

## INTRODUCTION

- Support for young people living with HIV (YPLHIV) aged 16-24 is critical but limited in Zambia (Mupambireyi et al., 2014; Skovdal and Ogutu, 2013)
- YPLHIV are often not spoken about openly within communities
- Limited disclosure is common in this group (Mburu et al., 2014)

## METHODS

- Qualitative cohort of 8 purposively sampled YPLHIV (4 young women, 4 young men) in 4 geographically spread Zambian urban communities
- Data collected in four rounds- 1,2,3&4
- Each participant was involved in three research activities (carried out at three-month intervals)
  1. Participant observations (Round 1,2&4)
  2. Individual in-depth interviews (Round 1,2&4)
  3. Participatory workshop (Round 3)
- Use of visual tools: collages (Fig. 1) and disclosure network diagrams (Fig. 2).
- Analysis: inductive and thematic analysis using workshop notes, IDI transcripts, and visual data



Figure 1. Collage created by YPLWH showing a description of themselves. This collage reflects a young man's future aspirations (marriage, cars, a nice house); maintaining health through good diet, personal hygiene and running; keeping time; and accessing the internet.

## KEY FINDINGS

### Limited disclosure

- Limited disclosure network (Fig 2.)
- YPLWH adjusted their lives to keep their HIV positive status a secret by fore-going opportunities (e.g. going on holiday)
- YPLWH often felt fatigued by keeping their status secret

"They might start asking you, 'what type of medicine is that and why do you always take it at the same time?'" (YWLWH, 16)

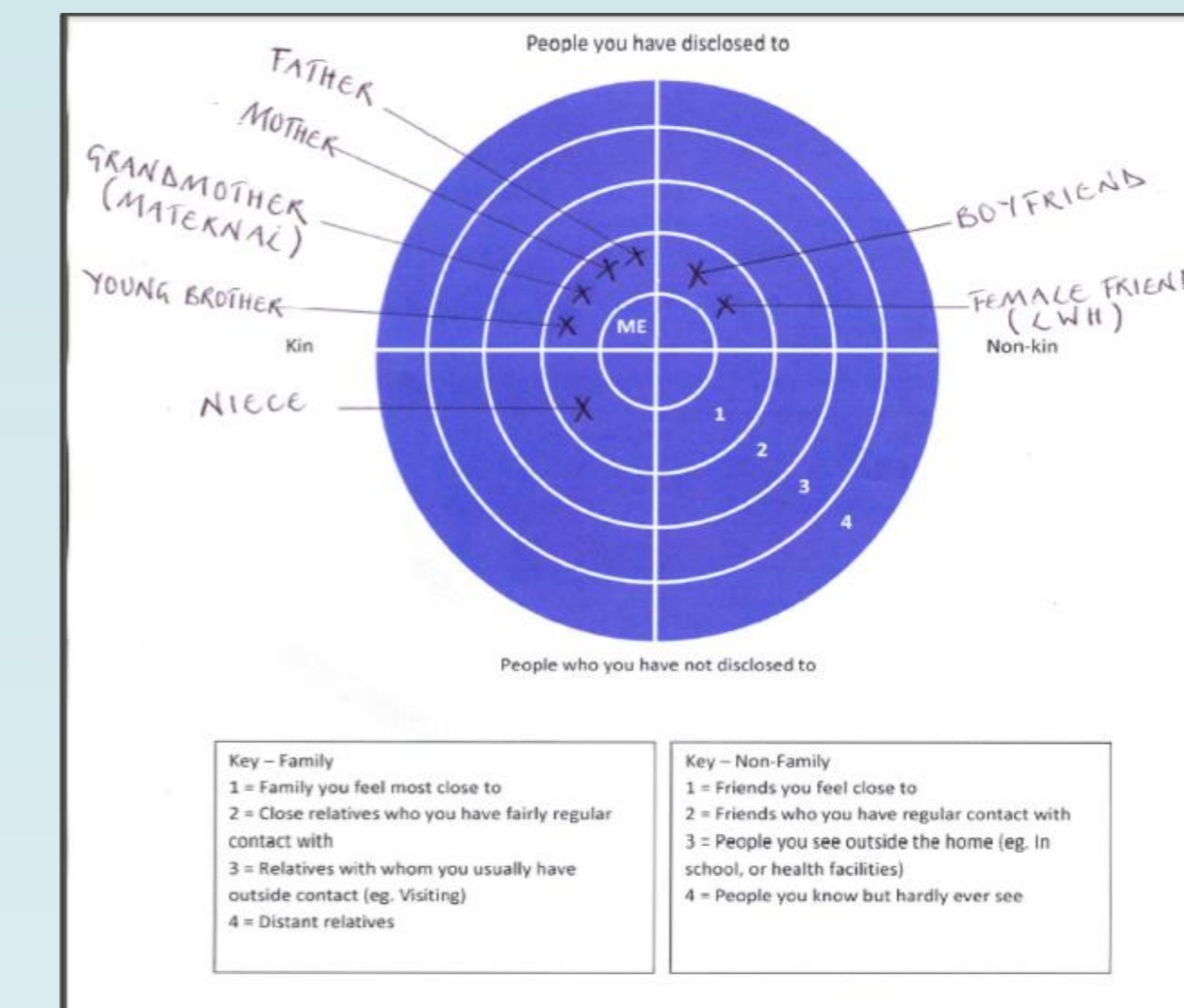


Figure 2. Disclosure network diagram by a YWLWH showing limited disclosure, mainly to family and 2 friends.

### Disclosure discouraged by parents/ guardians

- Parents often proscribed why and to whom YPLWH disclosed their HIV status (sometimes to conceal their own status)
- But guardians often felt that YPLWH in their care could be well understood by someone 'in their shoes'

"My mother said we cant tell my older brother, grand father and uncle... because questions will come, like 'why is she the only one taking?'" (YWLWH, 17)

"Mom said I shouldn't tell them otherwise they will start using it against me, like they do to her" (YWLWH, 19)

### Disclosure provides opportunities for support

- Disclosing to others has enabled friends and family to offer support
- Disclosure sometimes linked to receiving support from other YPLWH

"I have only told my male friends about my status... sometimes they remind me, even right now, when we are playing...when the time is 17:30 they say go home. They encourage me 'eat' and they say it's part of life" (YWLWH, 17)

"Because she also told me and I also told her" (YWLWH, 17)

"I have disclosed my HIV status to my parents, my wife and friend whom we share the drugs with when I run out" (YMLWH, 18)

### Desire to share experiences with others 'in their shoes'

- YPLWH often wanted to share experiences about managing HIV
- One participant had attended a support group: supportive to meet with others and for adherence
- Some YPLWH often felt that there were other YP in their shoes who need to be accessed

"They said I should have a balanced diet... sometimes I have dizziness, that's why I don't take... you can't tell who else is like me... how do they manage?" (YMLWH, 21).

"We ourselves in the current situation should be trained to encourage them... in most cases those who are HIV positive they are just in their parent's home thinking that they are helpless they can't do anything in order to help themselves" (YMLWH, 17).

## CONCLUSION

- Limited disclosure prevents YPLWH meeting and talking with other YPLWH, leading to isolation
- Limited disclosure sometimes desired by YPLWH, sometimes encouraged by parents/ guardians
- Interventions targeting YPLHIV should address relationships in the home and the benefits, challenges and strategies for disclosure YPLHIV to allow them to share experiences, concerns and feel less alone
- Support groups for YPLWH can enable sharing experiences with others 'in their shoes' and reduce isolation
- Virtual platforms and more involvement of this group as volunteers at the clinic were other suggestions that might help them find each other

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