



Stigma and nondisclosure remain important barriers to early HIV treatment retention during the early treatment period in Zambia and South Africa

#TUPEE550

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Background

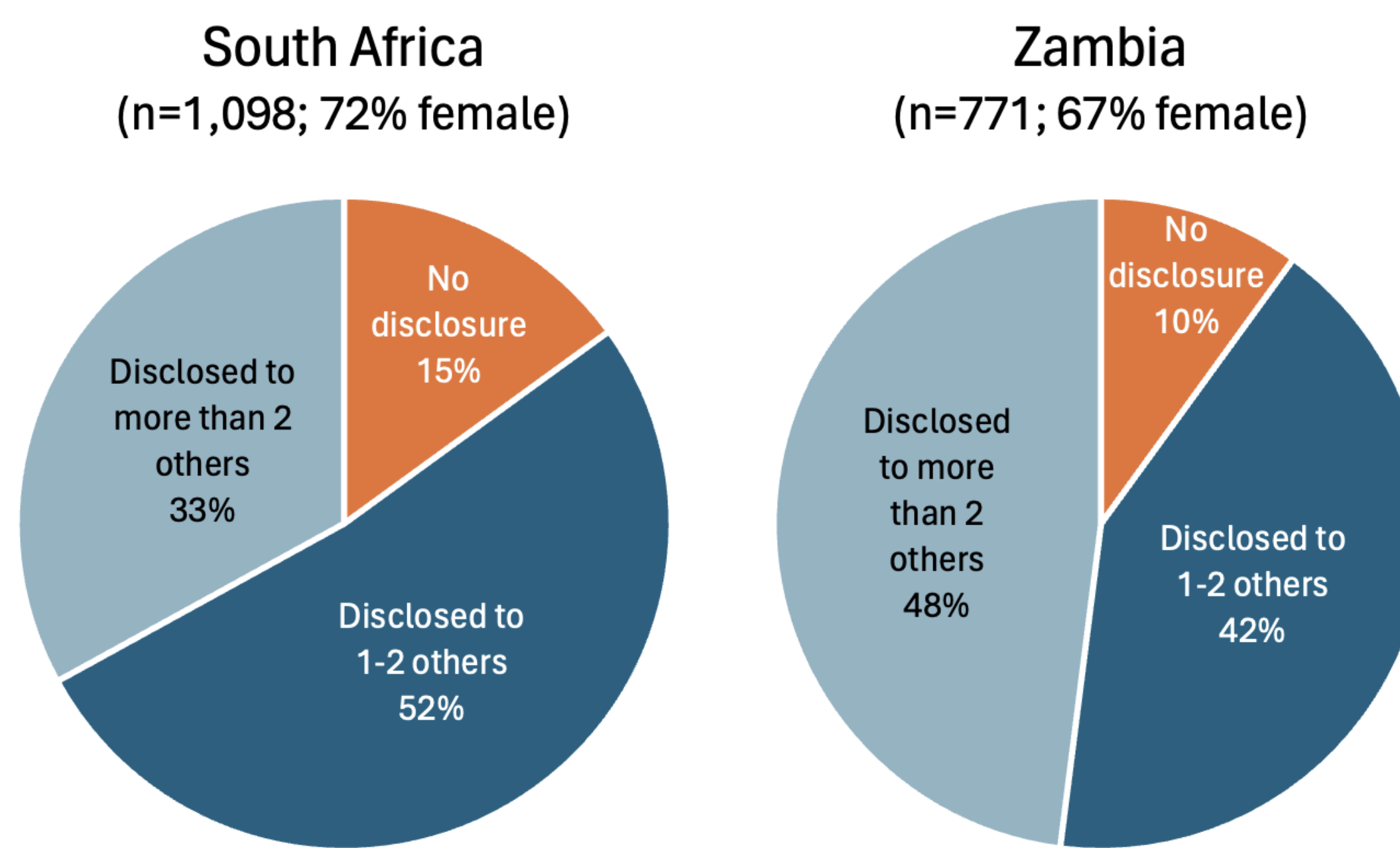
- Attrition from HIV treatment is highest during the first 6 months after antiretroviral therapy (ART) initiation¹.
- Stigma and fear of disclosure remain important reasons for disengagement.
- Stigma is a multi-layered issue, affecting clients at community, healthcare facility, interpersonal, and individual levels².
- We explored clients' experiences around stigma and disclosure during their first six months after ART initiation/re-initiation.

Methods

- Quantitative survey conducted from Aug 2022-Jun 2023 in Zambia (12 facilities in 2 provinces) and South Africa (18 facilities in 3 provinces).
- Enrolled adults who were starting, restarting, or on ART for ≤6 months, including those initiating ART on the day of study enrollment.
- Focus group discussions (FGDs) were conducted with a subset of survey participants up to 12 months after study enrollment

Quantitative Results

- 42% of respondents in South Africa and 36% in Zambia believe **that no one knows their status**.
- Females had lower odds** of disclosing their status to their partner/spouse than did males (SA OR 0.57 [95% CI 0.40, 0.83]; ZM 0.57 [0.46, 0.91]).
- Of respondents with the opportunity to disclose their status, most chose to disclose their positive status to **fewer than 2 people**.



Key Message:

Non-disclosure of HIV status due to fear of stigma remains a major barrier to retention on HIV treatment during the first six months after initiation.

Qualitative Results

- FGDs enrolled 129 clients in Zambia and 124 clients in SA
- Key themes reported by FGD participants included:
 - Fear of **not being loved** if a partner knew their status.
 - Lack of family support**; stigmatizing behaviors within households.
 - Reluctance to visit a clinic due to concerns regarding **privacy**.
 - Bypassing nearest facility and **seeking care at distant clinics** to avoid stigma, resulting in financial/opportunity costs and inconsistent engagement in care.

Stigma

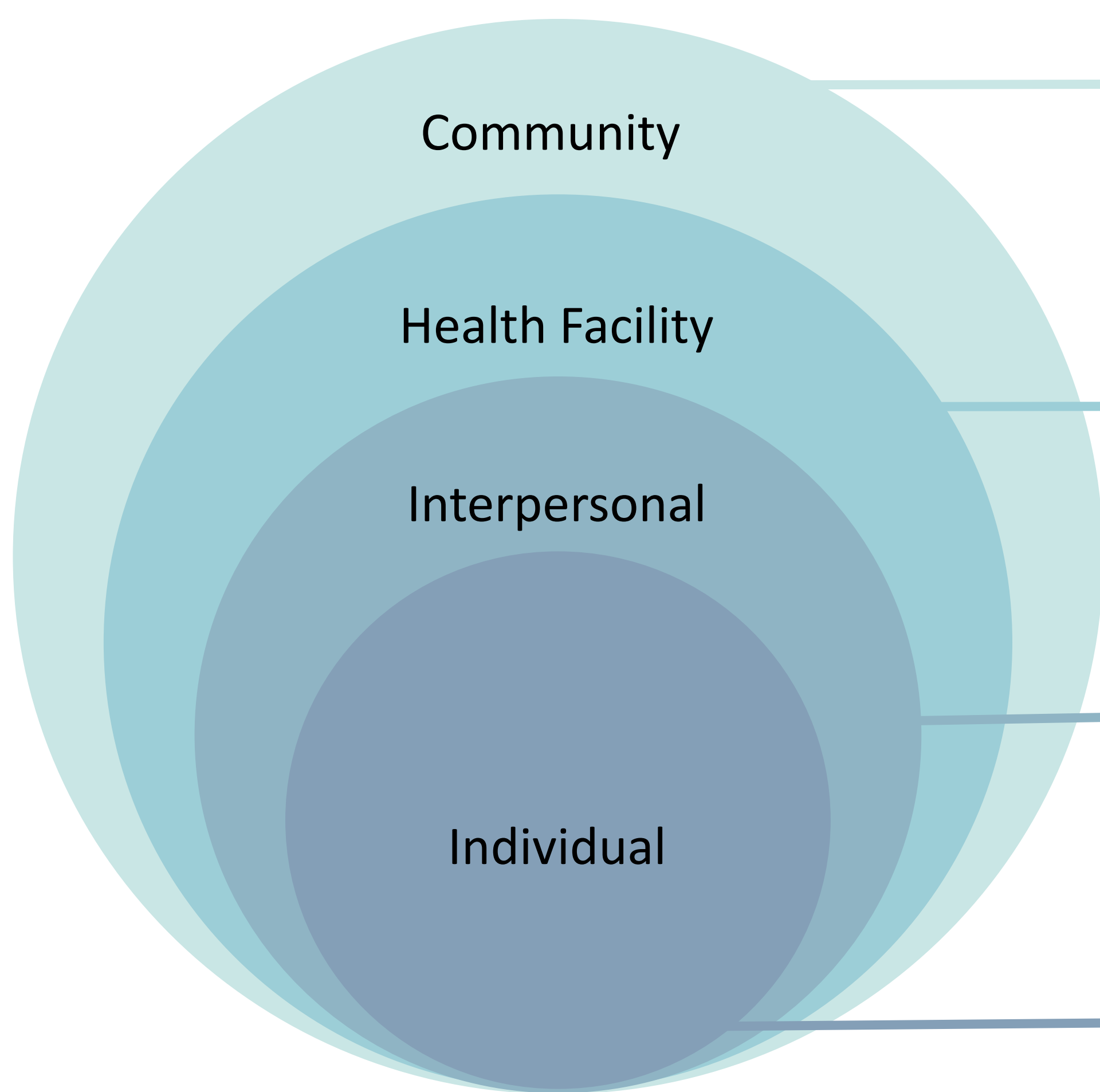
- Fear of seeing familiar faces at clinic
- Limited privacy at clinic
- Speculation and gossip in the community
- Acceptance and denial cycles

Results in...

- Limited care seeking
- Discouragement
- Fear of disclosure
- Inconsistent treatment

Key Message:

Stigma and HIV status non-disclosure emerged at all levels of the social-ecological model as barriers to remaining in care.



Clients experience ridicule, criticism, and gossip within communities:

"[People] fear being laughed at by friends. With some people you find that they even throw away their HIV drugs along the road because they fear being laughed at."

Some clients bypass nearby clinics, anxious that they may encounter acquaintances:

"Other people collecting, some people are heartless. You may think they keep my secret meanwhile they are saying other things to people."

Family support can deter or support adherence

"When I started taking treatment things changed at home...I was given... my own things that I must use separately for everything I do in the house. I was known as 'that person on treatment' at home."

Self-stigma:

"...The biggest challenge people pass through is acceptance that today I start medication, it is difficult... one side you accept, the other side its denial. You feel like you are dreaming, looking for the truth. Until at last you accept."

Conclusions

Twenty years after the launch of national HIV treatment programs in sub-Saharan Africa, stigma and fear of disclosure remain barriers to retention on ART. Models of care for clients in the early treatment period must maintain privacy and address ongoing, multi-level stigma fears.

References

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- Relf MV, Holzemer W, Holt L, Nyblade L, Ellis Caiola C. A Review of the State of the Science of HIV and Stigma: Context, Conceptualization, Measurement, Interventions, Gaps, and Future Priorities. *J Assoc Nurses AIDS Care.* 2021 May-Jun 01;32(3):392-407. doi: 10.1097/JNC.000000000000237. PMID: 33654005; PMCID: PMC9208366.

Further information about the study sites and populations can be found at sites.bu.edu/ambit



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