

The Power of Data: Preventing Depression in Women Recovering From Fistula Repair Surgery

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What is Obstetric Fistula?

- A serious obstetric complication, typically the result of prolonged obstructed labor, that leaves women unable to control bodily wastes
- Nonexistent in the industrialized world
- Most common among low-income women in the developing world who have no access to medical care during childbirth
- A treatable condition...medically

What is the Magnitude of this Problem?

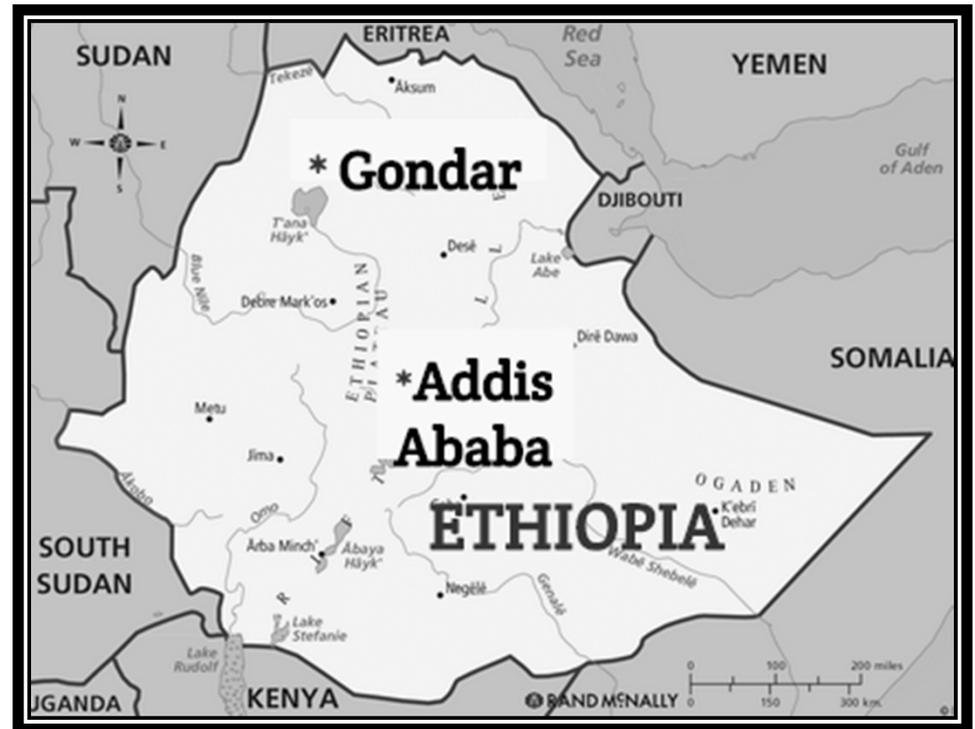
- About 50,000-100,000 women develop obstetric fistula each year.
- Across the globe, 2-3.5 million women suffer from obstetric fistula.
- The woman's baby is unlikely to survive.
- Over 70% of women with obstetric fistula have no living children.

The Literature on Obstetric Fistula

- Women with fistula cannot fulfill their societal roles, often deserted by husbands and family members. (Ahmed & Holtz, 2007)
- Depression and symptoms of PTSD are common. (Goh et al., 2005; Wilson et al., 2015)
- Even after successful treatment, women struggle to rejoin their communities. (Muleta et al., 2008)
- Worldwide, efforts to address this issue focus on its physical and not psychological consequences. (Weston et al., 2011)

Ethiopia

- Population: **96,633,458**
- Average births per woman: **5.23**
- Physicians per 10,000 people: **0.3**
- Female life expectancy: **63.15 years**
- Female literacy: **28.9%**
- Population living in poverty: **39%**



Fistula Foundation. (2014). *Fistula Foundation*. Retrieved from <https://www.fistulafoundation.org/countries-we-help/ethiopia/>

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Women in Ethiopia

Marriage

- Marriages arranged, women typically meet husband at wedding.
- Legal marriageable age is 18, but average age of women when married is 15.
- Husband is legal head of family.

Motherhood

- Women are expected to have children immediately after marriage.
- Childless women are stigmatized.
- Skilled medical attendants are present for only 6% of births.
- Infant mortality rate: 110 deaths/1,000 live births
- Maternal mortality rate: 860 deaths/100,000 live births (one of the highest in the world)
- Contraceptives are taboo (only 8% of women use them)

Education

- A large percentage of girls are not enrolled in primary school, and many drop out after primary school.

Ethiopia Women In Culture, Business and Travel. (2010). Petaluma: World Trade Press.

Project Goals

To develop and pilot-test a depression prevention program for women recovering from fistula repair surgery, that is:

- Adapted from existing evidence-based programs
- Able to be integrated into the existing healthcare system
- Acceptable to stakeholders and women with fistula
- Culturally relevant and accessible
- Safe
- Developed in collaboration with local partners, that will benefit local partners

The Importance of Collaborators

- The Fistula Foundation
- Women and Health Alliance International
- Experts from other disciplines (OBGYN, Anthropology)
- Co-Principal Investigators:
 - **Tracy Gladstone, PhD**
 - Wellesley Centers for Women
 - **Mulu Muleta, MD, PhD**
 - Country Director, WAHA Ethiopia



Research Plan: Use Data to Guide Intervention Development

- Stage 1:
 - Conduct qualitative interviews with stakeholders
- Stage 2:
 - Conduct qualitative interviews with fistula patients
- Stage 3:
 - Intervention development, training and implementation, evaluation

Stage 1: Stakeholders' Interview Themes

- Hospital Procedures
- Attitudes Toward Mental Health
- Mental Health Needs of Women with Fistula
- Expectations of Women with Fistula
- Would Mental Health Intervention be Acceptable?

Stakeholders' Words

- “The prevalence of depression and anxiety is high in fistula clinics...these women are isolated for long periods of time.”
- “We need a mental expert here. These women need emotional support even more than the physical.”
- “We want to talk to them, but don’t know how...We feel like this is the part we do not give. We focus on the medical care and not the mental status...we really, really need this.”
- “Nurses have clinical skills but they don’t have basic knowledge and skills of how to handle the mental issues of these mothers. They will be very happy if they have formal training.”
- “They have such an eagerness to be educated, especially if it means they will have a better life.”

Stage 2: Women's Interview Themes

- Knowledge about Fistula
- Social Support
- Coping
- Expectations for Surgery
- Interest in Treatment

Women's Words

- **Women talk about coping skills.**

When I am sad or feeling down “I do nothing, other than worry”

“The advice my family gives me is helpful too. They tell me to pray”

“When I’m sad I just sleep”

“When I feel anxious I talk to my friends...They say ayzosh, and that everything will be alright.”

- **Women have family support but have lost their husbands.**

“He did wait a year for me to get better...he left... abandoned me for another woman... that gave him a child”

“He hasn’t asked about me at all, he hasn’t come to see me since I have been here”

- **Women are interested in intervention.**

“I am interested in learning ways to decrease my worries.”

“I would like to learn how to prevent depression and sadness.”

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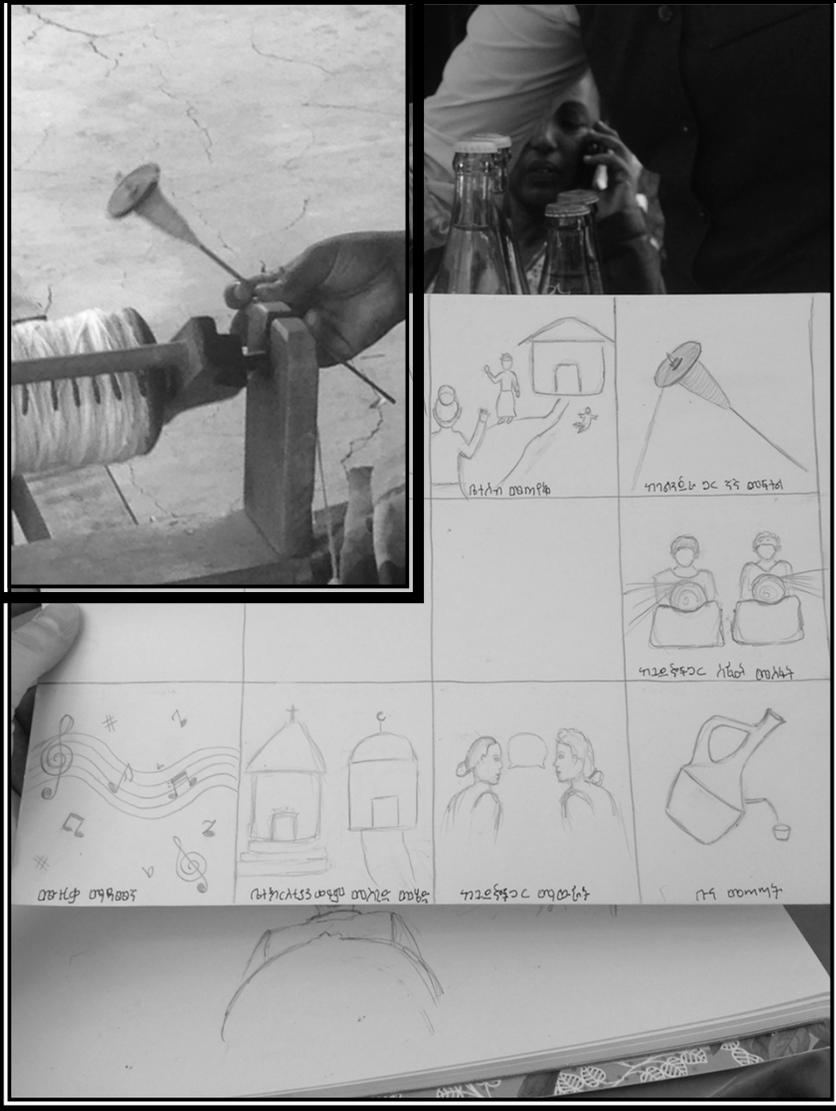
Stage 3: Intervention Sources

- Evidence-based depression interventions:
Coping with Depression, CATCH-IT, Common Elements Treatment Approach
- Qualitative data from stakeholders and women with fistula
 - * Importance of religion and social support
 - * Nurses as group leaders
- Literature review
- Consultation with collaborators in Ethiopia and US

Behavioral Activation: Activities

First Attempt:

1. Baskets looked like the baskets in which they serve food, and not the kind they would weave.
2. Omit picture suggesting food preparation, because that would not be fun.
3. Basket-making had to be social, with a friend and not a solitary activity.
4. Instead of a picture of a religious symbol, we needed our picture to show the church building because the act of physically going is so important, and because many people stand outside of the church building.
5. Corrected picture of spinning (visited women's collective)



Pilot Study

- Trained 5 nurses to lead groups
- Women in the hospital were invited to participate and compensated for travel
- Groups were generally conducted in the evenings when nurses were done with ward duties
- Nurses were supervised via Skype 2-3 times/week

Standard Measures

- **Self-Reporting Questionnaire (SRQ-20)**
 - Developed by World Health Organization
 - Assesses depression, anxiety, somatic symptoms in low-middle income countries
 - 20 items, scores 0-20, scores ≥ 7 suggest significant depression
 - Already translated into Amharic, and used successfully in Ethiopia
- **Harvard Trauma Questionnaire (HTQ)**
 - Developed by Harvard Program in Refugee Trauma
 - Assesses symptoms associated with trauma and Post-Traumatic Stress Disorder
 - 25 items, scores 1-4, scores > 2 suggest significant symptoms of trauma; ≥ 2.5 suggest PTSD
 - Already translated into Amharic, and used successfully in Ethiopia

Additional Measures

- **Group Leader Forms**
 - Fidelity to intervention
 - Session ratings - members' understanding, engagement, overall session rating
 - Overall ratings of leader enjoyment, participant enjoyment, helpfulness, understanding, interest in continuing such groups
- **Group Participant Forms**
 - Usage of skills - how frequently
 - Helpfulness of group
 - Recommendations for groups for other fistula patients
 - Follow-up: Usage of skills, wearing bracelet

Demographics

Group Size		Average Age	Average Length of Fistula (in months)
Group 1	n=5	34	75.6
Group 2	n=5	25.6	49.3
Group 3	n=6	23.2	33.4
Group 4	n=5	23.6	19.5
Group 5	n=5	23.4	68.4
TOTAL	n=26	25.9	48.6

(Lemlem was 16, and Muluwork was 15)

(Yalganesh had a fistula for 1.7 months, and Agegnehu had a fistula for 20 years)

Pre, Post and 3-Month Data

Group Size		SRQ			HTQ		
		<u>Pre</u>	<u>Post</u>	<u>3 Month</u>	<u>Pre</u>	<u>Post</u>	<u>3 Month</u>
Group 1	n=5 ⁺	12.4 ^a	3.6 ^{a,b **}	0 ^{b **}	2.05 ^a	1.09 ^{a,b **}	1.17 ^{b **}
Group 2	n=5 ⁺	16.8 ^a	1.6 ^{a,b **}	2 ^b	2.3 ^a	1.08 ^{a,b **}	1.17 ^b
Group 3	n=6 ⁺	8.7 ^a	5.17 ^{a,b}	2.7 ^b	1.85 ^a	1.2 ^{a,b **}	1.1 ^b
Group 4	n=5	14 ^a	5.4 ^{a,b **}	1 ^{b *}	2.5 ^a	1.2 ^{a,b **}	1.1 ^b
Group 5	n=5	11.6	1.6 ^{a,b **}	0 ^{b **}	1.8	1.1 ^{a,b **}	1.03 ^{b *}
Overall	n=26	12.42 ^a	3.5 ^{a,b **}	1.26 ^{b **}	2.1 ^a	1.13 ^{a,b **}	1.12 ^b

* p<.05, ** p<.01

+fistula surgery was unsuccessful for 1 woman in each group.

(In Group 3, Sewnet lived with fistula for 6 years, and her surgery failed - her SRQ score went up from 10 to 16. Also, in Group 3 Abinet was very ill with malaria at the end of the group, and her SRQ score was still 11 at the end of the group [from 13 at beginning]).

Group Leader Overall Ratings

- 5 nurses rated each of 9 modules.
- Ratings were on a likert scale ranging from 0 (session went very badly) to 10 (session went very well).
- Rating averages ranged from 8 - 10

Group Member Feedback Post Intervention

	Group 1	Group 2	Group 3	Group 4	Group 5
How much did you enjoy being in the group?	9.4	8	8.4	9.6	10
How helpful do you think this group was to learn new ways to feel better?	8.4	10	9	9	10
How interested or engaged were you in this group?	9.8	9	6	9.4	10
How much did you understand the material in this group?	9.4	10	9	9.4	10

*Ratings were based on a Likert scale ranging from 0, meaning not at all, to 10, meaning very much/very helpful.

Group Member Feedback (3-months)

How often do you...

TOTAL N=23	Never	1-2 times per month	1 day a week	3-4 days per week	Everyday	Total Responses
Wear the bracelet?	0	3	5	9	6	23
Remember how thoughts, feelings and behaviors are connected?	0	2	3	11	7	23
Do fun things?	0	0	6	12	5	23
Do relaxation?	0	1	7	10	5	23
Use problem solving skills?	0	2	2	11	7	22
Tell the story of when you went into labor?	2	3	3	2	6	16
Change unhelpful thoughts to feel better?	0	2	3	13	5	23

Group Member Feedback (3-months)

	Group 1 (n=4)	Group 2 (n=4)	Group 3 (n=6)	Group 4 (n=5)	Group 5 (n=4)	Average
Is the bracelet a useful reminder?	Yes	Yes	Yes	Yes	Yes	
How helpful do you think this group was to learn new ways to feel better?*	10	10	9.7	9.8	10	9.87
Would you recommend that fistula patients participate in this program in the future?	Yes	Yes	Yes	Yes	Yes	
Do you think that nurses should be trained in the hospital in the future?	Yes	Yes	Yes	Yes	Yes	

*Ratings were based on a Likert scale ranging from 0, meaning not at all helpful, to 10, meaning very helpful.

Future Work

- Enhance relationships with partners
- Seek funding to evaluate intervention against a no-intervention group
- Examine ability to disseminate this approach
- Explore ways of offering intervention to women post-surgical repair who have returned to their communities but are still struggling with the aftermath of fistula
- Explore ways of integrating mental health care into larger efforts to address maternal health

END

Intervention Sessions

- Introduction
- Psychoeducation
- Behavioral Activation
- Relaxation
- Problem Solving
- Trauma Narrative
- Cognitive Restructuring
- Review and Planning
- Celebration