

Improving Quality of Life for Women with Incurable Fistula: A Fistula Care *Plus* and TERREWODE Research Partnership in Uganda

WHAT IS FISTULA?

A genital fistula is an abnormal opening in the upper or lower female genital tract that causes uncontrollable, constant leakage of urine and/or feces. Obstetric fistula is usually caused by several days of obstructed labor without timely medical intervention. Iatrogenic fistula is caused by surgical error, most often during cesarean section. Traumatic fistula is caused by injury—for instance, through sexual violence, female genital mutilation, or accidents.

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BACKGROUND

Fistula and Social Reintegration

In addition to its health consequences, female genital fistula often results in intense social exclusion, with women reporting negative changes in their relationships and in community participation (Meurice 2017, Muleta 2008, Wall 2002). Many women with obstetric fistula also suffer from having lost their baby during the delivery that led to the condition. Together, these factors contribute to associations between fistula and trauma, depression, low self-esteem, stress, loss of libido, and suicidal ideation (Ahmed 2007, Goh 2005). Many fistula repair programs recognize the importance of social reintegration services in helping women to return to their families and communities after repair or to establish new lives elsewhere. Social reintegration addresses the comprehensive needs of fistula clients and supports them in being accepted as full members of their communities (Ahmed 2007, Paul 2010). Program and research literature have described models for social reintegration after fistula repair (Fistula Care 2011, Mselle 2012, Young-Lin 2015).

Incurable Fistula

For some women, fistula repair may not be possible; this may be the case if either the injury is too complex, accessible surgeons lack necessary skills, there are limited options for referral, and/or past repair attempts have failed (TERREWODE 2015, Fistula Care 2012). Social reintegration efforts must respond to different challenges for women with incurable fistula, as the factors that caused them to become socially excluded persist and are likely to be lifelong.

Fistula in Uganda

The 2016 Uganda Demographic and Health Survey found that 1.4% of Ugandan women report having ever experienced fistula-like symptoms (UBOS and ICF 2018). In 2011, the Ugandan Ministry of Health estimated that 200,000 women were living with obstetric fistula and fewer than 3% had sought care (UMOH Fistula Strategy 2011). Women living with fistula in Uganda face the challenges described above, including profound effects on marital and familial relationships, broader social isolation, and negative psychological impacts (Barageine 2015a, Barageine 2015b, Krause 2014).

Surgical treatment sites in Uganda report very high success rates. However, there are women who can access care but whose fistula is incurable in the local context. In Uganda, the term “women with incurable fistula” has been selected by the National Fistula Working Group as the most appropriate term for this group. The Working Group has proposed a definition of incurable



fistula: “Cases of fistula in which restoration of functional anatomy to achieve urinary or fecal continence is not possible through surgery by the most skilled surgical team working in an enabling environment.” National statistics on women with incurable fistula are unavailable and the latest Ugandan National Obstetric Fistula Strategy (2011/2012–2015/2016), does not address incurable fistula.

FISTULA CARE PLUS AND TERREWODE RESEARCH PARTNERSHIP

There is virtually no literature regarding the experiences and social reintegration needs of women with incurable fistula or the interventions that are effective in supporting them. EngenderHealth’s *Fistula Care Plus* (FC+) project partnered with a Ugandan organization, the Association for the Rehabilitation and Re-orientation of Women for Development (TERREWODE), to conduct research on the social reintegration needs of these women and evaluate the effects of interventions responding to these needs. The aims of this study were to document the sociodemographic profile and clinical history of women with incurable fistula in Uganda, identify their social reintegration needs, assess their

quality of life before and after receiving social reintegration services, identify priority interventions that optimize quality of life, and identify contextual factors that affect reintegration for women with incurable fistula. The Research Ethics Committee at Makerere University School of Medicine reviewed and approved this study.

EngenderHealth and TERREWODE conducted this study in the Buganda, Bunyoro, Busoga, Lango, and Teso subregions of Uganda. The study consulted fistula surgeons as well as fistula support groups in the study areas to identify potential women with incurable fistula. The study referred identified women to Mulago National Referral Hospital and Soroti Regional Referral Hospital for expert surgeons to assess and confirm their status. Women confirmed to have incurable fistula were invited to participate in the study. The study team administered a structured questionnaire to participants, documenting sociodemographic characteristics; fistula history; reproductive health status; psychosocial and economic status; and needs related to hygiene, nutrition, and sanitation. The study used three validated tools to assess well-being and quality of life at enrollment (Kelleher 1997, Skevington 2004, WHO 2008). See Table 1 for a description of these measures.

The TERREWODE Social Reintegration Package

The underlying principle of the TERREWODE model is that the aim of social reintegration is to restore a fistula survivor to a status of dignity and self-esteem where she can actively participate in community affairs and experience improved quality of life. TERREWODE has served more than 3,000 women successfully treated for fistula and more than 150 women with incurable fistula in Uganda, providing services such as education on fistula, personal hygiene, nutrition, sanitation, and family planning; psychosocial counseling and support; entrepreneurial and vocational skills development, including financial literacy; and empowerment through education on gender, governance, and human rights. TERREWODE also uses the sister-friend approach, which pairs women with supportive mentors, usually members of the Obstetric Fistula Awareness and Advocacy Network, which is a component of the Ministry of Health’s Village Health Teams. Sister-Friends provide community health education and mentorship support, assess survivors’ individualized needs, and provide relevant referrals and linkages to community services.

Each woman with incurable fistula enrolled in the study received the TERREWODE package of individualized social reintegration services, adjusted to reflect participants’ interests and the services available in each community. The package included:

- Training in legal rights; access to entrepreneurship, justice, and poverty alleviation programs; group formation and management support; and linkages to savings and credit schemes
- Vocational training in income generating skills of interest to the participants, specifically tailoring, produce sales, industrial design and crafts, and soap making
- Exposure visits to model farms to connect with rural female entrepreneurs and gain knowledge on modern farming as a sustainable source of income
- Comprehensive health education
- Pairing with a sister-friend in her community
- Linkages to community-based income generation, savings, and/or credit groups
- Ongoing psychosocial counseling (initially through a trained TERREWODE counselor and subsequently through a sister-friend at the community level)
- Support for accommodations, food, and other expenses during the training period



Table 1: Wellbeing and Quality of Life Measures

| Tool | Description |
|--|---|
| Self-Reporting Questionnaire (SRQ-20) | 20 yes/no questions assessing levels of general distress, summed to generate a score ranging from 0 to 20. Higher scores indicate higher levels of distress. A score of 8 or greater is the conventional cutoff point for distress. |
| World Health Organization Quality of Life (WHOQOL)-BREF | <ul style="list-style-type: none"> Two stand-alone questions related to overall quality of life and health satisfaction, answered on a five-point Likert scale. Higher scores denote higher quality of life or satisfaction. Questions on four quality of life domains: physical health, psychological health, social relationships, and environment. Domain scores are scaled from 0 to 100, with higher scores indicating higher quality of life. |
| Modified King’s Health Questionnaire | <ul style="list-style-type: none"> Two stand-alone Likert-scale questions, with responses transformed to a 0 to 100 scale. Lower scores indicate higher quality of life. Questions on seven domains: role limitations, physical health, social limitations, personal relationships, emotions, sleep/energy, and severity measures. Domain scores are scaled from 0 to 100, with lower scores denoting higher quality of life. <p><i>Note: the study team modified questions to focus specifically on fistula.</i></p> |

After completing the intake assessment, participants received a package of services based on the TERREWODE reintegration and support model, described below. Program materials were reviewed by the FC+ research team to verify service provision. Following the social reintegration program, the study team administered the three wellness/ quality of life tools again, along with a structured questionnaire to document requested and received reintegration services, and their perceived effects and value.

RESULTS

Participant Characteristics

Thirty women with incurable fistula enrolled in the study. Table 2 provides a summary of client characteristics. The mean age of participants was 35.1 years and more than half had lived with fistula for more than a decade. Almost all women believed that their fistula was obstetric in cause. Of these women, only one-quarter delivered their baby at home

Table 2: Participant Characteristics (n=30)

| Characteristic | Mean | Median (Range) |
|---|--------|----------------|
| Age | 35.1 | 12.0 (17-61) |
| Characteristic | Number | Percent |
| Educational attainment | | |
| None | 19 | 63.3% |
| Primary Level | 9 | 30.0% |
| Diploma | 1 | 3.3% |
| Missing | 1 | 3.3% |
| Relationship status | | |
| Single (never married) | 7 | 23.3% |
| Cohabiting (never married) | 1 | 3.3% |
| Married | 11 | 36.7% |
| Separated | 10 | 33.3% |
| Missing | 1 | 3.3% |
| Duration of fistula symptoms | | |
| 1–5 years | 7 | 23.3% |
| 6–10 years | 6 | 20.0% |
| 11–15 years | 7 | 23.3% |
| >15 years | 10 | 33.3% |
| Self-reported cause of fistula | | |
| Childbirth/delivery (obstetric) | 28 | 93% |
| Medical procedure (iatrogenic) | 1 | 3% |
| Congenital | 1 | 3% |
| Delivery location (among those reporting obstetric cause) (n=28) | | |
| Home | 7 | 25% |
| Health center II/III | 2 | 7% |
| Health center IV or district hospital | 9 | 32% |
| Regional/referral hospital | 10 | 36% |

Table 2 continued on next page



and nearly half reported having delivered via cesarean section. Two-thirds of the women had no formal schooling; nearly all of the remainder had completed primary-level education. More than one-third of the participants were married and one-third were separated. The majority, across current marital status categories, described negative changes in their intimate partner relationships due to fistula, including disrespectful treatment, infidelity, and violence. Nearly all participants were unemployed and half reported needing to borrow money or use savings in the past month to cover living costs.

Intervention Experience

Of the 30 enrolled participants, 27 (90%) completed the full intervention package and completed the endline questionnaires. Table 3 provides results for these 27 participants. Participants used all the of the intervention components offered, with the exceptions of community solidarity groups (used by 24), couples counseling (used by 7), family counseling (used by 11), and group counseling (used by 26). Participants reported finding most intervention components somewhat or very useful/helpful. Participants found the skills training, individual counseling, and group counseling to be the most useful/helpful intervention components.

Participants were also asked to identify specific individualized services and support they requested from TERREWODE, and report whether they received these services. Participants requested a wide variety of support services, most commonly financial, vocational, or entrepreneurial skills; counseling; health, nutrition, hygiene/sanitation, or fistula education; legal education, information, and aid; financial and material support (e.g., for sanitary products); information about additional medical treatment options (e.g., urinary diversion); support to begin/resume education; and business start-up capital. A few participants requested information about domestic violence, infertility, and obtaining their own land or a safe home.

All participants reported that most of their requested support needs were met. Of the 26 participants who reported

Table 2: Participant Characteristics (n=30) (continued from previous page)

| Characteristic | Number | Percent |
|---|--------|---------|
| Mode of delivery (among those reporting obstetric cause)(n=28) | | |
| Normal vaginal delivery | 6 | 21.4% |
| Assisted/operative vaginal delivery | 9 | 32.1% |
| Caesarean section | 13 | 46.4% |
| Missing | 2 | 7.1% |
| Delivery outcome (among those reporting obstetric cause) (n=28) | | |
| Stillbirth | 21 | 75% |
| Newborn who died | 2 | 7% |
| Newborn who survived | 5 | 18% |
| Employment status | | |
| Employed by nonfamily member | 1 | 3.3% |
| Unemployed | 29 | 96.7% |
| Has fistula affected ability to work? | | |
| Yes | 30 | 100.0% |
| No | 0 | 0.0% |
| Borrowed money or using savings in the past month to cover household costs | | |
| Yes | 14 | 47% |
| No | 16 | 53% |

that at least one need was not met, the vast majority (81%) identified start-up capital for businesses as their unmet need. Other unaddressed needs that were reported by only one to two participants included: a complete cure for fistula, infertility/childlessness support, family counseling, financial resources, land resources, a lawyer, medical treatment (e.g., heart treatment or uterine transplant), a safe home, and schooling. When asked how the intervention could be improved, participants identified several recommendations:

- Increased time for vocational training, so that skills can be practiced and fully acquired
- Support for start-up materials (e.g., sewing machines) to enable implementation of vocational skills
- Support in fundraising for income generation and other projects
- Home visits to demonstrate the application of hygiene/sanitation, self-care, and other skills (e.g., pit latrine maintenance)
- Access to material goods to support self-care for incurable fistula (e.g., adult diapers, detergents, and sanitary materials)
- More information on healthy sexual relations despite fistula

Additionally, 10 participants identified physiotherapy/physical education as an important service need that should be part of the reintegration service package.



Table 3: Participant Assessment of Reintegration Interventions (n=27, except as noted)

| Intervention Component | Participant Rating | Number | Percent |
|------------------------------------|-------------------------|--------|---------|
| Skills training | Not useful/helpful | 0 | 0.0% |
| | Somewhat useful/helpful | 225 | 7.4% |
| | Very useful/helpful | | 92.6% |
| Model farm exposure visits | Not useful/helpful | 0 | 0.0% |
| | Somewhat useful/helpful | 7 | 25.9% |
| | Very useful/helpful | 20 | 74.1% |
| Community solidarity group support | Not useful/helpful | 3 | 11.11% |
| | Somewhat useful/helpful | 6 | 22.2% |
| | Very useful/helpful | 15 | 55.6% |
| | N/A or did not receive | 3 | 11.1% |
| Sister-Friend support | Not useful/helpful | 1 | 3.7% |
| | Somewhat useful/helpful | 10 | 37.0% |
| | Very useful/helpful | 16 | 59.3% |
| Individual counseling | Not useful/helpful | 0 | 0.0% |
| | Somewhat useful/helpful | 1 | 3.7% |
| | Very useful/helpful | 26 | 96.3% |
| Couples counseling (n=7) | Not useful/helpful | 0 | 0.0% |
| | Somewhat useful/helpful | 2 | 28.6% |
| | Very useful/helpful | 5 | 71.4% |
| Family counseling (n=11) | Not useful/helpful | 0 | 0.0% |
| | Somewhat useful/helpful | 5 | 45.5% |
| | Very useful/helpful | 6 | 54.5% |
| Group counseling (n=26) | Not useful/helpful | 0 | 0.0% |
| | Somewhat useful/helpful | 3 | 11.5% |
| | Very useful/helpful | 23 | 88.5% |

Quality of Life

Participants reported significant improvements in well-being and quality of life after participation in the TERREWODE intervention, as assessed by the three study tools. See Table 4.

Before the intervention, all participants had SRQ-20 scores over eight, indicating that all were psychologically distressed. After the intervention, 11 participants (41%) had scores below eight, a significant reduction in proportion of psychologically distressed participants ($p=0.0003$). The mean total score reduced significantly after participation in the intervention ($p<0.0001$). Five individual SRQ-20 items did not change significantly after the intervention ($p>.05$):

- Q 4: Are you easily frightened?
- Q 8: Do you have trouble thinking clearly?
- Q12: Do you find it difficult to make decisions?
- Q17: Has the thought of ending your life been on your mind?
- Q20: Are you easily tired?

As measured by the WHOQOL-BREF, participants' mean score on overall quality of life significantly improved after the intervention ($0.7, p=0.0001$). Participants' mean score on health satisfaction also significantly improved after the intervention ($1.3, p<0.0001$). For each domain, participants' mean scores increased significantly ($p<0.001$) after the intervention. The physical health domain showed the largest increase in mean score. See Figure 1.

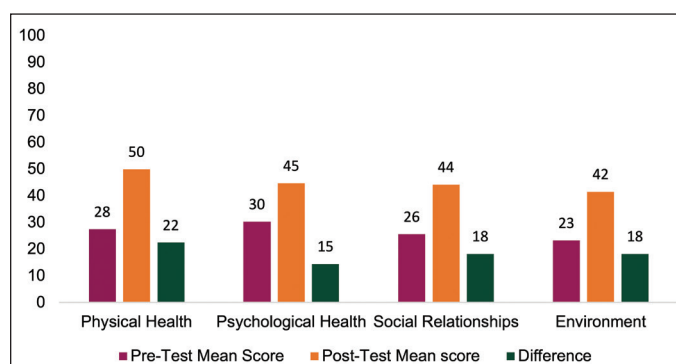


Figure 1: Improvements in Quality of Life Scores after the Intervention, per WHOQOL-BREF

Table 4: Improvement in Wellness and Quality of Life Scores after the Intervention

| | Pre-Intervention | | Post-Intervention | | Mean Difference | P value* |
|---|------------------|---------|-------------------|--------|-----------------|----------|
| | Mean | Range | Mean | Range | | |
| SRQ-20 | | | | | | |
| Overall score | 16 | 12-20 | 9 | 4-15 | 7.1 | <0.0001 |
| WHO-BREF | | | | | | |
| How would you rate your quality of life? | 2.0 | 1-3 | 2.7 | 2-4 | -0.7 | 0.001 |
| How satisfied are you with your health? | 1.7 | 1-3 | 2.9 | 2-4 | -1.2 | <0.0001 |
| Modified King's Health Questionnaire | | | | | | |
| How would you describe your health at the present? | 77.8 | 50-100 | 56.5 | 25-75 | 21.3 | <0.0001 |
| How much do you think your fistula condition affects your life? | 100 | 100-100 | 88.9 | 67-100 | 11.1 | 0.0013 |

*Significance was assessed with a threshold of p=0.05

On the modified King's Health Questionnaire, lower scores indicate better quality of life and/or reduced negative impacts of fistula. As measured by this tool, participants' mean score on overall health perception significantly improved after the intervention (-22.5, p<0.001). Participants' mean score on effects of fistula also significantly improved (-12.2, p<0.0001). For each domain, participants' mean scores improved significantly after the intervention (p<0.01). The largest differences in scores were within the social limitations (-42) and physical (-35) domains, with the severity measures domain having the least improvement (-25). See Figure 2.

PROGRAM IMPLICATIONS

Participants valued most components of the TERREWODE intervention and felt that many of their self-identified needs for support were addressed.

Additionally, improved scores across standardized instruments to assess wellness and quality of life indicate that the TERREWODE intervention yielded significant positive changes in participants' perception of and satisfaction with their health, psychosocial status, and the impact of their fistula condition on quality of life.

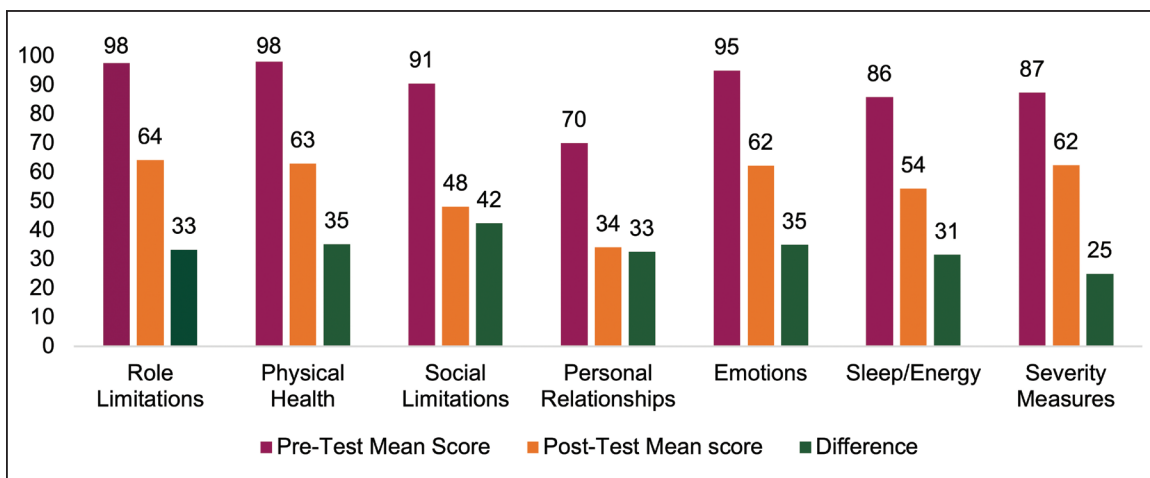


Figure 2: Improvements in Quality of Life Scores after the Intervention, per Modified King's Health Questionnaire

However, the inability of the intervention to provide capital or financial support or to address other broad needs (e.g., for advanced medical care, infertility treatment, and land or housing) meant that participants faced substantial challenges in achieving long-term financial independence and other personal goals. Participants also noted specific ways to strengthen the trainings and identified physiotherapy as an additional support service that would greatly benefit women with incurable fistula.

Use of standardized measures across settings will enable the comparison of the effectiveness of interventions across programs and populations. The burden of administering multiple tools to assess wellness and quality of life may be inappropriate in routine, non-research settings. **We recommend using the WHOQOL-BREF to assess program effectiveness because it appears to capture more variation in this population than other tools, avoids ceiling and floor effects, assesses multiple domains of quality of life, and has been validated among Sub-Saharan African populations.**

Policy Recommendations

In Uganda, the Ministry of Health's leadership in strategic dissemination will enable replication of the promising practices demonstrated through this study. Specific strategies may include:

- Advocacy to the Parliamentary Committee on Health to allocate resources from the national budget to support care for women with incurable fistula, including attention to physiotherapy
- Access for women with incurable fistula to Uganda's Social Assistance Grants for Empowerment scheme, which currently benefits the elderly primarily
- Engagement of line ministries—including the Ministry of Gender, Labour, and Social Development; the Ministry of Education and Sports; and the Ministry of Agriculture, Animal Industry, and Fisheries Agriculture—as well as local government authorities and community organizations to support services for women with incurable fistula
- Monitoring and reporting of incurable fistula diagnoses through the national Health Management Information System
- Incorporation of guidance regarding diagnosis of and services for women with incurable fistula into subsequent national fistula strategies and other relevant policy documents

As interventions for women with incurable fistula are expanded, it is important to maintain high standards and adherence to guidelines for diagnosis so that women are not

erroneously classified with this condition. It is important to note that this study focused on social reintegration for women with incurable fistula. There are also clinical interventions, notably surgical urinary diversion, that may be appropriate and useful for some women with incurable fistula. The program and policy recommendations in this brief do not preclude capacity building and support for such surgical alternatives.

CONCLUSION

While many practical effects of incurable fistula cannot be eliminated, individualized and multifaceted interventions can significantly mitigate the impact of this condition on women's quality of life. Such interventions may be useful in other settings with a fistula burden, and should be expanded in partnership with fistula repair sites and programs.

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The USAID-funded, EngenderHealth-led Fistula Care Plus project works to prevent fistula from occurring, treats and cares for women with fistula, and assists in the rehabilitation and reintegration of women with fistula. Fistula Care Plus partners with ministries of health, faith- and community-based organizations, nongovernmental organizations, United Nations agencies, and other stakeholders, including facilities providing surgical and nonsurgical fistula repair in South Asia and Sub-Saharan Africa. For more information about fistula and the Fistula Care Plus project, visit www.fistulacare.org.

TERREWODE is an organization based in Eastern Uganda that is pioneering best practices for the elimination of obstetric fistula. For more information, visit <http://terrewode.com/>.

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