Challenges in global estimation of obstetric fistula

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Objectives:

1. What estimates exist for the population-based prevalence and incidence of obstetric fistula?
2. What methods are used for estimation?
3. Explore use of the sisterhood approach for collecting population-based data on obstetric fistula using surveys of women of reproductive age
4. Discuss operational issues for its use (sample size requirements, training, questionnaire development)
Methods:

- Describe methods and compile estimates of population-based prevalence, incidence from published, unpublished literature
  - Using Pub Med and PopLine databases
  - From 1985 – 2005 in English and French
  - Broad search terms:
    - vaginal fistula/complications, vaginal fistula/epidemiology, vaginal fistula/etiology, vaginal fistula/pathology, vaginal fistula/physiopathology, vaginal fistula/prevention and control, vaginal fistula/psychology

Results of the literature search:

References from PubMed:
46 English
8 French

References from PopLine:
82 English

Located and met Inclusion criteria:
41 English, 7 French

Located and met Inclusion criteria:
21 English

Included estimates of pop-based Prevalence or incidence: 23
Three types of cited results:

1. Estimates quoted from other sources in the background/introduction
   - Many examples of secondary, tertiary citation
   - In some cases, original citation: personal communication, newsletter
2. Declarations by the authors: “surgeons estimate…”, no info on methods, data
3. Only 2 examples of estimates and methods (with varying degrees of transparency)

Type 1: background statistics
- 2 million (or > 2 million) in the world (Asia and Africa) cases;
- 50-100,000 new cases globally;
- Common citations:
  - 1989 WHO technical working group paper – not located – extrapolated from institutional rates of obstetric fistula
  - Murray/Lopez 1998 (Global Burden of Disease): background information: 2 million is for sub-Saharan Africa and citation is 1994 SM newsletter (previous citation by same author: no reference)
Type 2: declarations

<table>
<thead>
<tr>
<th>200,000 cases in Nigeria</th>
<th>5-10 per 1,000 deliveries in poorly served areas</th>
<th>East Africa: 3-4 cases per 1,000 deliveries</th>
</tr>
</thead>
<tbody>
<tr>
<td>400,000 untreated in Nigeria</td>
<td>500,000 untreated globally</td>
<td>6,000-15,000 new cases annually in East Africa</td>
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<tr>
<td>150,000 in N. Nigeria</td>
<td>1200 new cases each year in Tanzania</td>
<td>3,000 new cases annually in Kenya</td>
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<td>80,000-1 million in Nigeria</td>
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</tbody>
</table>

Type 3: data-based, transparent

- MOMA: prospective, population-based study of severe maternal morbidity in 6 major West African cities in Burkina Faso, Cote d'Ivoire, Mali, Mauritania, Niger, Senegal (Vangeenderhuysen et al. 2001)
  - 19,342 women followed up postpartum
  - Incidence: 10.3 cases per 100,000 deliveries
  - 0 in urban; 124 in rural [95%CI 15-446]; based on 2 cases
  - Extrapolated to Rural sub-Saharan Africa: minimum annual incidence of 33,451 cases
Type 3 – data-based, less transparent

- Murray/Lopez 1998 (Global Burden of Disease) provides model-based estimates of:
  - Regional, age specific estimates of the prevalence, incidence of recto-vaginal fistula; stress incontinence
  - Recto-vaginal fistula: 654,000 cases worldwide (262k in SSA, 194k India); average age at onset: 19; average duration: 10.7 yrs (… never seen quoted)
  - Global burden of disease: modeling approach well described for all causes of death/disability
  - Assumptions required for individual causes of disability appear not to be documented

Conclusions re: existing estimates

- The issue has attracted the attention of only a few epidemiologists, demographers (via Global Burden of Disease)
- Few references specifically acknowledge the need for research re: measurement
  - UNFPA meeting reports (Dhaka); Wall, Arrowsmith and colleagues: mention need for agreement on indicators and methods
- Measurement is clearly a huge gap, unless facility-based data can suffice.
How would one measure obstetric fistula at population-level?

Traditional approach:

- Ask a nationally representative sample of women of reproductive age about their pregnancy histories;
- Add a module that would include such questions as:
  - Do you leak urine and or feces constantly? Is this a problem that you have right now? Y/N
  - How long have you suffered from this condition? (with which pregnancy is it associated)? YRS or Mo/Yr
  - Possible treatment seeking behaviors
  - If no, have you ever had this condition? Treatment seeking
- Indicators:
  - Incidence = N of new cases/N of women 12-49
  - Fistula Rate = N of fistula among women 12-49/ N of women 12-49 (or higher)
  - Fistula Ratio = N of fistula/N of total deliveries (risk of fistula per delivery OR per 1st delivery)
### Traditional approach:

**Advantages**
- Asking the best source
  - best able to report dates, symptoms, treatment seeking

**Disadvantages**
- Unlikely these women would be reported in a household schedule
- Even if they were listed as household members, unlikely they’d be willing to report

### Sisterhood approach:

- Has been used to estimate adult female mortality, maternal mortality
- Was used to permit the use of surveys of women of repro age to a) gain information from women it was not possible to interview;
- To help alleviate sample size problems; by speaking with one respondent and asking about her sisters, you greatly expand the sample at relatively little cost (generally triple the sample)
Why suggest the sisterhood approach measurement of obstetric fistula?

1. Fistula is a very sensitive topic. It might be easier to talk about your sister than yourself;
2. Fistula is (statistically) a rare event even in highly prevalent areas
   - (MOMA study showed 0.1 per 1000 deliveries)
   - Cost-efficient means to expand the sample size are required
3. Sisterhood data are being collected currently by DHS and others for maternal mortality. Feasible to imagine piggy-backing onto a survey;
4. Many advantages to piggy-backing: data processing issues are known thanks to experience with maternal mortality measurement (imputation of missing data, calculation of standard errors)
Traditional DHS-type sibling history for measurement of maternal mortality

Please tell me the names of your [brothers] and sisters, starting with the oldest. For each sibling:

Is [NAME] male or female?

Is [NAME] still alive?

If alive: How old is [NAME]?

If died: In what year did [NAME] die?

If died: How many years ago did [NAME] die?

If died: How old was [NAME] when he/she died?

IF SISTER AGED 15+ HAS DIED, Was [NAME] pregnant when she died?

Did [NAME] die during childbirth?

Did [NAME] die during the 2 months after the end of a pregnancy or childbirth?

Proposed adaptation of DHS type sibling history for measurement of obstetric fistula

FOR LIVING SISTERS AGED 12+ When was the last time you spoke with [NAME]?

FOR LIVING SISTERS <13 GO TO NEXT SIBLING

Has [NAME] ever given birth? By given birth, I mean has she had any pregnancies that ended in either a live birth or a stillbirth?

If yes: Has [NAME] given birth since x month/y yr (5 years prior to survey)?

If yes: How many times has [NAME] given birth since x month/year?

Now, I have some questions about your sister’s [NAME’s] health. Sometimes women experience very difficult and long labor before childbirth. This long labor can injure some women and leave them unable to control their urine and or feces. These women leak urine/feces constantly. Does your sister have this condition now? That is, does she leak urine/feces constantly without being able to control it?

If yes: In what year did this happen to [NAME]?

If yes: Was the baby from this pregnancy born dead or alive?

If no: Did [NAME] ever have this condition?

If yes: Did [NAME] seek treatment (do anything) to address this problem?
### TABULATION OF RESULTS FROM SISTERHOOD APPROACH

<table>
<thead>
<tr>
<th>Age group</th>
<th>N of sisters</th>
<th>Person years of exposure</th>
<th>N of fistulas within 5 yrs prior to survey</th>
<th>Fistula rate Per 1,000 women D/C</th>
<th>Delivery rate Per 1,000 women ***</th>
<th>Fistula Ratio (fistula per delivery) E/F</th>
</tr>
</thead>
<tbody>
<tr>
<td>12-14</td>
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<td>15-19</td>
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<td>20-24</td>
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<td>25-29</td>
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<td>30-34</td>
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<td>35-39</td>
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<td>40-44</td>
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<td>45-49</td>
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<td>Total</td>
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</tbody>
</table>

*** Taken from the RESPONDENTS pregnancy history

**Reminder:**

- **Fistula Rate =** \( \frac{\text{N of fistula}}{\text{N of women 12-49}} \)
- **Delivery Rate =** \( \frac{\text{N of SB+LB}}{\text{N of women 12-49}} \)

**Fistula Rate/Delivery Rate = Fistula Ratio**

\( \frac{\text{N of fistula}}{\text{N of total deliveries}} \)

Probably not possible to interpret age-specific fistula rates due to small numbers
Sample Size requirements for use of sisterhood approach:

<table>
<thead>
<tr>
<th>Estimate</th>
<th>Assumptions</th>
<th>Required N of deliveries</th>
<th>Implied N of women</th>
<th>Implied N of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.3 cases of obstetric fistula per 100,000 deliveries: Incidence (Rural S-S Africa) Vangeeher-huyse 2001</td>
<td>50% relative margin of error (10-15 per 100,000 deliveries) 80% power</td>
<td>423,000+</td>
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<tr>
<td>102 per 100,000 women: Prevalence of recto-vaginal obstetric fistula SS Africa – Global Burden of Disease Murray, Lopez 1998</td>
<td>-50% relative margin of error (102-151 per 100,000 women) -80% power -2 sisters per respondent</td>
<td>86,634 women</td>
<td>28,878 respondents</td>
<td></td>
</tr>
<tr>
<td></td>
<td>33% relative error (102-133)</td>
<td>198,107</td>
<td>66,035 respondents</td>
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</tr>
</tbody>
</table>

Overall conclusions:

- In countries with suspected high prevalence, it might be feasible to use the sisterhood approach to measure prevalence
  - Probably not worth the cost of the large sample requirements if only for obstetric fistula
- Additional work is needed to determine appropriate estimates of prevalence to use for sample size calculation
- Qualitative work to determine the formulation of the questions in the questionnaire a must!
Overall conclusions:

• There is urgent need for baseline measures of both process and outcome
  – To date no agreement on what those indicators should be
  – Should try and avoid the trap other initiatives have fallen into
    (what to measure vs what to evaluate (Ronsmans 2001))
  – Clear that population and facility-based indicators could be helpful - traditional approach
    • Need further refinement for some currently available indicators; for example: indications for cesarean section rate
  – Development of indicators to reflect health infrastructure related to fistula