

DEPARTMENT OF HEALTH RESEARCH BRIEF

Verbal Autopsy with Participatory Action Research (VAPAR)
 Expanding the knowledge base through partnerships for
 action on health equity
 Series 4, Number 1, January 2023



Community health worker: at the forefront of addressing HIV and TB lost to follow-up

VAPAR promotes evidence generation and use with services and rural communities. Our current work focusses on building community health worker (CHW) capacities in rapid evidence generation for HIV and TB, as a main health problem throughout Bushbuckridge sub-district. The high rate of lost to follow-up of HIV and TB patients have been confirmed as a persistent health priority at local level in Bushbuckridge.

This brief presents - Part 1: mortality data from MRC/Wits- Agincourt Unit's Health and socio-Demographic Surveillance System (HDSS); and Part 2: evidence generated by communities to better understand how local action by CHWs could address HIV and TB lost to follow-up.

1: Verbal Autopsy (VA)

(a) Burden of disease

Verbal autopsy (VA) is a survey method to measure levels and medical cause(s) of all deaths (inside and outside health facilities) in populations. We analysed VA data from the Agincourt HDSS to quantify the burden of HIV/AIDs and TB over time, from 2012 to 2021.

From our analysis, the following is noted:

- **variation** in the annual mortality rate for HIV and TB, with a notable increase in mortality from 2018 followed by a reduction in HIV mortality from 2019 and TB mortality from 2020 (Fig 1).

- **20-49-year-olds largely affected** - account for 61% HIV, 52% TB deaths and 64% overall
- **66% TB deaths were male**, HIV-related deaths 44%:56% (M:F)

HIV and mortality trend, 2012 to 2021

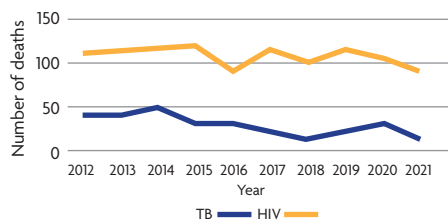


Figure 1: Number of annual HIV and TB deaths, 2012 to 2021, MRC/Wits Agincourt HDSS

(b) Circumstances of mortality

We produced a method to assess individual needs and behaviours at and around time of death, and health system responsiveness, for inclusion with burden of disease data.

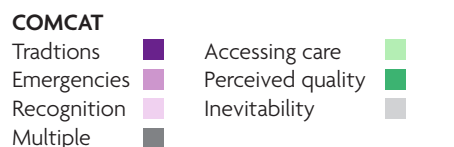
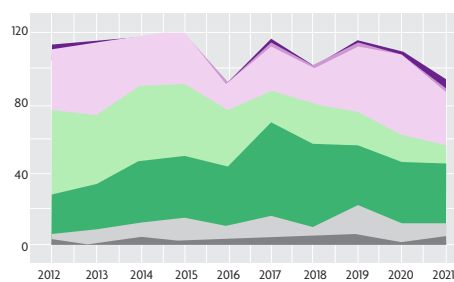
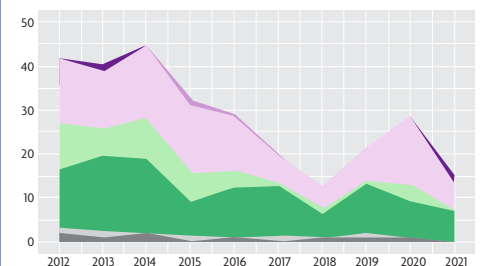


Figure 2: Circumstances of Mortality Categories (CoMCATs) by year for HIV/AIDS related deaths in Agincourt HDSS 2012-21



COMCAT

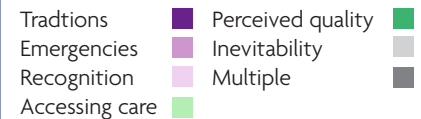


Figure 3: Circumstances of Mortality Categories (CoMCATs) by year for TB related deaths in Agincourt HDSS 2012-21

The main circumstantial categories corresponding to the HIV/TB burden were:

HIV (Fig. 2)

- 33% reported issues with perceived quality
- 28% reported failures to recognise severity
- proportional reduction in accessing care as CoMCAT

TB (Fig. 3)

- 54% reported issues with perceived quality
- 8% reported failures to recognise severity
- notable increase in recognise severity during 2020



2: Participatory Action Research (PAR)

Working closely with 50 CHWs from five local areas in Bushbuckridge sub-district, HIV/TB loss to follow-up were confirmed as a local health priority. We used participatory action research (PAR) methods to progress the understand of service delivery and service uptake issues affecting communities and the health system and contributing to this priority.

(a) Causes of loss to follow-up

Underlying socio-economic causes of HIV and TB lost to follow-up, as identified by the CHWs include factors relating to unemployment and poverty, including the lack of transportation or inability to afford public transport to visit health facilities to collect medication or for follow-up visits; food insecurity, specifically as some of the medication to treat HIV and TB needs to be taken with meals. In some instances, patients relocated and the lack of a referral system and poor integration of services made it difficult to know if a patient was receiving treatment from another health facility.

Service delivery at health facilities was also reported to contribute to patients being lost to follow-up. This included long waiting times, not providing sufficient information on the disease and the importance of treatment

adherence, perceived negative attitude of health care workers and allegations that HIV and TB status of patients were not treated as confidential. Periods of interruption in supply of medication was also reported to influence treatment continuation.

At a societal level, the lack of support, harassment and judgement were indicated as reasons why HIV or TB interrupted their treatment. Peer pressure and religious or cultural beliefs were reported as further reasons why patients would be lost to follow-up.

At individual level, some patients were reported to be in denial of their diagnosis, or ignorant of the implications thereof. Many patients did not disclose their disease status out of fear of stigma and discrimination. The number of tablets to be taken for the treatment of HIV and TB, the size of the tablets, and side-effects of the medication were further reasons why treatment was interrupted. Alcohol consumption and tobacco use also affected individual decision making with regards to health seeking behaviour.

(b) Impacts of patients being lost to follow-up

The CHW reported the interruption in the long-term treatment of HIV and TB, due to patient being lost to follow-up to

be linked to illness, disability and death. This in turn resulted in children being orphaned, additional socio-economic burdens on households and families. Treatment interruption also resulted in drug resistance and higher rates of disease transmission.

A high lost to follow-up rate was also considered to negatively reflect on the CHWs, as it is perceived to be related to CHWs not performing their duties. This was reported to cause stress and anxiety amongst the CHWs as other factors, such as not having the correct contact details for patients on file, are significantly impacting on their ability to trace patients who have been lost to follow-up.

(c) Local action

An action agenda was developed by CHW representatives from each local area, from which one action was selected for prioritisation in each local area. All the priority actions were led by CHWs: establishing local support groups, presenting health talks at local clinics, performing direct observed treatment (DOT) with TB clients and education of patients and their families on the need for disclosure of disease status.



Action Agendas

Priority actions	Ongoing activities	Notes from collective reflection
Conducting support groups (Hluvukani)	Support groups conducted at clinics and in the community, focused on patients with chronic diseases.	The sub-district management and community stakeholders confirmed that these activities have been taking place and acknowledged the value thereof.
Re-introducing support groups (Thulamahashe)	CHWs are conducting a support group with patients who were previously part of this support group and are in the process of recruiting new patients.	
Conducting health talks in the facility (Dwarsloop)	Health talks are conducted in the health facility every morning. The CHWs also conduct health talks when doing home visits.	Stakeholders also reported that the workload of the nurses and outreach team leaders have been reduced because CHWs understand their roles and are able to work more independently.
TB 'DOT'ing (Marite)	CHWs conduct TB DOTing with patients referred from AQUITY (a developmental partner), three times a week.	CHWs reiterated that they are able to perform their duties very well because they now have confidence and understand their roles better.
Educating family and patients on disclosure (Belfast)	CHWs conducted a support group on disclosure, for patients along with one family member, with support from OTLs, OPMs and clinic committee member.	

d) Reflections

CHWs reported that the Community Mobilisation Training (Fig. 4) not only assisted them to fulfil the activities committed to in the action agendas, but also improved their confidence, skills and knowledge. CHWs reported to feel

recognised by the health systems, communities and local authorities; with improved engagement and partnership between the different stakeholders.

The sub-district health system management acknowledged the CHW's role in improving community health and social issues, confirming the urgent need to address CHWs employment as the

utility of this cadre of workers has been clearly demonstrated.

The positive outcomes of this process led to the establishment of a sub-district CHW platform, led by the outreach team focal person and consisting of a CHW representative from each local area in the sub-district.

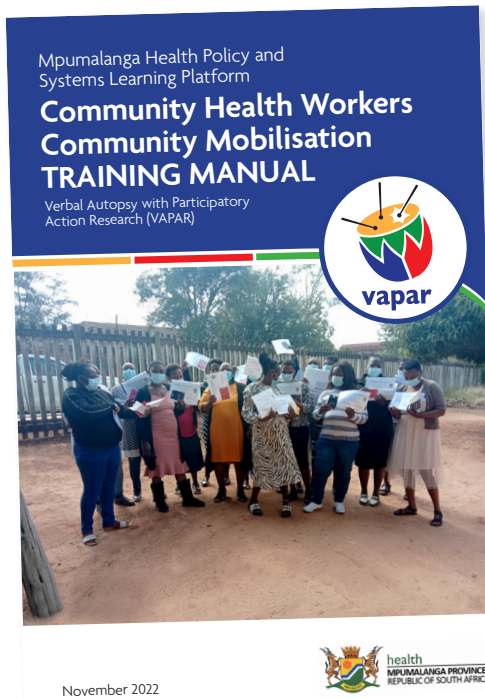


Figure 4: CHW Community Mobilisation Training Manual

www.vapar.org

The research is supported by the Health Systems Research Initiative from Department for International Development (DFID)/ Medical Research Council (MRC)/ Wellcome Trust/ Economic and Social Research Council (ESRC) (MR/N005597/1, MR/P014844/1) and with support from the University of Aberdeen Grand Challenges Research Fund (GCRF), Scottish Funding Council (SFC). The work is a collaboration between the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa, Directorate for Maternal, Child, Women and Youth Health and Nutrition, Mpumalanga Department of Health, South Africa, Queen Margaret University, Edinburgh, Scotland UK and the University of Aberdeen, Scotland UK. Image credits: © VAPAR 2021 Permissions have been secured for the reproduction of images.



Queen Margaret University
EDINBURGH

