Barriers to recruitment and retention of pregnant HIV-positive black South African women into PMTCT intervention programs: A loss to follow-up

Shandir Ramlagan[1,2], Sibusiso Sifunda[1,2], Rob Ruiter[2]

1. Human Sciences Research Council
2. Maastricht University

Participant recruitment and retention:

- Major challenge in behavioural intervention, implementation and evaluation.
- Major cause of intervention ineffectiveness.

In trying to understand the loss-to-follow-up, too often we are left with missing quantitative data and more importantly missing participants.

Aims & Objectives

- Understanding loss to follow-up in a rural setting among HIV positive pregnant women.
  - This study is part of a 5 year NIH funded R01 RCT.
- Perspective of fieldworkers and project coordinators on loss to follow-up.
- Utilising qualitative and quantitative analysis to understand loss to follow-up.

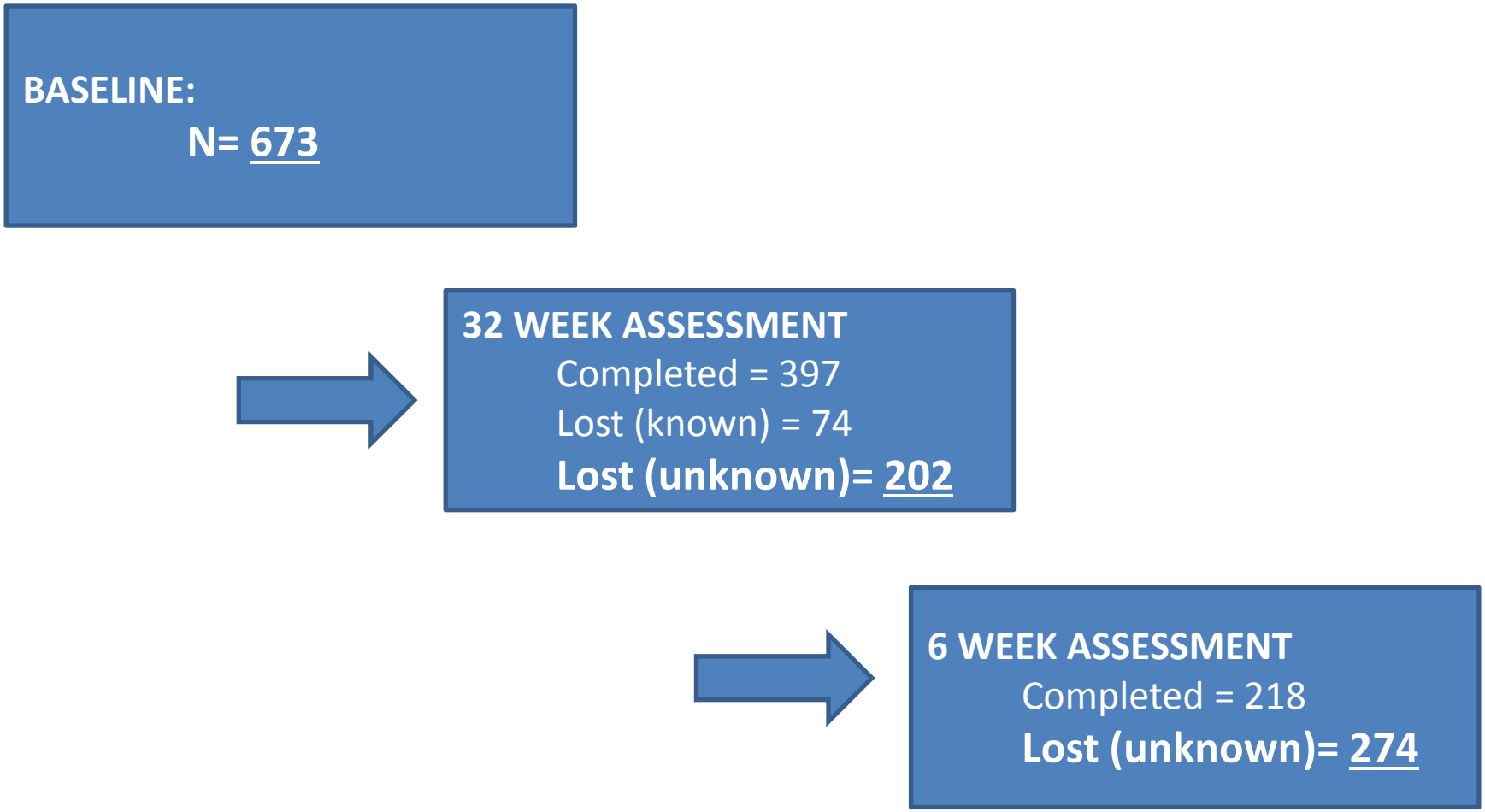
Study Overview:

- Sample: N= 673 HIV positive women from 12 Community Health Centres (CHC's) in rural Mpumalanga.
- Randomisation: 6 control CHC's and 6 experimental CHC's (matched).
- Measures: demographic, psychosocial, knowledge, health, adherence, intervention exposure:
  - baseline (less than 3 months pregnant)
  - 32 week pregnant
  - 6 weeks post-partum
- Intervention: 2 group and 1 individual PMTCT session were given prior to birth.

Mix Methods paper:

- Quantitative:
  - SPSS 22 run data describing loss to follow-up (6 week incomplete).
- Qualitative:
  - In-depth interviews utilising a structured guide was completed and recorded
    - Fieldworkers (FW):
      - female (n=7) and male (n=2)
    - Project coordinators (PC):
      - female (n=1) and male (n=1)
- Interviews were transcribed verbatim, loaded into ATLAS.ti and analysed using grounded theory.

RESULTS


BASELINE:
N= 673
32 WEEK ASSESSMENT
Completed = 397
Lost (known) = 74
Lost (unknown)= 202
6 WEEK ASSESSMENT
Completed = 218
Lost (unknown)= 274

Retention Strategies Utilised

- Appointment cards
- Reminder phone calls (up to 3 numbers)
- Interviews and intervention session at scheduled clinic visits
- WhatsApp messages
- Use of Clinic Home Based Carers to locate missing participants
- Incentives:
  - R50 (USD4) cash for the first interview (baseline) (1hour)
  - A gift bag of baby cosmetics after completion of 2 intervention sessions
  - R150 (USD12) for the second interview (32 week pregnant) (1 hour)
  - R100 (USD8) for the third interview (6 week post-natal) (15min)
- Intervention knowledge itself

Results: Qualitative

- Frequently cited reasons for loss-to-follow-up:
  - Fear of stigma/discrimination
  - Fear of loss of partner
  - Non-disclosure of status***
  - Miscarriage
  - Holidays (Christmas, Easter)

Results: *Patient file*

- Patients attend CHC's to obtain a maternity card and perform baseline medical assessments to fast track when it comes time for delivery:

"The participants come, because most of them, they say that when they don't have maternity record at the time of delivery, they (nurses) don't really attend (to) them" (FW)

Results: *Loss of Employment*

- Once employment contracts end, people go home which could be 2000km away:

"people relocate and they come from different places, they are there to work … now the contract has ended and she is pregnant so the person goes back home" (PC)

Results: *Group Dynamics*

- Having intimate knowledge of participants to ensure group dynamics works is a must:

"…when a person comes and notice 3 or 4 prostitutes she'd ask herself why I'm with prostitutes." (FW)

Results: *Going Home* *(1/2)*

- Travel home for family support:

“What I’ve noticed about 32 weeks is that those who are not staying here start to going back home when they’re 7 months pregnant to give birth at home” (FW)

Results: *Returning from Home* *(2/2)*

- On return, new rental is sought which could be serviced by a different clinic:

"… the ones that don't come back are those that rent a room and when she come back the landlord told her that they already taken her room and gave it to someone else and then she had to go to another place and look for a room to stay." (FW)

Results: *Culture* *(1/3)*

- Pregnancies are not announced in certain cultures:

"because some of them they believe that according to their culture they don't say anything about their pregnancy until we see it ourselves." (FW)

"…people will use their witchcraft to make (one) lose their babies … some they come for their first visit when they are 6 months … and they come even if they are 8 months"(FW)

"… it's not a woman who should tell a man that she's pregnant, is the man who should tell" (FW)

Results: *Culture* *(2/3)*

- Traditional rituals need to take place pre and post birth:

"They say without drinking Isihlambezo before birth you can (be) 10 months yet still be pregnant…that's why these women go back home before 32 weeks because they want drink Isihlambezo…it's traditional medicine." (FW)

"…Isiphandla, some of them they do it at 6 weeks, what do you call it (when the umbilical cord fall off)… then they'll slaughter a goat." (FW)

Results: *Culture* *(3/3)*

- Cultural family specific practices also occur:

"After you giving birth to the baby; at his father's home they'll check if the baby has lines on the hand and if the lines are not the same you have to wait for the baby's grandfather to confirm … either it matches … anyone in the family, one should be the same" (FW)

Conclusions

- Opening a patient file is seen as more important for future delivery.
- Presenting late for first ante-natal visit due to cultural beilefs.
- Understanding group dynamics.
- Traveling home from about 32 weeks pregnant to maybe 6 months post partum.
- Movement within the community.

Limitations

- Interviews with only fieldworkers and project coordinators.
- All participants are not past their 6 week window period.

Recommendations

- Interventions need to be planned in conjunction with the pregnant woman taking into consideration her possible travel.
- A national integrated computer based system needs to be set up so patients are not lost when they move between clinics and provinces.
- Community dialogs need to occur to raise awareness around presenting early at the clinic when pregnant.
- More systematic studies to understand loss to follow up are needed

Thank You

- National Institute of Health
  - Implementing Comprehensive PMTCT and HIV Prevention for South African Couples
  - 1R01HD078187-01A1
- Human Sciences Research Council and University of Miami research team
  - Prof Karl Peltzer
  - Prof Deborah Jones
  - Ms Violeta Rodriguez
  - All fieldworkers and supervisors