Psycho-social and Reproductive Consequences of Obstetric Fistula

Weston Wakasiaka Khisa, MD
OBGYN & Fistula Surgeon
Kenyatta Hospital
Nairobi, Kenya
CONSIDER THIS..........

“In an unequal world, women are the most unequal amongst the unequaled.” Jaya Rao, 1979

- Child birth is a natural process, ideally bringing joy to families.
- Instead Child Birth brings forth Obstetric Fistula, Physical and Psychosocial trauma.
- These women are often depressed, dejected with suicidal ideation (Khisa, 2011).
- Fistula development is a reflection of multiple inequalities in women’s lives (Wall, 2005).
CONSIDER THIS..........

- Fistula inhibits a woman’s social interactions, eroding her economic power and disrupts relationships. (UNFPA., 2015; Muleta et al. 2008).

- Poverty complicates a woman’s journey with fistula care and social support. (Tina 2016, Khisa 2015, Muleta 2007).

- Every fistula patient has her own unique identity and experience with fistula (Khisa 2012, 2016, Tina 2016).

- It causes substantial emotional challenges and depression (Gebresilase, 2014, Khisa 2011).
THE GAPS

→ Although women’s experiences have been documented; Long-term follow up at community level is lacking:(Lombard et al, 2015; Omari, 2015).

The main ???? Is: Suppose this Fistula affected MEN!

☐ How long would it have taken us to respond?
☐ How would we have responded? Slow & Lethargic?
☐ OR Just Fast-Furious & Quick - like lightening?

→ Unfortunately, the world is silently watching as this Fistula robs women their dignity and youthful lives.
Village Talk!

Eh! did you know those girls also smell urine like their mother? Hahahaha..... maybe they also use their mother’s urine to cook. YAK !!!!!

Stigma runs DEEP! Even children are stigmatized.

Again! they are Talking about MOM, No mercy! No shame! Let’s Run Away ...Avoid conflict.

No! MOM Deserved Better Care, It’s her Basic Right. I will Fight....
WHAT DO WOMEN’S TALES TELL?

- Community level barriers impeach on women’s basic Rights.
- Pregnancy and Child Birth is a Stressful Journey.
HAVE HEALTH SYSTEMS FAILED WOMEN?

- Lack of access to EMoC Fuels Fistula occurrence.
- Inefficient health systems break women’s Physical, Emotional and Psychosocial Well-being.

An Insult to a Doctor on Strike Leaves a Sour Taste in the Mouth & a Chronic Scar that Will Never Heal... Said a young Kenyan Doctor.
Why study Fistula?

To Gain Understanding of Issues Affecting Women Who Live With Fistula In Kenya.
Objectives

1. To profile fistula patients
2. Gain understanding of women’s experiences before and after fistula repair.
3. Establish reproductive consequences of the fistula problem.
1) Kenyatta National Hospital
2) Kisii Hospital
3) Coast General Hospital

Criteria

These sites were easily accessible with existing community networks
Study Procedures

Stage 1
- Phenomenology paradigm was applied
- In-depth interview tools were developed & pilot tested

Stage 2
- Participants informed about the study
- Eligible, willing & consenting participants were enrolled.

Stage 3
- Interviews were recorded
- Transcribed per vertim
- Thematic analysis was utilized for analysis
FINDINGS

QUANTITATIVE AND QUALITATIVE
Patient Profiles

- A total of 1224 women took part in the cohort study.
- 60.9% were married, (6.0% divorced & 6.5% separated)
- 64.7% had one or more children still alive.
- 70.3% had a skilled attendant
- 44.6%-developed fistula at the first childbirth
- 62.9% –had educated primary school level. - 17.0% having had no education.
- Low Employment
DURATION OF LEAKAGE

The period of leakage was diverse.

- (39.0%)--Within 0-12 months within one year
- 7.9%-- More than 108 months varied from
Qualitative Findings Key

Overarching Themes

Overarching Phenomenon

Pathway to Social Isolation
- Negative Social Interaction
- Poor Role Identity & Diminished Employability

Pathway to Social Integration
- Miracle Phase
- Post Miracle Phase
Social isolation was a major emerged theme soon after fistula developed

1. Women became *Vulnerable*.
2. **Negative social** interactions was very common.
3. **Poor role identity**, in terms of loss of social functioning.
4. **Financial hardships**, through diminished employability.
5. **Erosion of self-worth**; leading to psychological distress, and in some cases, suicidal tendencies.
They call us (Fistula Patients) *Ekenyaminyonge* (Mongoose). Others call me *mobochohu*! (The hollow one).

‘I had no feelings I was like dry wood! My spirit was crushed..... many thoughts crossed my mind, at some point I just wanted to kill myself so my mother and her house could be more habitable especially for those who have no sin, no terrible smell’ KR006

• Every time I joined a group of female patients, they would start spitting, saying *(urine is here seeeeeeeeeee)*, ... then one by one they would stand up and leave me alone. *Silence......starts to sob* R004:
I Fear going to meet people because of the fear of wetting my clothes.

The Nurses told my Husband to give me space since I was disabled!? My husband left without a word; suddenly I was dirty, homeless like the Mongoose.

I stayed at the hospital for 6 months-no visitors!. From then, I lived alone, still I am alone but alive.

I Felt Like Dying!
EROSION OF SELF WORTH & PSYCHOSOCIAL IMPACT OF FISTULA

□ My life is upside down, I never knew the joy of youth. He married 2 weeks after fistula R003

□ For ten years, I had no hope of fistula repair.
  • This fistula problem has caused me a lot of sadness because even when I get a job somewhere I cannot sustain it KR009

□ Where will I go after fistula repair? R005

□ Who can accommodate a woman with a catheter in her house? Tell me, who? R016

□ What if this surgery does not succeed? Where will I go?

□ Still if it succeeds where will I go? R005
COMMUNITY PERCEPTIONS &
PSYCHOSOCIAL IMPACT OF FISTULA-

What Does the Community Say about Fistula!

They say........we are Bewitched

□ Others say: She has NO BREAKS. She is a prostitute.
□ She has a terminal illness; she has AIDS that is why she leaks urine nonstop.
□ Because of such experiences from neighbours, friends and family, most women choose to keep their condition to themselves like a Mongoose!
Stress and Coping Strategies

I had to run away from home,…what could I do?

I found someone to support my daily living as I met his sexual & house keeping needs.

They say this one (woman with fistula) should not come near the visitors. When I hear this, I can’t sleep well at night; I keep waking up to clean myself and change my clothing KR003.

I climbed a tree with a rope around my neck then….I saw my 3yr old son calling to breast feed…I came down, then it hit me….My son needs me most….5 years on I am still alive today.
Impact of Fistula on the Family

Some of the children tell my son that I urinate on my bed at night.

Do you really expect us to eat and drink urine the way you do?” Tell us, they ask, laughing all the way to or from school.

This fistula has traumatized and isolated my children.
PSYCHOSOCIAL IMPACT AFTER SURGERY
MIRACULOUS PHASE

- It is a rebirth, am new and fresh
- I sleep like a new born baby till morning.
- I don’t wet the bed or need rags anymore.
- All that fear and stigma is now history.
- I dress the way I want, no worries no stress.

- My flesh and my spirit are in agreement for the very first time.
- I see hope in the future.
- I feel really nice, I am completely healed.
- I feel whole again.
- It’s just an incredible feeling.
- I am on top of the world! that is how I feel.
Men are described as creatures, not to be embraced, done with, closed chapter of my life, nothing special.

My dear after 32 years of misery I have no slightest taste for men RC008

- I have no intention of having a relationship with any man, not even the father of my children. Ten years of pain and loneliness have taught me never to trust a man; never. Men are all pretenders I must admit RC004
Negative Reproductive Health Views-2

- I have not given it a thought (meaning sex with husband). Loss of libido

- My mind was focused on my healing. However, three days ago he (husband) demanded to have sex with me, when I declined he became violent and wanted to rape me so I screamed and neighbours came to my rescue. He is a beast.

- 76.2% said that family planning services were free but they were unwilling to use it.
POST OP- WOMEN SPEAK LOUDER

† We are women NOT Stinking Mongoose
† What we need is a Home-Family & Kids!!!!

Inwardly We Desire
☐ Love & Kindness
☐ Education
☐ Employement!
CONCLUSION

1. Closing the fistula does not automatically translate to psychosocial well being.

2. From the start; Surgeons must work in teams: Psychologists, Psychiatrists and Social Workers etc.

3. Lack of Community & HCP Involvement

Questions

- HCP must Strive to stop new Fistula
- NEVER GET TIRED! Keep Closing the old Taps!