts and residential addresses were obtained from them during the first meeting. Using contact addresses and directions obtained from the VHTs during this initial contact, the women were traced to their individual villages and communities, where a second in-depth interview was conducted at a venue chosen by the participant, 1–2 months after the initial interview.

Unstructured interviews were employed in order to enable the women to express their views freely and the meanings they attached to their experiences in living with OF in community. To clarify the questions, an interview guide was used. There was some flexibility in the order of questions and in the prompts employed to enhance understanding of the unique challenges of the women.

With the permission of the participants, the interviews were audio taped in the local Luganda dialect and later translated into English. A journal was kept for recording detailed field notes about challenges, best intervention, lessons and best practices incidents that were heard, seen, experienced, and thought about during the process of data collection, in order to better comprehend and interpret the content of the interviews.

Community meetings using the PRA process followed the eight steps mentioned above. This was guided by the following questions: What difficulties community has living with women with the OF condition; what the community think about these women; and if the women are involved in community events, how community treat women with the condition. The challenges women with OF face, how the community deals with the challenges, participants were asked to list the challenges. The research assistants were documenting and the responses and all the proceeding were recorded with voice recorder and later transcribed from the local language into English. Responses were recorded and handwritten notes were taken. At the end of each meeting a detailed report was transcribed from the local language into English and documented.

In-depth interviews were held with five women. The interviews lasted for two and half hours with each of the women. Interviews were conducted with interview guide until a point of saturation was reached, and guided by the following questions: The challenges were faced by women with OF in this community, what their experiences have been with the OF condition? What has been happening with them after OF treatment? Who do they live with (probing for husband, parents, relatives, and children? How have their families and communities been caring for them? The women's opinion was sought on how they would like community to care for them. A voice recorder was used to eliminate the interruption of note taking during the interviews.

Focus groups discussions (FDGs) to explore ways through which communities can help and how to identify the women who have undergone surgical treatment in the area. The FDGs were mainly neighbors and family of the women. An implementation plan was developed together with all the participants. A baseline and end-line surveys were conducted for an evaluation using a questionnaire to capture challenges of reintegration, as well as changes in the social and economic life of the women.

### *Data analysis*

Thematic analysis was employed. This entailed reading and rereading transcribed interviews to gain insight and deeper meaning in order to identify themes and categories. The analysis was done concurrently with data gathering, which helped to know what to ask in the next interview and to cross check information from each interview with subsequent participants. This process made it possible to recognize the saturation point at which no new information emerged from the data.

## Results

The study results are from three data sets, the community reflection meetings, Focus group discussions and in-depth interviews. The community was composed of the 7 different categories as indicated in Table 1 below:

| Category | #Total | Women | Men |
|---|---|---|---|
| Community leaders | 10 | 4 | 6 |
| Religious leader | 8 | | 8 |
| Village Health teams | 18 | 8 | 10 |
| Traditional birth attendants | 6 | 6 | - |
| Health workers | 8 | 2 | 6 |
| Teacher | 16 | 7 | 9 |
| Women repaired of OF | 5 | 5 | |
| Other community members | 34 | 19 | 15 |
| **TOTAL** | **105** | **51** | **54** |

**Table 1:** Categories of community participants

At the first meeting (community assessment) there was awareness on OF community was not know about the OF condition, community demanded to know more about OF condition more specific how to identify women with the OF condition. After the explanation, it was unanimously agreed by all the participants that OF condition is a challenge that required community's concerted effort to end. The following were the suggested ways to identify women with the OF condition:

- With the help of the elderly women in the community to look out for these women who have a permanent offensive smell on them and are lonely. The OF women are generally visibly miserable and keep alone to themselves.
- By use of the VHTs and health workers using a "comb through approach" in the community – this is where the VHT who know all the people in the areas they operate, goes house to house asking if they are women with the OF condition.
- Through church leaders at Sunday church gatherings to speak about the condition and make an appeal for the women with OF to come out for help.
- Community to stop stigmatizing these women with negative talk about their condition because it is a medical condition not witchcraft or a curse as it has been known.
- Men to be at the forefront of the spreading the message that

women with OF, it is not their own making but a mismanaged child birth process which is preventable and treated at no cost.

- TBAs to use their popularity among women to identify them,
- Use of posters that are clearly made in the local language for all women with OF who hide to come out and seek treatment.

The study participants also noted that the messages going out should be clear: that OF is not witchcraft, but a medical condition that can be treated; women with repaired OF can give birth again, they can also wait for three months after treatment to resume normal sex life; and that women with OF are not hopeless or useless they deserve equal social treatment.

At the first meeting of the women with repaired OF, women were not ready to disclose about their condition due to fear and stigma, but as the interaction continued, they were able to open up and speak. When asked about the OF condition, one of them said:

"This condition is the worst thing that has ever happened to me, the pain, the hurt and the regret. I can only compare it with the loss of my mother. I have seen hatred, insults, abuse and how my own relatives turned against me [cries]. I am not worthy to live in this place, but I have nowhere else to go but to stay…" **SN- Kibiga**

Another woman also had this to say:

"This condition was sent to me by my co-wife, as witchcraft. She had said I would never see happiness in my life and indeed she was right. I have never seen happiness. I lost my child and I started leaking. But now I have hope after treatment**"**. **KJ- Mulagi**

The third woman likened the OF condition to "hell" when asked if she knew what hell was, she said:

"A place of suffering in quietness, no one knows what I'm going through but they keep calling me names" **FT- Kibiga**.

***Challenges as viewed by the community***

There was general lack of understanding of the OF condition in the community including Village Health Teams (VHTs) who are expected to be aware of health issues. The community associated OF with curse, witchcraft and thus the women are seen to be bringing bad omen to the community. Some of the challenges identified by the respondents included: women being uncooperative, smelly, they keep themselves alone and in hiding, they are a curse in the community, we cannot harvest produce when they are in the villages; we have to chase them away during the sowing period. One of the community participants said:

"Last year we had to chase the woman who was leaking, because she was a problem. She had a repulsive smell, whenever she passed your home something bad would happen to you, you either lose a child or if you planted some crops, the harvest time will be the worst time of no yield" *C***lan leader- Mulagi**

"I wish I knew this earlier we would not have chased her! She was helpful in the community, very useful for baby seating whenever other family members went to the garden" **VHT – lady Mulagi**.

They were of the view that "women with OF cannot be treated, the cost of treatment is so high and yet the leaking does not cure"*:*

"That disease (the OF condition) is non-curable, no one can stand it, the woman cannot produce children, these women are useless, who can stay with such a person?" **Community member – Male-Kibiga**

More of the challenges identified were that the women were miserable, had no friends, and could not do any productive work in the community. They are not involved in any activity because of their awful smell. Some of the women were reported to have come from other places after being chased away, and came to look for work. They were said to always be on the move from one village to another:

"They are not settled that is why they are shunned, if a woman is chased by the husband how can we, as community accept her*"* **LC - Kibiga**

***Challenges as viewed by women with repaired OF***

The two women in Kibiga were young with an average age of 21 years, had not had any formal education and had fistula at their first pregnancy, while the second at the third pregnancy and the babies had died. One SN has a son aged 7 years. Both women live with their husbands who have been taking care of them. The three women in Mulagi were elderly with an average age of 77 years, none had a husband. Two of the three the husbands abandoned them while the other third was a widow. They never had any formal education and had lived with OF for over 50 years. They mentioned were used to the condition, did not required to be have any treatment, they did not consider the OF a curable condition (Table 2).

| SN # | Age | Average age | Sub-county | Marital status | Education | Number of children | Lives with | Years with OF |
|---|---|---|---|---|---|---|---|---|
| **KJ** | 80 | | Mulagi | Widow | None | 3 | alone | 57 |
| **NS** | 78 | 77 | Mulagi | Abandoned | None | 2 | daughter | 58 |
| **RN** | 72 | | Mulagi | Abandoned | None | 0 | relative | 55 |
| **FT** | 23 | 21 | Kibiga | Married | None | 1 | husband | 2 |
| **SN** | 19 | | Kibiga | Married | None | 0 | husband | 1.3 |

**Table 2:** Demographic characteristics of women repaired from OF.

When asked what challenges they had faced with OF condition in the community, they had the following to say.

"I was told I am half a human being, I cannot get a hoe from the NAADS program, and the people do not want to share anything with me. But my husband was given a hoe and yet in other families both the man and woman got a hoe" **SN-Kibiga.**

"I am the most hated person here in this village. I was once compared to a thief that was killed, that I should have been the one to die, and what hurt me most this was said in my presence by my mother –in –law" **FT- Kibiga.**

"Every abuse, every bad name is directed to me, even the drunkards when they are passing by, they swear never to sleep with the women of a he-goat smell. With this situation there is no one, who can get used to such a situation. On the contrary, my husband consoles me" **FT- Kibiga.**

Another challenge reported by the women was living with the condition for more than 50 years. They have never benefited from any community program in the area. They are not allowed to go for political rallies during the elections, where members are given sugar and soap. They live in constant fear of community members.

"My own son wants me dead, he says I am an outcast in the community everyone hates me, I should never call him my son, he wants to take the land and sell it" **NS- Mulagi.**

"The community people have been arbitrating on this case but I have not had justice, I am waiting for death and I go… but I am so bitter with everyone, I don't know if God will even accept me…. there is nothing good here." **NS- Mulagi.**

Women expressed lack of care from community members, who did not allow the OF women to join village clubs like other women, they were abandoned Table 3. They also thought that, not going to school was a big challenge they had realized. Also, old age had hindered them from accessing anything good like others do, and no-one respected them. One of them said:

"I have also been shunned by small children in this village, no one respects me; children sing and shout about me, what they hear their parents say about me. You hear them calling me names of goats imagine that!" **RN- Mulagi.**

| Community | Women with repaired OF |
|---|---|
| Not easily identified | Negative talk and gossip |
| Poor- no income- cannot work | Cannot be employed |
| Lack socialization-loners | Live in doubt about relationships |
| Few or no opportunities | Regret, anger, bitterness |
| Offensive repellant odor | Abuse, Insults, hum |
| Keep in hiding | Suffer humiliation |
| Cannot have sex; men abandon them | Community do not understand us |
| Lost self esteem | We are regarded as non-citizens |
| Segregated | We cannot mingle, go to church |
| Useless, hopeless, non-productive | |

**Table 3:** Summary of identified challenges by community and women

***Developing and implementing a work plan***

After the community understanding and appreciating the OF challenge, some actions were agreed upon. These included: finding out where the women lived or stayed, to pay a visit to the family, to provide support to the women and to console them; to show compassion and counsel the women to feel free; to make a contribution of basic needs such as money, soap, sugar, clothes and food staff (beans and posho or maize flour) to the family, particularly to the women; to invite the women to join social groups in the village such as village saving box groups, church and digging clubs; to inform community leaders about the women and that their needs for help; and to encourage women to become advocates for the campaign to end fistula (Table 4).

| Intervention (Action) | Output | Outcome | Impact |
|---|---|---|---|
| Visiting the family or the woman | Console them<br>Advise on hygiene<br>Counsel them to follow hospital instructions | Self esteem<br>Restore hope & dignity<br>Self confidence | Health women and families |
| Make a contribution to the family | Money<br>Food staff<br>Soap | Feel cared for and loved | Poverty reduction |
| Encourage them to become advocates on the campaign to end Fistula | Freely talk about the OF<br>Share her testimony | Self confidence<br>Share challenges<br>Sit in public | Stigma mitigation |
| Search for help from various organizations that could help the victims fit in to the community | NAADs program<br>World Vision<br>Government programs | Modern Agriculture practices<br>Skills development | Social inclusion and self-reliant |
| Encourage OF women to join social development groups with development targets so that they up lift their standards of living | Village boxes | Improved standards of living | Equal opportunities for all, and participation |
| Give women emotional support | Prayer<br>phone call | Self esteem | |

**Table 4:** Community implementation of their work plan.

The women's views included that the community: should understand their OF situation; to be patient with them; to welcome them back; to involve them in the community activities like voting, attending church; to support them; to stopping discriminating them; to stop negative gossip about their smell; to stop name calling; to assure them that they are not a curse or witches; and to accept them as they are. Some of them said as below:

"I know that I smell but I do not want to be reminded all the time about it, I did not cause this to myself, I do not want to be like this (cries and sniffs) It's sad for me here." **FT- Kibiga**

"Those days when I still had fistula I used to stay in my house and I did not want people to be near me because I knew that after they leave my place they will go and gossip about me on how I smell and all those words. These people do not understand that I don't leak anymore." **RN- Mulagi**

A work plan was developed together with the community, where the agreed upon interventions had outputs, outcome, with a set timeline of eight weeks. The interventions are simple and easy to carry out. It was agreed that after eight weeks an evaluation would be conducted to assess if there is any change in the lives of the women or any positive responsiveness of the community to the agreed upon actions. It was agreed that the evaluation would be participatory together with the women present. To assess how community performed on the agreed actions. Five outcomes were agreed upon as follows; (i) to have the women accepted and socially included in community activities, (ii) participation in the community programs, (iii) have equal opportunities like the rest of the women in the community, (iv) stigma mitigation, and (v) poverty reduction (Table 5).

| Intervention | Output | Outcome |
|---|---|---|
| Welcome them back in to the community | Feel accepted and gaining back their dignity | Increased inclusion and acceptance |
| Community should be patient with them | Reduces shame | Reduced stigma |
| Community should be supportive to them | Feel loved and cared for | Built confidence |
| To involve them in community groups | Find belonging | Participation and involvement |
| To be cared for without any discrimination | Reduces inequality | Equal opportunities |

**Table 5:** Views OF repaired women on how the community can help them

**Evaluation of the interventions**

The evaluation of the interventions was done after eight weeks. It was a one-day process with each of the sub- counties. Reflection meetings, key informant interviews (KIIs) and focus group discussion (FDGs) were held. Two reflection meetings were held, one before and another after breaking up in KIIs and FDGs. The first reflection meeting was to reflect and review progress on what was agreed upon to be done according the work plan that was developed eight weeks ago. Respondents went to their groups to discuss how they had performed and what challenges they met during implementation. Later all the participants came back together for presentations and discussions on emerging issues. The five women (key informants) were asked individual questions using a questionnaire that was filled for them by the PI. Below are the findings:

**Actions by community**

Community participants in Kibiga were able to visit the families of the two women with OF, made a contribution of money (26,000/=, equivalent of 6 USD), some basic items for them such as soap, sugar (2 kg) and food stuffs (13 kg of beans). They were monitoring the family to see how they were faring. The Local Council (LC) ensured that the FT joined the village savings box group that saves money (contributing 1000/=, equivalent of 20 US cents per week). The LC official paid for her covering a whole month. The women were encouraged to attend church services and were even picked to go to church on Sundays. One of them said:

"Our group chose one person (a VHT member- a lady) whom we have been giving our contributions to for the women, and she had been delivering our messages and we have all visited the family" **VHT- Kibiga**

*In Mulagi all the women were visited by two community members, who contributed 3 USD which was divided amongst the three women. The two members made sure the women are involved in community activities. Challenges for not acting on what was agreed upon included; the women live very far away, they bounced when they went to visit and never went again, Women with OF have no phone could not be reached before the visit, and the roads going where they live is very bad and place is far away. One member had this to say:*

"They (women) live very far away, the road is very bad, I did not have money to hire a bike, and I did not call because I did not have their telephone numbers" **Community – member - Mulagi**

***Evaluation of individual fistula women***

Women were evaluated on an individual basis. All the five women were visited and received contributions (of money, soap, beans and sugar) from the community members. Three received phone calls from members of the community. Two of the women joined social groups (savings and digging groups). Two were prayed for at the local church, one was given a platform to speak at the church about the OF condition and how the community people had come to pray with her at her home. One of the women received counseling and was given a lift on motorbike by the local council (LC) chairman to the hospital when she was unwell. She said:

"Ever since I lived in this place, I have never received anyone come to see me, sit down with me and talk to me so well like in the last two months, thank you for coming here to fish me out of for the people to know me." **RN- Mulagi**

When asked how they felt after the above interventions, four reported to be happy, two reported that could afford a smile, one reported that she felt loved, while the others said they felt respected, recognized, and that they had company. One of them said:

"I last received such attention when I was young; the people are so nice to me, I am happy I can smile, and I have people around me, some I don't know them they come from far away from my village" **JK-Mulagi**

The actions of the community helped the women to speak out, they were able to mingle with other women, and joined groups where they learned new ideas on farming as a business, saving, hygiene and nutrition. They reported that were now respected by the community. One of the women had this to say:

"Imagine myself being visited by a Pastor at my home, where there is no chair he came and sat on a mat and when he invited me to church he asked me to stand up and walk upfront, I have never imagined this kind of recognition. I thank you and God". **SN- Kibiga**

Some of the women's expectations were not met; as one of them said:

"No man has visited me it is only women who have been coming here, I still fear to go to church it is the men who have been harassing me." **RN- Mulagi**

***Which type of people took what actions?***

All the women mentioned to were visited by other women, three mentioned men, local council leaders and VHTs, and, two reported a pastor and a teacher and one clan member.

***Any change seen in their lives after the action?***

Women reported mixed feelings to have seen a big change in the behavior of the community members. The community members had become understanding and kind. The women reported experiencing happiness and care; they are able to participate in community activities, and were able to speak freely about their condition. However, one woman was miserable about the way her husband just changed and no longer needed her in his life. Some of the women had the following to say about the changes they were experiencing.

**"***T*he community has been treating me very well but I don't know what has happened to my husband. He is changed and has been chasing me away. I am now miserable and have nowhere to go*"* **FT- Kibiga**

"My dear all of a sudden my neighbors and other community people are so kind to me, I have never seen this. Glory to God." **NS- Kibiga**

"I am participating in community events and functions. I was called to attend a village committee meeting where I offered myself for election. I was not elected but I had some votes." **RN- Mulagi**

"I am not ashamed any more like I was before this training. My people now understand that I am well and I am not smelling anymore." **SN- Kibiga**

"I have not lacked any soap ever since this project was introduced, I am so happy I feel loved, thank you madam for this help that is given to me, I get a visitor every week that comes home with something for me" **SN- Mulagi**

The women reported that their relationship with the husband's relatives had also improved, save for the one, whose husband had chased her away. None of the women had been introduced to any organization in the area, apart from the church where they were welcomed. When asked about any suggestions to improve on the actions, all the women reported that their community was doing what they never expected and were grateful and happy. They had this to say:

"The people have shown me a good heart. I pray they continue to help me because I need their support and company. I am a better person than I was three months before this project was brought here.**" RN-Mulagi**

"What the community is doing for me I wish all the other elderly sick people in this village can also be help" **SN- Mulagi**

"I would also like to join the village saving box group, I have heard about it but I have not joined" **FT –Kibiga**

"Community men could repair the roof of my leaking house for me, can they do this?" **JK- Mulagi**

"Next time I should be elected as village woman leader for health. I understand the needs for a very depressing condition and would be a better person (laughs)" **JK- Mulagi**

## Discussion

This pilot study was meant to identify re-integration challenges, develop re-integration strategies that are sustainable and affordable, apply the strategies in the community setting, and evaluate them over a period of about six months. When communities are sensitized on the causes and challenges of OF, they become responsive. They are willing to help. This mitigates the stigma on the women. Such positive community actions make women with OF feel respected and happy and to open up. Thus, community PRA model can enhance women's participation in community activities and facilitate affordable and sustainable social reintegration. Five concepts upon which the participatory approach was based are social inclusion, participation, equal opportunities, poverty reduction and stigma mitigation. The outcomes of the approach as an intervention are discussed below.

### *Social inclusion*

Because OF the smell from the fistula women, the leak and their limited understanding of their condition, they are forced to keep to themselves, away from the world and from the community who shun them. This finding is in agreement with a study in Tanzania [16]. This situation is exacerbated by abuse (name calling labeling as witches) and more especially abandonment by husbands, family members and the community. The women are lonely, anxious, suffer depression and social exclusion. But the community was instrumental in bringing these hopeless women back in community after clear understanding of the condition.

This research has shown that enabling people understand OF and are provided with information about treatment, OF is demystified. With OF accepted in society the affected women attain social inclusion. The fact that community members could visit the women in their homes, were invited to churches and local council meetings is evidence of acceptance by the community. This is consistent with other studies on social capital [17,18]

***Participation***

The OF condition renders OF women not to be in control of their urine and fecal matter: the two items considered most private. This had led to these women being powerless, hopeless and more importantly, to lose self-esteem. While the women felt not worthy to participate in activities outside their home environs, the communities were busy excluding them. The research has proved that providing knowledge helped to bridge the gap, and the community to appreciation of the situation. Women began to participate in church activities, in the savings schemes, local council meetings and even in contesting for political and leadership positions, and interacting with the community during home visits. Some of the women regained their self-esteem and felt worthy of making a contribution for the good of the community.

***Poverty reduction***

The women had become less productive due to their condition. Some of them who had been repaired of OF had serious back problem which stopped them from hard-work, such as cultivating. However, support from the community through this project begun to turn this around. The invitation of some of the women to participate in the savings group, the cash contributions made, allowing the women to participate and act as LC 1 chairpersons for one month, joining digging groups were efforts to address biting poverty the women were experiencing.

***Equalization of opportunities***

Equity has been elusive for a long time. While Uganda has equal opportunity policies such as the Equal Opportunities Commission, but its practical application has been a problem. Gender inequality exists in Ugandan communities and its worse talking about equalizing opportunities for a marginalized section of the community such as OF treated women. The project has however shown that community owned processes and working together can help to address the inequality issue. The community identified the five areas of intervention, made the work plan and implemented it.

***Stigma mitigation***

The lack of information about OF creates stigma to the women. The information gap is filled with myths about OF relating it to witch craft etc. The project has evidence to show that creating awareness changes people's attitude and reduces stigma. The project empowered the women and the community to talk freely about the OF condition and in the process over 30 women in the two districts came out of hiding to declare that they had OF and were seeking treatment over the project period. This shows that the magnitude of the problem is big and largely hidden. The women are now ready to talk about it and help others to get treatment. The different strategies the women have charted out in their lessons learnt is worth following up by the project team.

## Conclusion

Six months is a relatively short time in the life of a person. What happens over time is not known. But from the pilot we can conclude that what happens in the future must depend on continual public education on OF, community support and community action. For this approach to be institutionalized, it needs to be scaled up countrywide and become contextualized in each community. What happens in Kiboga may not happen in another district or country. Thus, the local community initiated actions should be the basis of social re-integration of repaired OF women, and indeed the basis of dealing with those who still have the condition, and who need to be treated. The policy on reproductive health (RH) should include a component on OF, with the aim of mainstreaming it in RH programmes.

A brief on OF needs to be be circulated to all health facilities. During the training of midwives, emphasis of should be put on OF prevention. A major session on OF should be done during ante-natal care. There is need to target midwives/nurses and VHTs to carryout OF-awareness campaigns during outreaches. OF should be included in the checklist of midwives and VHTs for their routine work. Continuous community awareness is a major component of integration. Functional Adult Literacy (FAL), a program which enables adult women to acquire basic numeracy and literacy, can be used as a forum for sensitizing women as most of the women with OF are uneducated. Economic empowerment to absorb the cost of treatment is critical in the integration process. There is need to include OF in gender mainstreaming for national development. All categories of society should participate including men, women, and political, religious and cultural leaders.

### Ethical consideration

Ethical approval to conduct the study was obtained from the 116th Higher Degrees Research and Ethics Committee meeting of the School of Public Health (HDREC), and Uganda National Council for Science and Technology. Permission to conduct the study was obtained from Makerere University School of Public Health Fellowship Program. All participants gave written and signed informed consent, were interviewed and followed for a period of four months.

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## References

1. Waaldijk K, Armiya'u Y (1993) The obstetric fistula: a major public health problem still unsolved. Int Urogynecol J 4: p. 126-8.
2. Kabayambi J, Barageine JK, Matovu JKB, Kashesya JB (2014) Living with Obstetric Fistula: Perceived Causes, Challenges and Coping Strategies among Women Attending the Fistula Clinic at Mulago Hospital, Uganda: International Journal of Tropical Disease & Health 4: p. 352-361.
3. Bangser M (2006) "Obstetric fistula and stigma." The Lancet. 367: p. 535-536.
4. Miller S, Webster M, Cowan B (2005) Obstetric Fistula: A Preventable Tragedy Journal of Midwifery and Women's Health 50: p. 286-294.
5. Abrams P, Ridder D, et al. (2012) Obstetric Fistula in the Developing World. Societe Internationale d'Urologie (SIU).
6. United Nation General Assembly (UNGA) 2012, Supporting efforts to end obstetric fistula 67th session Item 28 (a) of the provisional agenda on the advancement of women. 2012, United Nations: New York.
7. Mselle LT, Moland KM, Evjen-Olsen B, Mvungi A, Kohi TW (2011) I am nothing: experiences of loss among women suffering from severe birth injuries in Tanzania BMC Women's Health 1: p. 1472-6874.
8. Wall LL, Kirschner C, Smith A (2004) The obstetric vesico-vaginal fistula: characteristics of 899 patients from Jos, Nigeria. Am J Obstetric Gynecology 190: p. 1011-9.
9. Truscott A (2008) Congo ceasefire brings little relief for women. PMCID: PMC2443208 179: p. 133-134.
10. Stone L (1992) Cultural influences in community participation in health. Social Science & Medicine 35: p. 409-417.
11. Nichter M (1984) Project community diagnosis: Participatory research as a first step toward community involvement in primary health care. Social Science & Medicine 19: p. 237-252.
12. International Institute for Environment and Development 1994 Whose Eden? An Overview of Community Approaches to Wildlife Management,. July 1994 ed. IED and ODA, London. 98-102.
13. Graham A, Seleela P (2001) The postive path using appreciative inquiry in Rural Indian Communities., ed. D.I. MYRADA, Canada.
14. EQUINET 2007 Reclaiming the Resources for Health: A Regional Analysis of Equity in Health in East and Southern Africa., T.R.N.f.E.i.H.i.E.a.S.A.S. Committee, Editor. 2007.
15. CEHURD, C.f.H.H.R.D 2014 Community participation in Helath system Governance, in Community empowerment project, C.f.H.H.R.D. CEHURD, Editor. 2014, CEHURD: KAMPALA.
16. Mselle LT, Moland KM, Mvungi A, Kohi TW (2012) Hoping for a Normal Life Again": Reintegration After Fistula Repair in Rural Tanzania. J Obstet Gynaecol Can 34: p. 927-938.
17. Castillo FA, Okuonzi SA et al (2006) "Why some survive: coping, resilience and social capital during conflict" Injury and Violence 4: 2.
18. Okuonzi SA (2003) Building social capital for health information" Health Policy and Development Vol 1: 1: Editorial; a publication of Uganda Martyrs University, Nkozi Uganda.