

Post-Surgical Experiences of Ugandan Women with Obstetric Fistula

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MAKING LIFELONG CONNECTIONS

8 MAY 2014

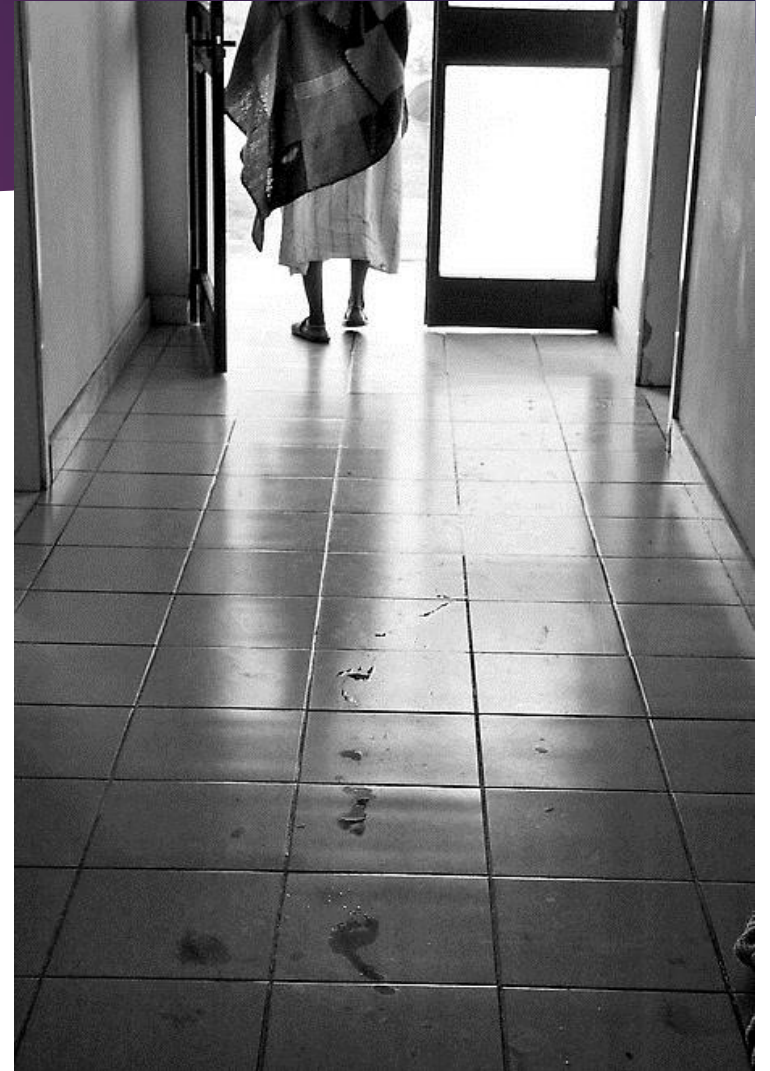


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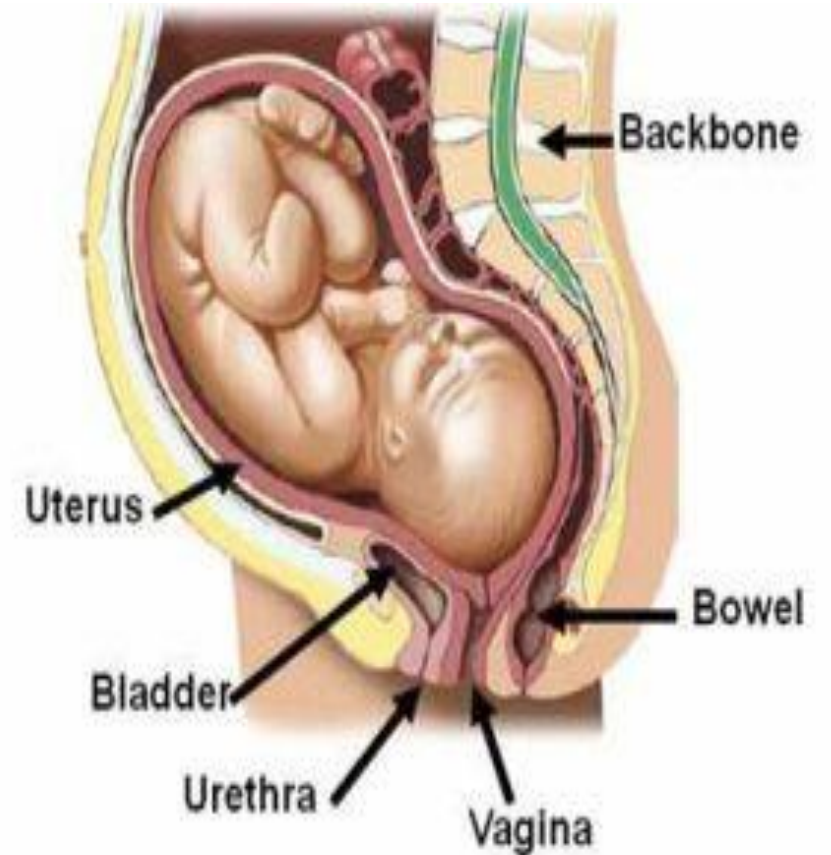
Presentation Overview

- ▶ Work in Progress
- ▶ Background
- ▶ Study details



What is Obstetric Fistula?

- ▶ Childbirth injury due to prolonged obstructed labor
 - ▶ Sexual violence or iatrogenic causes (surgeries)
- ▶ Pressure of baby's head against maternal pelvis impedes blood flow to bladder, vagina and rectum
- ▶ Necrotic tissue sloughs, results in hole between adjacent organs
 - ▶ Vesico-vaginal Fistula (VVF)
 - ▶ Recto-vaginal Fistula (RVF)



Obstructed Labor Injury Complex

- ▶ Obstetric fistula associated with a wide range of gynecologic, skeletal, neurologic and dermatologic injuries
 - ▶ Leaking urine and/or feces
 - ▶ Scarring
 - ▶ Pituitary and hypothalamic dysfunction
 - ▶ Infection
 - ▶ Vaginal and genital ulcerations
 - ▶ Perineal and bladder nerve injury
 - ▶ Foot drop
 - ▶ Complex neuropathic bladder dysfunction
 - ▶ High rates of secondary infertility



Psychological Sequelae of Obstetric Fistula

- ▶ 90% of infants die
- ▶ Depression, low QOL
- ▶ Lose economic productivity ability
- ▶ Stigmatization/marginalization
 - ▶ Varies by context, length of time with fistula
 - ▶ Divorce

Epidemiology of Obstetric Fistula

- ▶ Estimating incidence and prevalence difficult due to methodological challenges
- ▶ World Health Organization estimates 2 – 3 million women living with obstetric fistula world-wide, most in sub-Saharan Africa
- ▶ Approximately 100,000 new cases annually (1-2 per 1,000 deliveries)
- ▶ Causes
 - ▶ Three Delays Model
 - ▶ Reduced pelvic capacity/development

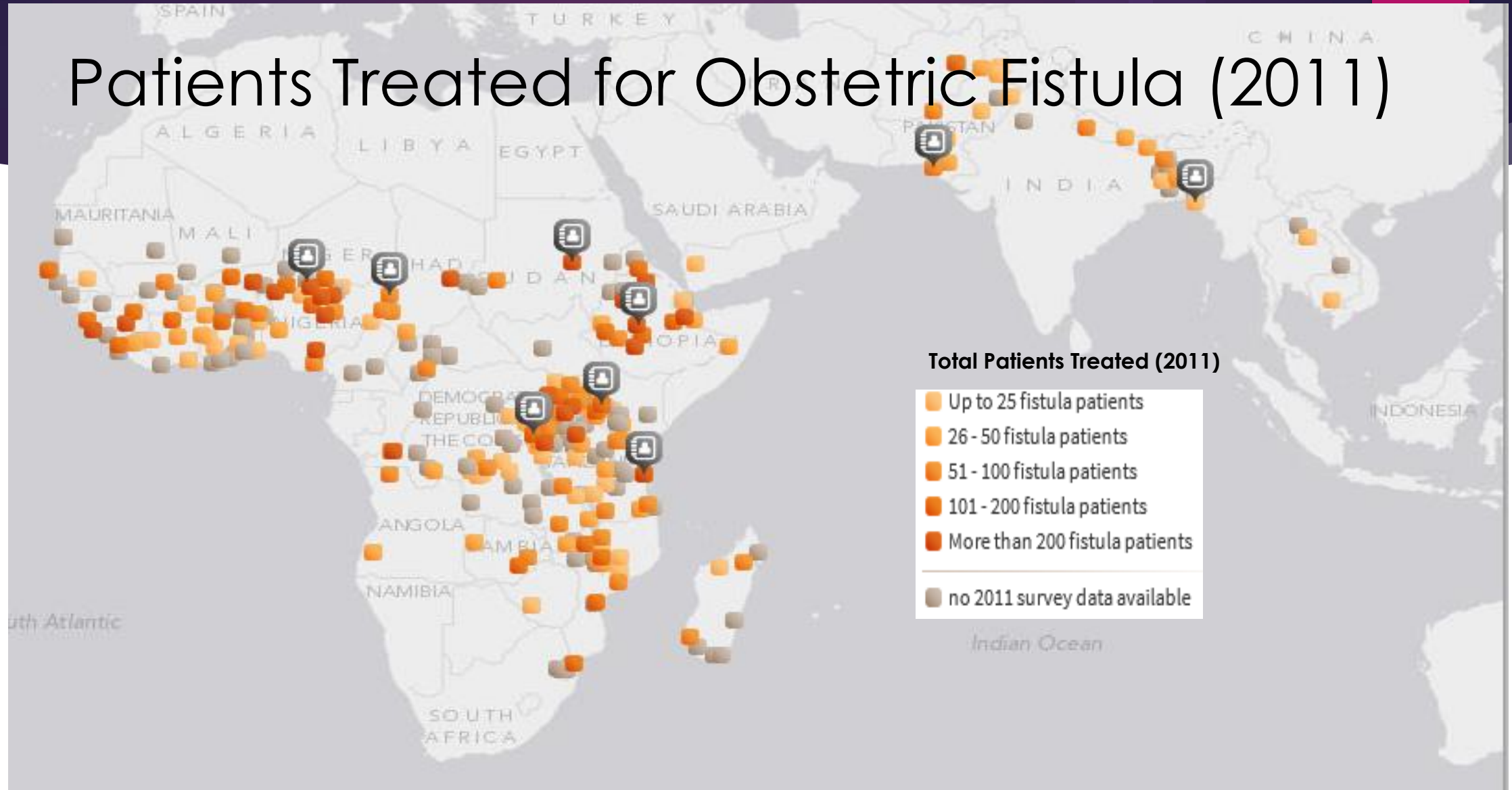
Study Rationale

- ▶ Focus on improving access to surgery over past decade
 - ▶ 60 – 90% success rate of surgeries
- ▶ Success of fistula surgery defined as short-term clinical outcomes
 - ▶ Assumption of social and emotional effects
- ▶ Residual incontinence
 - ▶ Lower QOL of life with persistent incontinence
- ▶ Little attention has been paid to success of the surgery from the **woman's perspective**
 - ▶ Ability to reintegrate, regain previous roles

Sparse literature on post-repair reintegration

- ▶ Surgery leads to improved perceived quality of life
- ▶ Most women able to resume household and farming responsibilities
- ▶ Returning to work very important
 - ▶ Ability to provide for oneself restored value as woman
- ▶ Lingering physical problems (e.g., residual incontinence, pain, fatigue) less able to resume previous roles
- ▶ What else matters
 - ▶ Length of time lived with fistula
 - ▶ Family support (economic and emotional)

Patients Treated for Obstetric Fistula (2011)



Ugandan Context

- ▶ Population 33.5 million, 25% below national poverty line
- ▶ Est. 240,000 prevalent fistula cases, 2.0% lifetime prevalence among women aged 15 - 49
- ▶ Chronic health system shortages
- ▶ Total fertility rate 6.2
- ▶ MMR: 438 per 100,000 live births
- ▶ 41.6% births at home, 3.1% births cesarean
- ▶ 47% facilities have emergency transport
- ▶ Ugandan national Fistula Technical Working Group



Study Aims

- ▶ 1. To understand the process of family and community reintegration post fistula surgery.
- ▶ 2. To develop, pilot test and modify a measurement tool to assess long-term success of family and community reintegration among women returning home after obstetric fistula surgery.
- ▶ 3. To assess the feasibility of long-term follow-up of reintegration after fistula surgery utilizing mobile phone technology

Methods – Qualitative Component

- ▶ Eligibility criteria:
 - ▶ Obstetric fistula surgery 6 – 24 months previously
 - ▶ Reside within 100 km of Mulago Hospital
 - ▶ Luganda or English
 - ▶ Capable of providing informed consent
- ▶ 15 in-depth interviews
- ▶ 4-6 focus groups

In-depth Interviews

- ▶ Normal life prior to development of obstetric fistula
- ▶ Pregnancy and delivery leading to obstetric fistula
- ▶ Changes to normal life due to obstetric fistula
- ▶ Care-seeking experience for obstetric fistula
- ▶ Experience of healing from the fistula surgery and returning to normal life
- ▶ Supports/challenges
- ▶ Hopes and goals
- ▶ Mental health throughout

Focus Groups

- ▶ How did having the fistula affect role within family and community
- ▶ How did having the fistula repair affect role within family and community
- ▶ Supports/challenges



Measurement Tool Development

- ▶ Return to Normal Living Index
- ▶ Quality of Life (WHO)
- ▶ Qualitative results will inform tool development/modification
- ▶ Tool to be tested within a small longitudinal sample

Methods – Quantitative Component



- ▶ Desired sample size: 60 women
- ▶ Eligibility criteria:
 - ▶ Confirmed imminent or completed obstetric fistula surgery
 - ▶ Reside in area with cellular coverage, or consistent travel to such area (e.g., weekly market)
- ▶ Data collection periods: baseline, 2 weeks, 3 mo, 6 mo, 9 mo, 12 mo
 - ▶ Baseline and 2 weeks: in hospital, in person collection
 - ▶ All other f/u periods: via mobile phone

Tool Validation

- ▶ Reliability
 - ▶ Internal consistency reliability (α)
 - ▶ Temporal stability (Baseline – 2 weeks)
- ▶ Validity
 - ▶ Construct validity
 - ▶ Other measures
 - ▶ Depression, QOL, self-esteem
 - ▶ Confirmatory factor analysis
- ▶ Long-term outcomes



Next Steps

- ▶ Current: collect data!
- ▶ Validate tool in other cultural contexts
- ▶ Use qualitative information to inform intervention programming
- ▶ Use of tool within intervention framework



Thank you!

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