Global Treatment Access Review

Participatory Methodology

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United Nations Entity for Gender Equality and the Empowerment of Women

Presentation overview

- What research exists?
- Research questions
- Theoretical Framework
- Key review principles
- Methodology
- Multiple dimensions of 'holistic-wellbeing pre-consultation' exercise

Doing things differently

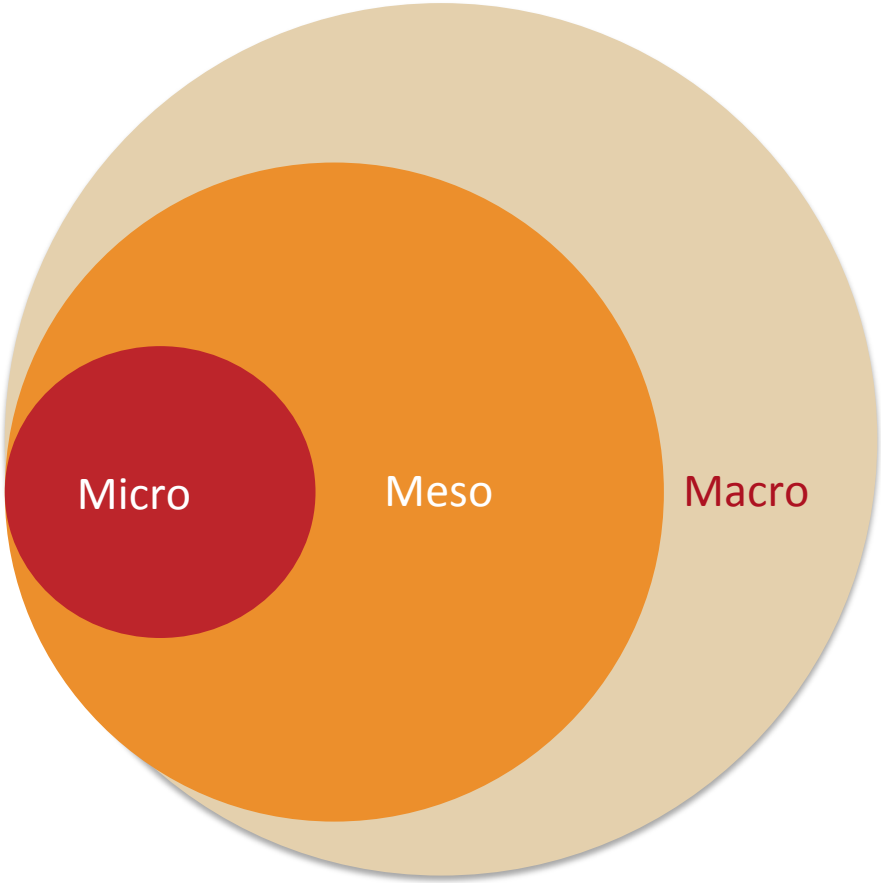
- Major **gaps** in research and data exist
- Few **inclusive** studies exist
- **Women with HIV are best placed** to frame and prioritize issues and areas to be interrogated
- Each phase of this project looked at macro-, micro- and meso-**levels**

Learning from past research

- **Grassroots-up** research design with on-going community involvement, is *essential* to address an epidemic effectively
- Quantitative not enough – **mixed method** approaches key
- **Qualitative *precedes and informs*** quantitative
- **Intrinsic** and *instrumental* benefits of **MIWA**
- Women living with HIV are **early warning systems** – not anecdote

Research question: "What are the treatment barriers that women are experiencing?"

Exploring Treatment Access at different levels



“I am living with HIV since 2007; married and I’ve got two sons. After several years of marriage, my husband was very ill and his health deteriorated so much, we went to the hospital and after doing lot of tests and analyses proved to us that he was infected with the virus, and a few days after his death, doctors have conducted tests for me and my sons. I was shocked to discover my disease and since started my journey with the torment of society that does not have mercy on the one hand and on the other hand, his family refused to accept us, me. It did not stop at that, even my sister accused me of moral corruption because of the virus and then she and my brothers kicked me off from my father's house, where I didn’t go there since. I was also exposed to many cases of stigma and discrimination, for example; while I had to stay in hospital for several days, and specifically in the Department of Rheumatology the medical team put a banner reading: “‘Beware sick with AIDS’.”

Tunisia

Key principles of Global Review

KEY DOCUMENTS: WHO 2001; ICW 2004

Further key elements:

- MIWA
- Appreciative Inquiry
- Interactive – building on experiences
- Dual learning
- Grounded in diverse realities

Participation in the review:

"At the end of every discussion everyone felt very happy to share their experiences … They recommended that every discussion and problem they shared should be implemented for advocacy … They want that the next generation should not face the same problems that they are facing now: We hope, and our expectation is, for not only a change but a huge revolution in the place where we belong.'"

Facilitator, Nepal

Methodology

Facilitated by women living with HIV

A **Global Reference Group** of 14 women living with HIV in all their diversities guided the project

- **Phase I** discussion to set parameters for an extensive literature review
- **Phase II** discussions to further investigate key themes and to gather new information on women's experiences of treatment access.

… contd.

Methodology *contd*.

Phase II discussions involved:

- listserv discussion with 19 women from 12 countries
- 'community dialogues' in 4 countries by women with HIV with 175 women
- in-depth interviews with 9 women from 8 countries
- **203 women with HIV in all their diversities from 17 countries involved**

- **Phase III** (ongoing) in-depth **country case studies** – Zimbabwe, Uganda, Kenya
  - in-depth FGD and key informant interviews using tools refined by experience with Phase II
  - policy analysis of key parameters (also defined by Phase I, II)
  - and epidemiological background

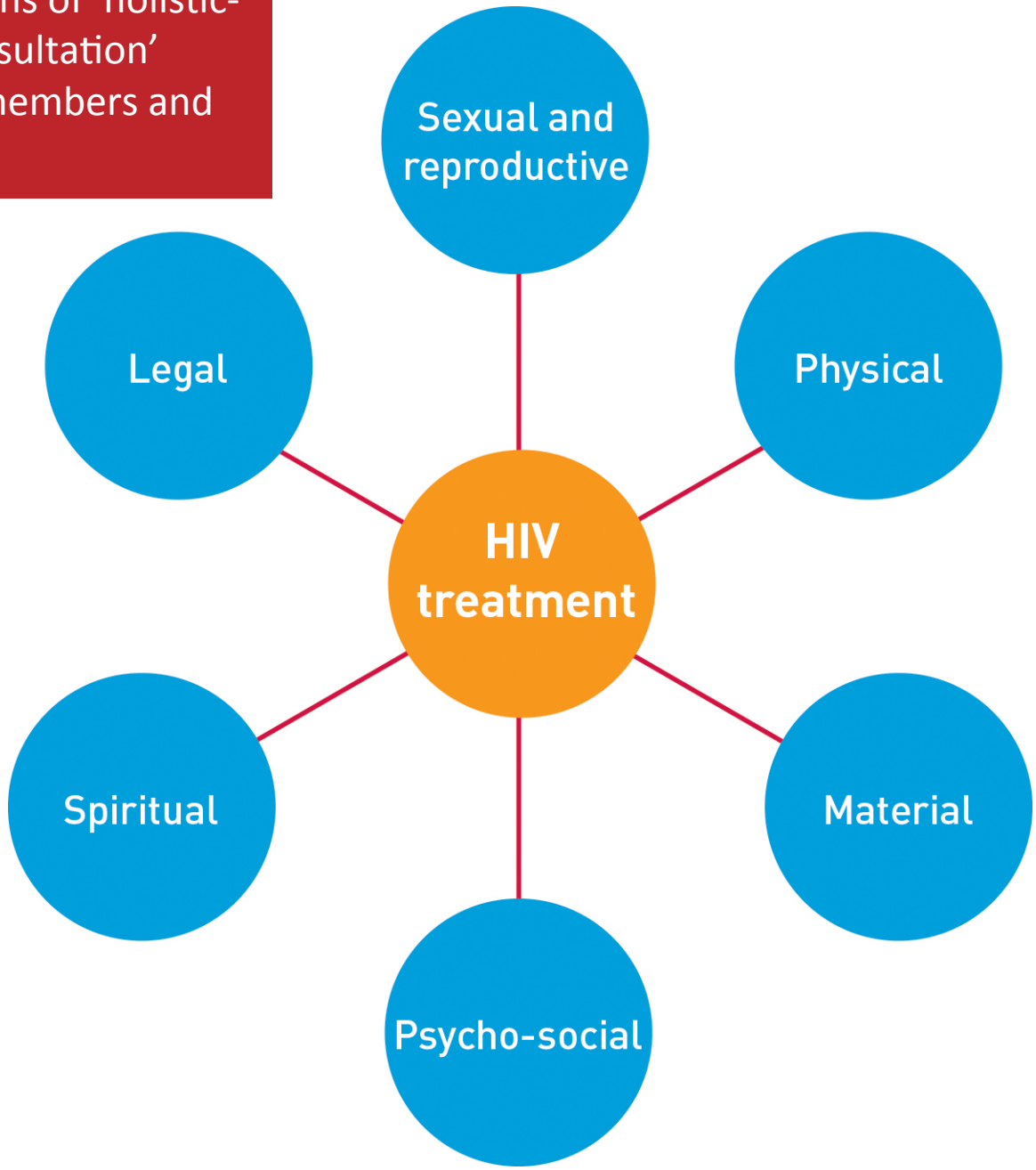
Women living with HIV across the life-span in all our diversities

- Inclusion of women with HIV in all our diversity!
- Women with lived experience of treatment
- Phase I and II informed Phase III

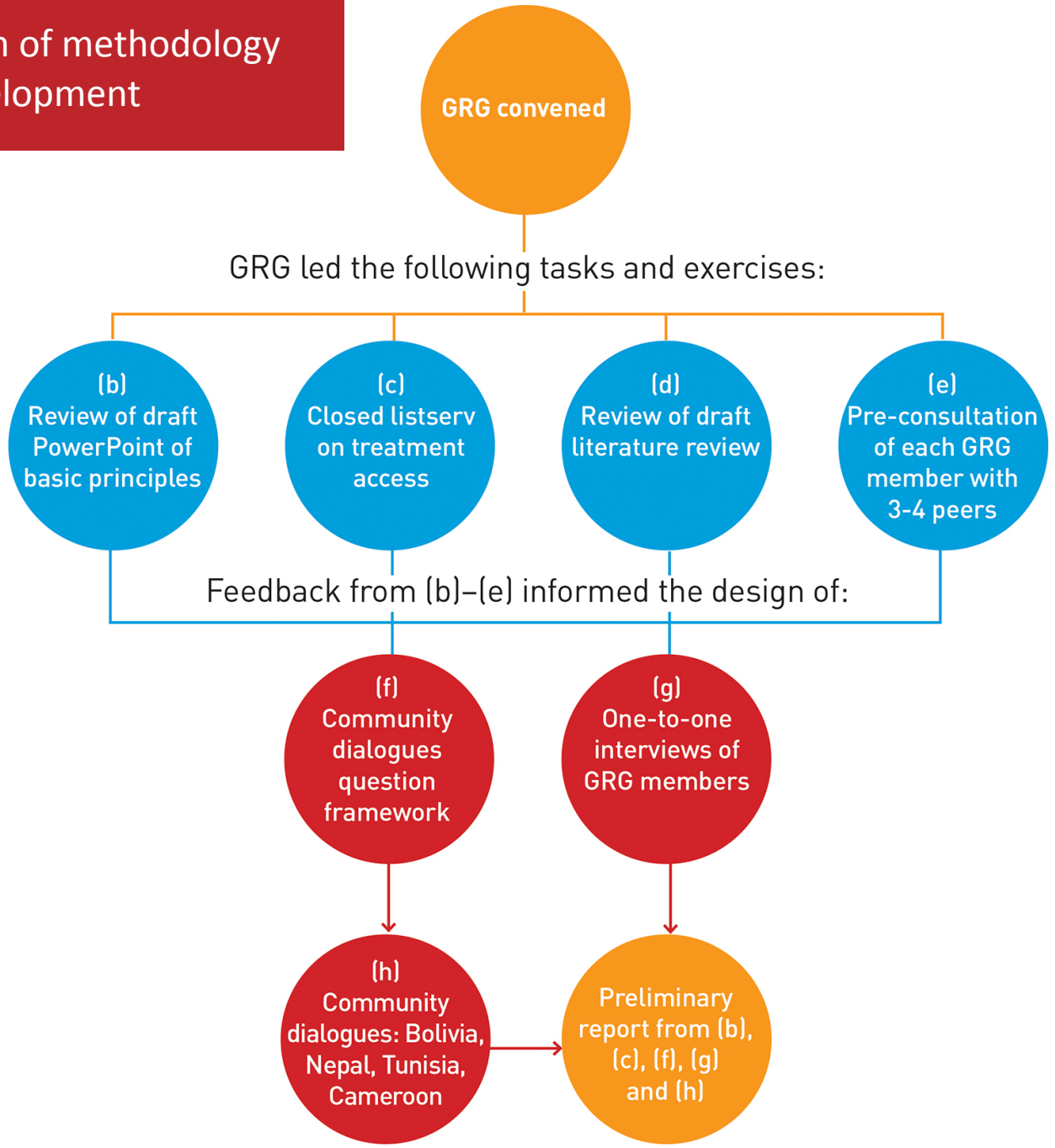
"If the messaging about treatment, adherence and healthy living starts young and continues, it is easier for us to understand why it [treatment] is important. … There is nothing for children or young people about this."

Interview, Nepal

Multiple dimensions of 'holistic-wellbeing pre-consultation' exercise by GRG members and their peers



Flow diagram of methodology process development



Thank you

"The participatory methodology is an exercise of empowerment at individual and community level. There are no experts, saviours or victims when we use this methodology, we learn and help one another. In all areas of life, women are the experts." Violeta Ross

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Global Treatment Access Review
Findings

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Presentation Overview

- Introduction: Findings from Global Treatment Review
- Data Findings
- Progress in access & adherence
- Micro-Level barriers
- Meso-Level barriers
- Macro-Level barriers

Introduction

- **First ever global study** of care and treatment access for women living with HIV of this scale led by and for women living with HIV

- Deepening our understanding to achieve global goals including 90-90-90 and “Fast Track” targets

- Information helps women understand **when, whether** to start and **continue** with treatment

“I take 9 pills, I have a sore throat, for 18 years I am taking tablets – I used to take up to 22 tablets – they are large tablets. … That's why sometimes I stopped taking them … the routine of the drug already has me tired.”

Interview, Bolivia

“Some husbands do not want their wife to go to the hospital. In this case the woman goes to hospital secretly … she will miss the appointment if she can’t justify the reason to go out the day that she is supposed to collect medicine.”

FGD among Muslim women, Cameroon

Findings: Data

Data on ART initiation & retention:

- **not disaggregated by age and sex/gender**

Uneven progress in access & adherence:

- **Initiation: more (peri-natal) women than men**
- **Retention: more men than women**

Extra data needed for gender- and rights-based approach to ART:

- **Sex workers, trans men &women, adolescent girls, young women - *women of any age who are not pregnant/lactating***
- **Documentation of women's experiences as patients:**
  - confidentiality, treatment literacy, disrespect, abuse

Findings: Micro- (Individual) Level Treatment Barriers

- **Violence** & fear of violence most commonly cited barriers – partner; family; community
- Includes stigma and discrimination
- Side effects of HIV treatment: eg appearance; sexuality
- Inability to meet basic needs: housing, food security, livelihoods – women prioritising children & others

"I was really in favour of early treatment and to have this Option B+. But now my worry is: are we being given this as an option or is this being pushed on us with no option?" ***Interview, Zimbabwe***

Findings: Meso-Level Treatment Barriers

- Gender roles and responsibilities
- Violations of rights to privacy, confidentiality and bodily integrity in healthcare services
- Violations during and after labour, including forced and coerced sterilization
- Poor communication in healthcare

Findings: Meso-Level Treatment Barriers

- Lack of counselling and discussion
- Mental health and self-stigma
- Care-giving responsibilities
- Stigma and discrimination

Findings: Macro-Level Treatment Barriers

Punitive laws, including criminalization exacerbate structural and community violence against women living with HIV and/or from key affected populations and impede access to treatment.

"The Legal environment in Uganda and the 'HIV prevention and control law' has created lots of fears. People who were strong and accessing medication they are now hiding away because of the fear of being seen and known to be HIV positive now that you can be criminalized for HIV transmission" Interview Uganda

“Most of us live in the far village, which takes 1 hour to 2 ½ hours by public transport, which is really costly and some us live nearer to hospital. So some months we don’t visit the hospital to take ARTs too, sometimes we manage to get money from a neighbour if we don’t have our own.”

FGD Nepal

Findings: Facilitators of Treatment Access

- **Peer-led treatment literacy and support groups** - directly linked to accessing & remaining on ART over time
- **Better adherence** through community support groups
- **Building trusting relationships with health providers** – important to staying on treatment
- **Gaining strength, value and motivation from roles** within families as mothers, partners and caregivers, and as leaders within their communities.

"It motivates me when I look at my children and my other siblings, who are negative, and my father. I have to push on with life."

Interview, Uganda

Thank you

"We do need targeted programmes to develop treatment literacy and treatment advocacy skills and as much as we work in partnership, we do need women only spaces as well because there are very gender specific issues to treatment, not just around pregnancy." **Interview, UK**

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