#### **ORIGINAL RESEARCH ARTICLE**

## Stakeholders' perceptions on improving women's health after obstetric fistula repair: results from a qualitative study in Guinea

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#### Abstract

The holistic care of obstetric fistula remains a significant public health concern in developing countries. Improving women's outcomes after repair requires perspectives on post-surgical period within which women have to fulfil their social roles and expectations, mainly becoming pregnant, cooking, resuming farming activities or sexual intercourse. Our objective was to explore stakeholders' perceptions of women's health and well-being after fistula repair, and their perspectives on strategies for improving their quality of life in Guinea. A qualitative study involving representatives from the Ministry of Health, regional, district and hospital managers, representatives of NGOs and funding bodies, local leaders, women who underwent fistula surgery and their relatives (husbands, family members), health providers and community health workers at different levels was conducted. Thematic analysis was performed using NVivo software. Overall, 41 in-depth interviews and seven focus group discussions were conducted with 83 various stakeholders. Unanimously, respondents perceived women treated for obstetric fistula are "diminished" and "vulnerable". This "vulnerability" encompasses physical, socio-emotional and economic dimensions. The high risk of maternal and neonatal complications such as fistula recurrence, abortion or stillbirth in these women was mentioned. Stakeholders emphasized the need for a multidisciplinary approach to improve women's health after repair. Social support, economic empowerment and medical follow-up were identified as key components to mitigate women's vulnerability for successful post-repair reintegration. The programmatic level in Guinea should consider women's health after fistula repair a vital component of the holistic fistula care. (*Afr J Reprod Health 2022; 26[8]: 30-40*).

Keywords: Fistula; qualitative methods; women's health; Guinea

## Résumé

La prise en charge holistique de la fistule obstétricale reste un problème de santé publique important dans les pays en développement. L'amélioration des résultats des femmes après la réparation nécessite des perspectives sur la période post-chirurgicale au cours de laquelle les femmes doivent remplir leurs rôles et attentes sociaux, principalement tomber enceinte, cuisiner, reprendre les activités agricoles ou les rapports sexuels. Notre objectif était d'explorer les perceptions des parties prenantes sur la santé et le bien-être des femmes après la réparation de la fistule, et leurs points de vue sur les stratégies pour améliorer leur qualité de vie en Guinée. Une étude qualitative impliquant des représentants du Ministère de la Santé, des responsables de régions, de districts et d'hôpitaux, des représentants d'ONG et de bailleurs de fonds, des leaders locaux, des femmes opérées de la fistule et leurs proches (maris, membres de la famille), des prestataires de santé et des agents de santé communautaires à différents niveaux ont été menés. L'analyse thématique a été réalisée à l'aide du logiciel NVivo. Au total, 41 entretiens approfondis et sept groupes de discussion ont été menés avec 83 parties prenantes diverses. À l'unanimité, les personnes interrogées percoivent les femmes traitées pour une fistule obstétricale comme « diminuées » et « vulnérables ». Cette « vulnérabilité » englobe des dimensions physiques, socio-émotionnelles et économiques. Le risque élevé de complications maternelles et néonatales telles que la récidive de la fistule, l'avortement ou la mortinaissance chez ces femmes a été mentionné. Les parties prenantes ont souligné la nécessité d'une approche multidisciplinaire pour améliorer la santé des femmes après la réparation. Le soutien social, l'autonomisation économique et le suivi médical ont été identifiés comme des éléments clés pour atténuer la vulnérabilité des femmes en vue d'une réintégration réussie après réparation. Le niveau programmatique en Guinée devrait considérer la santé des femmes après la réparation de la fistule comme une composante essentielle des soins holistiques de la fistule. (Afr J Reprod Health 2022; 26[8]: 30-40).

Mots-clés: Fistule; méthodes qualitatives; santé des femmes; Guinée

## Introduction

Obstetric fistula remains a severe medical condition in which a fistula (hole) develops between vagina, bladder and rectum. Most commonly, it occurs after prolonged labour when the head of the unborn child compresses the birth canal and leads to tissue necrosis<sup>1,2</sup>. In addition to the significant physical impact of uncontrolled leakage of urine, obstetric fistula can result in detrimental psychological and social effects including social isolation, repudiation by the husband or depression<sup>2,3</sup>.

Due to the lack of quality emergency obstetric care, sub-Saharan Africa carries the largest burden of obstetric fistula with an estimated lifetime prevalence of 3.0 cases per 1,000 women of reproductive age (95% CI: 1.3-5.5)<sup>4,5</sup>. In Guinea, for example, the prevalence of obstetric fistula among women of reproductive age is estimated to be  $4.1\%^{6}$ . Because of the substantial numbers of women affected by this condition, international mobilisation against fistula and provision of additional funding have been made to curb the disease in recent years<sup>7</sup>. This allowed for the implementation of targeted prevention, treatment and reintegration activities in many sub-Saharan countries, and resulted in more women with fistula being repaired worldwide and increased quality of fistula surgical care<sup>8–11</sup>. Over the past decade, more than 87,000 fistula repairs have been supported globally by the USAID funded Fistula Care Project (30,000 repairs) and the United Nations Population Fund (57,000 repairs) in 15 countries across Africa and Asia<sup>11</sup>.

Alongside these improvements, concerns about how best to sustain the gains achieved after surgery are arising, particularly after treated women have returned in their communities and resumed a new social life without fistula. Women of reproductive age who have undergone successful fistula repair and resumed a sexual life without fistula wish to fulfil their social roles and expectations, for which childbearing is essential<sup>12</sup>. This is particularly important due to the common cooccurrence of stillbirth during deliveries leading to fistula and long-term maternal and child health outcomes after fistula repair<sup>13,14</sup>. Despite counselling at discharge from fistula repair, lapses in follow-up care result in risks for women's physical and psychosocial well-being. This emphasizes the limitations to counselling approaches for ensuring appropriate pregnancy-related care is achieved for

post-repair pregnancies. Finally, despite the successful repair of the fistula, 16 to 32% of repaired women face stress incontinence due to residual damage and about 14% delivery-related fistula recurrences during the first 24 months post-repair<sup>15,16</sup>.

The consequences of persistent adverse experiences and elevated post-repair risks are not limited to these physical consequences; they further reduce women's capacity to perform household tasks and economic activities, resulting in the worsening of poverty and the reduction of their value in the community<sup>17</sup>; hence their physical and social well-being remains compromised after the fistula surgery.

These findings emphasise the need to identify strategies to improve the follow-up of women post repair. Some studies have recommended strategies that include 1) post-repair counseling of women before discharge from repair hospitals to provide information about fistula follow-up, when to resume daily activities and sexual intercourse, and the importance of continued health care engagement after hospital discharge; and 2) implementation of post-repair follow-up care. However, information about the most promising modalities. locally and culturally adapted approaches, and integration into routine maternal and child health programmes is lacking in Guinea<sup>18</sup>. To fill this gap in knowledge and building on the existing literature, there is a need for additional data from stakeholders directly involved in fistula programming as well as women and community members. Such data would guide policymakers and strategic planning efforts in Guinea in order to enhance current program and establish future plans for obstetric fistula, more specifically its long term follow-up, and maternal and child health at large. Therefore, we sought to explore stakeholders' perceptions on women's health after fistula repair and their perspectives of strategies for improving the health of women post-repair of fistula in Guinea.

## Methods

## Study setting

Guinea is a coastal West African country with an estimated population of 12 million people in 2019, most rural inhabitants (65%) and poor (55%)<sup>19</sup>. The Guinean health care system faces many challenges

including a chronic shortage of qualified physicians and nurses and poor clinical infrastructure, particularly in rural and mountainous areas. Only 16% of health professionals (doctors, state midwives and state nurses) work in rural areas where they serve about two-thirds of the population<sup>20</sup>. The large proportion of women delivering at home (47%) and the lack of high quality emergency obstetric care cause persistent elevated rates of maternal morbidity, including obstetric fistula  $(4.1\%)^5$ . Since 2006, the Ministry of Health in Guinea has partnered with international non-governmental organisations, local partners and United Nations agencies to integrate and decentralize the management of obstetric fistula into the health system, with an emphasis on training local surgeons. As a result, a National Fistula Day was instituted in 2010 and national strategic plans for fistula prevention and care were developed in 2012 and in 2016<sup>21</sup>. The latest plan (2016-2020) targeted integration of fistula care into the seven regional referral hospitals and two University teaching hospitals<sup>22</sup>. A social immersion program, aiming at helping repaired women to reintegrate into family and social life, was part of fistula care in two of the seven regional referral hospitals<sup>23</sup>. Fistula prevention is a strategic goal of Guinea's reproductive health policy, described within the National strategic plan for the repositioning of family planning adopted in  $2016^{22}$ .

## Study design

This was a qualitative descriptive study among key stakeholders involved in fistula programming in Guinea.

## Study population

The study population included a variety of key informants (representatives from the Ministry of Health, regional, district and hospital managers, representatives of NGOs and funding bodies, local leaders), women who underwent fistula surgery and their relatives (husbands, family members), health providers and community health workers (Table 1).

KIIs: Key Informant Interviews; IDIs: In-Depth-Interviews; FGDs: Focus Group Discussions; CHW: community health worker; NGO: nongovernmental organization; OF: obstetric fisula; USAID: United States Agency for International Development. Based on initial discussions with representatives of the National Directorate for Family and Nutrition of the Ministry of Health and Managers of the fistula repair hospitals, a list of key stakeholders involved in fistula prevention, care and reintegration programs in Guinea was established to purposively sample a range of key decision-makers and program providers. We then used snowball sampling to select additional study participants<sup>24,25</sup>.

## Data collection

Data collection methods included key informant interviews (KIIs), in-depth interviews (IDIs) and focus group discussions (FGDs). We conducted KIIs representatives of the MoH, NGOs. with international organisations, local community leaders and services and program managers. The information collected included their perceptions of women with fistula, the health issues they face after repair, and recommended approaches for improving their health after corrective surgery. IDIs were conducted with women who had experienced fistula and fistula surgery, husbands and family members, community health workers and health providers. IDIs explored participants' perceptions of women who experienced fistula surgery, health issues they might encounter and what they need to stay safe and healthy after repair. FGDs were conducted separately with women who have undergone fistula surgery, community health workers and health providers to discuss the challenges encountered by women after repair and ways to improve their health post-repair. The number of participants included in each data collection technique was determined by the achievement of data saturation.

Guinean investigators and two final year medical students collected the data after a three day protocol training session. Interview guides were pretested in the Ignace Deen University Hospital and adapted. The FGD topic guide was pre-tested with final year medical students at the Gamal University of Conakry. Interviews were recorded with an audio recorder and lasted from 40 to almost 90 minutes. Data collection covered two months, from December 2016 to January 2017.

## Data analysis

Recorded audios were first de-identified, transcribed verbatim and translated into English by the research

| Stakeholders          | Stakeholders subgroup              |      | Numbers |                           |
|-----------------------|------------------------------------|------|---------|---------------------------|
|                       |                                    | KIIs | IDIs    | FGDs                      |
| Policy makers and     | National Director for Family and   | 7    | 0       | 0                         |
| health services       | Nutrition                          |      |         |                           |
| managers              |                                    |      |         |                           |
| Community leaders     | Leaders of local governments,      | 5    | 0       | 0                         |
|                       | religious leaders                  |      |         |                           |
| Health care providers | Fistula surgeons, midwives, nurses | 11   | 0       | 5 (2 with CHWs and 3 with |
|                       | and assistant nurses/midwives      |      |         | health care workers)      |
|                       | involved in fistula care, CHWs     |      |         |                           |
| NGOs and Funding      | USAID, EngenderHealth, Amref       | 4    | 0       | 0                         |
| bodies                | Health Africa, Fraternité Medicale |      |         |                           |
|                       | Guinée                             |      |         |                           |
| Community             | Women treated for fistula, their   | 0    | 14      | 2 (with women who         |
|                       | partners and family members, women |      |         | experienced OF)           |
|                       | who never experienced fistula      |      |         |                           |
| Total                 |                                    | 27   | 14      | 7 (with 42 participants)  |

**Table 1:** Key stakeholder type and number by data collection method

team and a different translator verified them to ensure the conformity of the translation. Data analysis was concurrent to data collection (iterative starting with data coding process). and classification<sup>26</sup> in efforts to further inform continued research. We used the questions from IDs, KIIs and FGDs guides as initial categories to code and classify the data. Deductive codes derived from the existing literature and the study guides were directly applied to the data while the codes not expected (inductive codes) were applied as they emerged from the data. The themes that emerged (recurrent themes) were used to develop a codebook. Based on that, a thematic content analysis was conducted and the results explained by concepts that are grounded in the data. The study data was analysed using NVivo software (QSR International Pty Ltd. Cardigan UK).

## Results

Overall, 41 interviews (27 KIIs and 14 IDIs) and 7 FGDs (with 42 participants) were conducted among various stakeholders in Guinea (n=83; Table 1).

## Perceived health risk after fistula repair

The core theme that emerged from our research describing women treated for fistula was "vulnerability". Women treated for fistula are considered "vulnerable" as compared to "normal" women who have never experienced fistula. This concept of "vulnerability" includes physical, socioemotional and economic dimensions (Figure 1). Most respondents felt that women with fistula, even those who got successful surgery, are more likely to experience health problems in the future such as maternal and neonatal complications during pregnancy and childbirth than women who have not yet experienced fistula.

"You know that someone who already has undergone fistula surgery is no longer as before. If they have operated on you, you have a disability while the others do not; they have never undergone surgery. So, the one who underwent the operation has more risks, especially when she get early pregnancy after surgery" (Female, Community member, FGD, Kissidougou).

Community members and women who had already experienced fistula said that such risks exist for those women who do not follow the advice provided by health care workers about safe delivery by elective c-section at a health facility.

"An operated and healed woman should not give birth by herself. Once at term, she should go to hospital to be operated; she should not dare to push; if she pushes, she may suffer back from the disease." (Women treated for fistula, IDI, Labé).

Health care providers emphasized the fact that the risk of complications were high if the woman enters the labour before seeking care in a health facility.

Stakeholders described women treated for fistula as physically diminished by the disease and the surgery.

"She must know that she is no longer as the others; she now is a "half-woman", so I would tell her to be careful [during physical and sexual activities] for she already is disabled. If she now



Figure 1: Concepts of vulnerability in women who underwent obstetric fistula repair

*behaves like the others, it can't work.* '' (Female, Community member, FGD, Kissidougou).

Physical vulnerability encompasses the sequelae of obstructed labour complex injury, pain, fatigue or infertility.

"When we are having sex, [my partner] is satisfied while I am suffering from backache... all my body aches after sexual intercourse.... Since [sex] is an obligation in the household, I buy medicines to take [beforehand] so that before the pain comes, the medicine is [already] circulating in my body" (Woman treated for fistula, IDI, Labé).

Socio-emotional vulnerability that includes mental vulnerability was characterized by reliance on others, stigmatization of women who lack support from their relatives (spouses, parents), and social pressure to fulfil marital duties such as resuming farm activities or sexual intercourse, becoming pregnant again or cooking.

"When I got fistula, my husband did not take care of me anymore. After the delivery, I had oedema all over my body; it is my mother who came to take care of me. When my husband realised that I was still leaking urine, he didn't look at me at all. It was my mother who was cooking feeding me." (Women treated for fistula, IDI, Labé).

Added to that was the anxiety of fistula recurrence that keeps some women isolated from usually normal activities (sexual intercourse, dance, expression of joy, etc.).

"My health is my main concern above all. Thank God I'm cured, I don't want to have sex anymore because I'm afraid for my disease to come back" (Women treated for fistula, IDI, Kissdougou).

Economically, stakeholders were concerned that returning within their communities will again expose women to the same determinants (poverty, weak health system, sociocultural barriers) that led to the formation of the previously repaired fistula given the level of household poverty. This poverty results in continuing financial barriers to accessing health care and lack of autonomy and decision making.

"You know, poverty is the main cause of this problem. When women returned into their families, because they are very poor, they cannot even take the initiative to come back to the hospital for check-up, they would tell you that they did not get the transportation fees. This makes their follow-up difficult and maintains them in poor health and at risk" (Manager, KII, N'Zerekore).

In the same vain, women treated for fistula pointed out to poverty for impeding them fron resorting to health services.

"Our parents and husbands are the one who are supposed to help us, but we are aware that they can't because of poverty. There are many hospitals but if they are paying and we do not

have what must be paid, here is the suffering" (Woman treated for fistula, IDI, Labé).

#### Sexuality and pregnancy after fistula repair

Despite most stakeholders agreeing that women can return to a normal sexual life after successful closure of fistula and that women of reproductive age have reproductive potential; many felt that the potential for pregnancy was reduced compared to women who have never suffered from fistula. In fact, Some parents believe that women treated for fistula should stop all sexual activity while extending the period of abstinence recommended by doctors.

"Because of the surgery and pain, they can no longer get pregnant like normal women as they have become 'half-persons'. They even have to avoid sexual intercourse and pregnancies to avoid a recurrence of the disease" (Female, Parent, IDI, Kissidougou).

The majority of parents and women interviewed perceived women treated for fistula to be "weak" compared to "normal" women, making them vulnerable to poor health. The reasons given for women's vulnerability included the physical (i.e., menopause, pain, fatigue, various scars, amenorrhea, hysterectomy), psychological (i.e., trauma, fear of recurrence) and social (i.e., prolonged social isolation, absence of a husband) sequelae of fistula.

"These women are already weakened by the disease before the surgery. They used to be isolated and could not eat and drink enough because of the urine leakage and stigma. After the surgery, they are tired and some have pain. You know, their health cannot be like before the surgery anymore" (Female, Community Member, FGD, Kissidougou).

Most participants thought that early resumption of sexual intercourse (i.e. before prescribed - after three months from surgery-) and home delivery or late (after labour has started) hospital delivery were the key risk factors of adverse health outcomes after women return to the community. Women complained that some husbands/partners are not supportive when it comes to recommended abstinence to allow for complete healing.

"The problem is that if for instance you undergo [fistula surgery], you recover, you get back home, your husband refuses to abstain until the required deadline, and you have nowhere to take *refuge.* '' (Woman treated for fistula, FGD, Labé).

Women's substantial fear of fistula recurrence creates psychological and physical blockage that health care workers call the "anxiety of recurrence". Women treated for fistula reported limiting certain behaviors to avoid fistula recurrence and the associated physical, mental and social consequences. The psychological domain of this blockage refers to deprivation (e.g.shouting, quarreling, not drinking water for fear of urine leakage), refusal to have sex, restrictions on certain activities such as walking, dancing and hard physical work (as prescribed), isolation and stigma experienced. The physical dimension is related to pain during sexual intercourse, fibrosis, amenorrhea and scarring.

"We have suffered too much; if God then has mercy on us to restore our health, we must avoid (sex), because this sex matter does not finish

(Woman treated for fistula, FGD, Kissidougou). The anxiety of recurrence leads health care workers to prescribe an extended period of sexual abstinence beyond what is recommended by evidence-based guidelines (i.e. three months), but women may also deliberately extend this period, as shown in the following quote:

"There is no sexual intercourse between my husband and I yet because I am complying with the three-month marital rest period prescribed at the hospital, which I personally decided to extend to six months" (Women treated for fistula, IDI, Kissidougou).

However, some health care workers doubt women's ability to abstain for the prescribed time due to illiteracy or their low decision-making power. In addition, while some men are concerned about their wives' health and are willing to support their reintegration, women expressed concern about husbands' bad behaviours that often lead to coercing early sex or abandoning them. Furthermore, some husbands believed that it was their right to marry another woman while waiting for their wife who underwent fistula surgery to recover fully. This attitude sometimes led women to ignore risks and resume sexual intercourse, become pregnant (social expectations) or take up pastoral work (social roles) in order to keep their homes (to avoid husbands' abandonment).

Therefore, Health care workers recommended that women treated for fistula rest in order to heal

**BOX 1:** Proposed content of interventions to improve the health of women after obstetric fistula repair

| 1. | Social support |  |
|----|----------------|--|
|----|----------------|--|

- Social immersion in a host family (eg. 3 weeks)
- Home visit to woman and her family
  - Hosting of woman around delivery or for treatment of specific health issue
- 2. Economic empowerment
  - Training of woman on income generating activity
  - Support and follow-up of woman over time to ensure she start an income generating activity
- 3. Medical follow-up
  - Training of health providers and facilities managers
    Health insurance subscription for woman (eg. one
  - Regular home visit to woman and counseling for
  - Regular nome visit to woman and counseling for both woman and partner
  - Awareness raising about post-repair health challenges fwith family during home visits.

entirely before resuming sex or considering becoming pregnant to prevent recurrence; however, the length of abstinence varied across respondent type, ranging from three months to three years after repair.

"After fistula repair, we recommend women to rest well by abstaining from sexual intercourse and physical efforts during at least 3 months. We also tell them to come back for post-discharge follow-up after the first three months..." (Provider, IDI, Kissidougou).

Women who had already had surgery made it clear that sexual intercourse or pregnancy should only be considered six months after repair, with some even suggesting two years abstinence.

# Interventions to improve women health after fistula repair

Improving the reproductive and social lives of women following fistula repair has to be integrative, and oriented using a human rights framework. Key Guinean stakeholders agreed with this perspective, with most respondents sharing that this represents a multifaceted problem requiring a multidisciplinary approach involving a broad variety of stakeholders e.g., (providers, managers, women and their families, policy makers, local health insurance and micro-credit companies).

"If there is good coordination, each stakeholder can take care of a given component of fistula care. This brings synergy and complementarity instead of duplication and competition." (NGO Representative, KII, Conakry). Overall, stakeholders emphasised the need for interventions can reduce women's that "vulnerability" after fistula repair. These interventions should focus on restoring women's physical, socio-emotional and economic strengths to make them "normal" women again. Policymakers suggested that these interventions be integrated into existing fistula prevention and management programs.

"To improve their health, health providers in nearby health centers and community health workers should be involved in the followed-up of these women within their communities. Through home visits, they can advise women and their parents on what to do to avoid recurrence" (Health Manager, KII, Labé).

Women treated for fistula recommended counselling prior to hospital discharge on when and how to have sex, as well as how to manage pregnancy and childbirth after fistula repair.

"Before we leave the hospital, doctors can tell us the period we must abstain from sex, and what we must do if we are pregnant. If we know that, we will follow their advice because we know what we have been through with this disease" (Women treated for fistula, IDI, Kissidougou).

HCWs further specified that this advice should also include the following content: scheduling follow-up visits for women at three months following surgery, family planning counseling and provision to assist women in avoiding early pregnancies (including contraception free of cost starting at six months posthospital discharge), personal hygiene, compliance with recommendations on sexual abstinence and physical rest, regular antenatal care for subsequent pregnancy and elective c-section. They also recommend that psychological counselling be provided to women after fistula repair

"These women, as well as their partners and parents, should receive counselling regarding their follow-up, personal hygiene, sex and family planning, and the management of potential future pregnancies. Their family members should know that they must support these women" (Midwife, FGD, Kissidougou).

Providers also cited the social immersion program (a program that assigns the woman after fistula repair for three weeks to a trained volunteer host family to help her gradually resume social roles before her return home) as a mean to mitigate socio-emotional

vulnerability and restore self-confidence and self-esteem.

"After the intervention, once the woman is cured, it is good to send her to a family for a few days before she returns home." (Midwife, FGD, Labé).

One community member suggested the implementation of community-based medical follow-up, whereby HCWs or Community Health Workers (CHWs) working near the woman's residence would schedule regular home visits as part of their usual outreach activities.

"In or near the villages, there are health centers, and doctors working there can visit these women when they go out for awareness and vaccination; this can allow them to know about their health after surgery. Even community health workers in the villages cans also help for the follow-up" (Female, Community Member, FGD, Labé).

Some managers advised subscribing women to local health insurance scheme.

"It is important to enrol women in a health assurance scheme because most often, we have problems with referrals. Here, the delay in seeking care is the root cause of maternal and neonatal mortality and obstetric fistula. If the health insurances are strengthened, referrals and transportation of women will be done timely." (Health Manager, IDI, Kissidougou).

Stakeholders also mentioned the need to involve women's families, including parents and partners.

"In some families, it is the parents or the husband who decides, so they must be involved to keep the woman in good health. Most of the time, they must accept for the woman to do anything, including seeking health." (Health Manager, KII, N'Zerekore).

To complement this, women treated for fistula and their families suggested home visits or even phone calls to maintain contact with the repair hospitals and be able to seek advice when it is needed.

"Health care providers should maintain phone contact with women to encourage them to present themselves or to call the hospital if they have health concerns." (Male, Parent, IDI, Kankan).

To address the economic vulnerability, most respondents suggested economic empowerment activities to improve women's contribution to health care decision making, increase their value in the home and address any medical or other social issues. To this end, facility managers and representatives of fistula management NGOs suggested training on income generating activities to make them autonomous and reinforce their decision-making power.

"These women are often deprived. That is why, after the operation, it is necessary to help them economically by teaching them to set up incomegenerating activities such as saponification, either individually or in groups." (NGO Representative, KII, Kankan).

Providers requested that economic empowerment activities be conducted by local micro-finance organizations that already are active in rural Guinea. However, most participants recommended not to provide direct money to women but instead support them over time. The reason was that cash money will not be used for the purpose it was given for but instead women tend to give back the money to their families in an effort to gain their esteem and break the pity paradigm built around them.

## Discussion

The findings of this study revealed that women who underwent fistula surgery are perceived by themselves and by other stakeholders as vulnerable and in need of health care engagement and social services to avoid adverse health outcomes during the post-repair period such as mental health disorders, fistula recurrence, spontaneous abortion, stillbirth or maternal death.

classification stakeholders' Our of perceptions of women's vulnerability after fistula repair into three dimensions (physical, socioemotional and economic) is consistent with the existing literature on the breadth of post-repair concerns<sup>27</sup>. Holistic programming is important to address physical health issues including post-repair fistula recurrence, persistent incontinence and unsuccessful surgery<sup>18,28</sup>, maternal and child morbidity and mortality<sup>15,29</sup>, and poor sexual health<sup>12,30,31</sup>: socio-emotional vulnerabilities including social stigma, mental health (e.g., depression, anxiety and post-traumatic stress disorder)<sup>32</sup>, and economic insecurity<sup>33</sup>. Holistic programming is also likely to address the complex relationships between the physical, psychosocial, and economic risks. For example, supporting women to reduce economic vulnerability has the potential to

reduce the extreme poverty which leads women to resume farming and other heavy labour that in turn carries a high risk of adverse physical health<sup>34</sup>. Helping women to develop new opportunities for resuming work and gaining economic autonomy is extremely important for restoring dignity<sup>34,35</sup>. Reducing social and economic vulnerabilities will preserve their physical health and reduce the likelihood of fistula recurrence which will protect them from entering into a negative spiral of physical, psychosocial, and economic adversity<sup>17,34</sup>.

The occurrence of fistula in a woman represents a social injustice and is a barometer of health system performance and sexual and reproductive health rights<sup>7,36</sup>. Thus, ensuring treated women are not exposed to the same determinants that led to the occurrence of the first fistula is paramount, including distal factors. As highlighted by our key local informants, the importance of women's social and economic reintegration, and existing interventions have been shown to improve women's physical, mental and reproductive health after fistula repair<sup>37</sup>. However, few current fistula management programmes in Guinea provide support to women after hospital discharge and social immersion in host families<sup>12,23,29</sup>. Services currently offered are facility-based, limited in time, and not sustained once the woman leaves the repair hospital. Interventions such as sexual and reproductive health counselling at discharge, psychological counselling, skill empowerment, literacy classes or support groups are not systematic in Guinea where activities are delivered at the fistula camp and the woman asked to come back for an evaluation at 3-month post fistula repair at her own expense<sup>12,29,38</sup>. In Guinea, physical therapy is part of the routine care provided to women in repair hospitals; however, it is similarly limited by the lack of community-based delivery.

Within the array of services offered to women with fistula, much less attention has been paid to persistent or incident adverse health conditions after repair<sup>39,40</sup>. Findings from the current study and others on this area support the need for an intervention that goes beyond repair and hospital stay to address challenges such as family and community perceptions or behaviours, geographical barriers, transportation costs, and the absence of supportive priorities or resources in many fistula programmes<sup>41,42</sup>. An example of intervention tailored to the context and informed by the existing literature could include medical follow-up, socioemotional support and economic empowerment. However, the implementation modalities and how to integrate these into routine maternal and neonatal health are need to be well explored.<sup>8</sup> Also

health care need to be well explored<sup>18</sup>. Also, anticipated logistical challenges (e.g., geographical dispersion of women living with fistula) and the need to involve multiple actors including the health system, community and private sector (local insurance and micro-credit companies) should be considered. Formative research to evaluate acceptability and feasibility of such intervention would need to be conducted.

## **Ethical considerations**

This study protocol was approved by the Institutional Review Board of the Institute of Tropical Medicine of Antwerp, Belgium (IRB# 968/14), and the National Ethics Committee for Health Research of Guinea (Ref# 22/CNERS/14).

## Strengths and limitations of the study

Our study represents the viewpoints of the diverse group of stakeholders involved in fistula care management in Guinea, ranging from government, clinical,d social care providers to community members including most importantly women living with fistula. Considering their expert involvement in this process, and representation across the variety of relevant stakeholders, these viewpoints could be regarded as a reliable source of priorities for improving fistula management in the country. While the qualitative orientation of our study is a strength for obtaining nuanced perspectives, the findings must be considered in light of the general limitations of qualitative methods. Furthermore, information bias may be present in this type of study where stakeholders (especially community members and government officers) may overemphasize negative impacts for financial gain.

## Conclusion

Current obstetric fistula management in Guinea mainly focuses on the surgical treatment of women. In the perspectives of stakeholders involved in fistula care, surgical treatment is insufficient for overcoming the broad challenges inherent in living with obstetric fistula. Therefore, it is essential to consider holistic management strategies that address

the socio-emotional, physical and economic vulnerability of women treated for fistula. This includes short and long-term strategies and interventions to facilitate their social reintegration and result in their well-being.

## **Competing interests**

The authors declare no competing interests.

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## Authors' contribution

AD, TD and VDB initiated the study and developed the study protocol. All authors approved the study protocol. AD, MD, ADi collected the data. AD, MD and AME conducted the analysis and developed the draft manuscript. ADi, TD and VDB critically reviewed the manuscript. All authors read and then approved the final manuscript.

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