Women's Pelvic Floor Disorders, Gondar, Ethiopia JLA (James Lind Alliance) Priority Setting Partnership

Zelalem Mengistu(MD,MPH)

Associate professor of Obstetrics & Gynecology

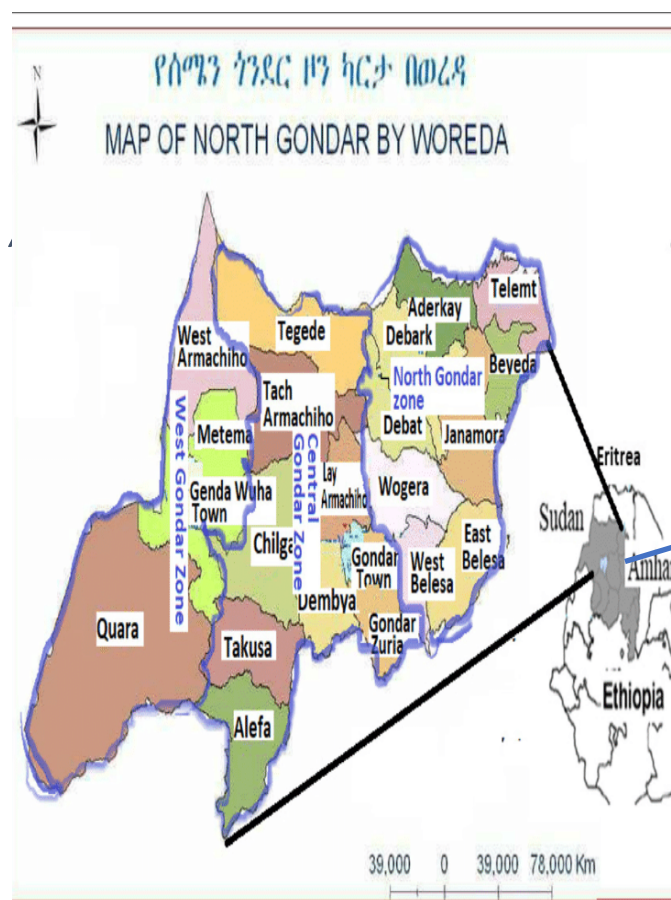University of Global Health Equity

Kigali, Rwanda

Pelvic floor disorders

- Urinary incontinence
- Fecal incontinence
- Pelvic organ prolapse

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Study setting

- Northwest Ethiopia, Amhara region
- 727km from Addis Ababa(The capital)

The context of PFDs

- A major public health problem in Ethiopia

- Result in emotional, physical, social, and economic suffering of women and their families

- Much has not been done in making the health care services available and accessible

- To give patient centered solution, generating robust evidence is paramount

the context ....

- To date research has been done by researchers, pharmaceutical and technology industries

- There is mismatch between the uncertainties researched and the questions by end users

- Involving patients, carers, and health care providers to identify uncertainties is found to be crucial

the context ….

- Priority setting partnership(PSP) methodology developed by James Lind Alliance (JLA) a non-profit initiative(2004) partner of NIHR

- JLA PSP brings patients, carers, and clinicians together

- JLA PSP has been exercised in developed countries

- It has never been practiced in Ethiopia

How does a JLA PSP work?

Preparatory work

| Read the JLA Guidebook www.jla.nihr.ac.uk/jla-guidebook | Complete readiness questionnaire available by emailing jla@soton.ac.uk | JLA allocates a JLA Adviser to Chair the PSP Steering Group |

1 Create a Steering Group
Composed with equal representation of patients, carers and clinicians, this group agrees the plan of action or 'protocol' and takes responsibility for the PSP.

2 Gather evidence uncertainties
By asking patients, carers and clinicians to respond to a survey asking what questions they have for research, and by searching existing literature to find evidence gaps.

3 Summarising the responses gathered
With the help of an Information Specialist, the PSP sorts all the responses and creates summary questions. This becomes the long list of summary questions.

4 Evidence checking
The long list of summary questions is checked against existing research evidence to ensure they are true uncertainties. Any questions that have already been answered by research are removed.

5 Interim Priority setting
To reduce the remaining long list of summary questions to a shorter list so they can be discussed at a workshop, a wide range of patients, carers and clinicians are asked to vote on the most important questions in an interim priority setting survey. This is usually via an online ranking survey.

6 Workshop
The highest ranked 25-30 questions from the interim priority setting survey are discussed in a workshop of patients, carers and clinicians who together agree the 'Top 10' list of priorities.

7 Publish and promote Top 10 research priorities
Top 10 is announced and published on the JLA website and promoted to researchers and funders. The PSP works with researchers and funders to further develop the priorities into specific research questions.

Follow up work

| Possible publication of full report or articles about PSP findings | Continue long-term promotion of research priorities | Long-term tracking of impact of PSP |

The aim of the study

- To identify top 10 unanswered questions

- In the first phase gathering the questions survey 392 participants were involved (251 patients, 69 carer and 72 health professional

- The second phase 124 participants (72 patients, 15 carers and 37 health professionals)

- The next step will be to hold a workshop

Examples of questions

Ref	Amharic	English
SQ11	በወቅቱ ህክምና ስለማግኘት?	Which are the factors and obstacles/delays affecting seeking treatment for women with PFDs in the Amhara region of Ethiopia?
SQ42	ባቅራቢያ ባሉ ጤና ተቋማት የሚሰሩ የሕክምና ሞያተኞች ማከም እንዲችሉ ስለማስቻል?	How can the capacity (skill) of Health Professionals be improved at primary health care units?
SQ43	በጤና ተቋማት ቅድሚያ እንዲሰጠው ስለማድረግ?	How can PFD healthcare be prioritised (on a health care system level) ?
SQ33	በስነ ልቦና ላይ ስላለው ተጽኖ?	What psychological impacts do PFDs have on women in the Amhara region?
SQ16	የማህፀን መውጣት ህክምና ፈዋሽነት፤ደህንነት፤ አስተማማኝነት እና ተስማሚነቱን በተመለከተ	How safe, effective, as well as adapted to the local livelihood are the different surgical and nonsurgical/noninvasive treatment options of POP in the Amhara region of Ethiopia
SQ27	ከህክምናው በኋላ ያለው የህይዎት መሻሻልና ከህክምናው በፊት አድናለው ብለው ስለነበራቸው ተስፋ በተመለከተ	How do women's quality of life improve after receiving successful treatment of POP/UI and how does that compare with the hopes they have before receiving treatment?
SQ29	ባይታከም ስለሚመጡ ችግሮች?	Are there other complications or increased likelihood of developing other conditions because of untreated PFDs (POP/UI) in the context of the Amhara region?
SQ40	ችግሩ ያለባቸውን ሴቶች እንዴት ማግኘት እንደሚቻል?	How can identification of women with PFD be done closer to home, proactively?
SQ32	በየእለት ህይወት ላይ ስላለው ተጽኖ እና ህክምና ሳያገኙ እንዴት ከችግሩጋ መኖር እንደቻሉ?	What are PFDs' (POP/UI) impacts for a woman's daily life, occupation, and economic situation and which coping strategies are women using when treatment is not available?
SQ31	በማህበራዊ ህይዎት ላይ ስላለው ተጽኖ?	What are PFDs' social effects for a woman from the Amhara region? Include community events such as funerals, religious gatherings, contact with neighbors
SQ18	ከቀዶ ህክምና በኋላ ተመልሶ የመከሰት (የማገርሸት) እድሉን በተመለከተ	How likely is recurrence after POP/UI-related surgery (considering rural women's livelihood)?

Uncovered Ethical issues

- Maintaining the following integral principles of JLA PSPs:
  - Equality in understanding
  - Transparency
  - Going back to untreated women for ranking

Ethical issues...

Equal in understanding

- All participants were given equal opportunities and rights

- A steering committee was organized using equal representation

- Each step was under the steering committee's guidance

- Participants had difficulty of comprehending the essence of the survey
  - Audio recorder used to be able to review their responses

- The process raises the ethical dilemma of being heard, given that the process is using external rather than internal synthesis.

Ethical issues….

Transparency

- It is about having clear insight into the process and how it operates
- Comprehending and checking the process makes it unrealistic to conclude about transparency
- The steering committee closely followed and guided each step of the process
- Audio recorders were also used not to miss the contextual meanings

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Ethical issues….

Going back to the same women to ask them to prioritise

- While knowing the women are still waiting for treatment, but then we do not help them

- Should we offer priority treatment to them?

- Is this fair to other women, who have not been involved in the interviews?

- Some new women, were approached which would give more new participants

- Facilitated the treatment of few women who have been found severely ill and required urgent treatment.

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Conclusions and Recommendations

- Tools proven in the global north is not without consequences of ethical dilemma ,however, it was possible to develop research priorities representing participants (carers and patients) by making context dependent methodologic modification

- Thirty-six questions have been developed and the top 20+ were prioritized which will ultimately help these women

- Methodologically proven ways of research priority Setting Partnership for global south is required while maintaining the basic principles of PSPs.

Thank you for your attention!

Zelalem Mengistu(MD, MPH)