



### ‘Setting the Scene’: Persons lost to follow up with HIV/ TB treatment

VAPAR yi tlakusa vumbhoni byo tumbuluxa na ku tirhisa na vukorhokeri na miganga ya le makaya. Ntirho wa hina wa sweswi wu kongoma eka ku aka vuswikoti bya vatirhi va rihanyo ra vaaki eka ku tumbuluxiwa ka vumbhoni hi xihantla eka HIV na TB, tani hi xiphico lexikulu xa rihanyo emigangeni va vatirhisani. Xitlhokovetselo lexi xi humesa- xiphemu xa 1: datha yak u fa ku suka eka MRC/ Wits- Agincourt Unit’s Health and socio-Demographic Surveillance System (HDSS); xi yenge xa 2: vumbhoni lebyi tumbuluxiweke hi miganga ku twisisa ku antswa Ndlela leyi goza ra laha kaya r inga lulamisaka ha yona timhaka leti hlawuriweke; na xiphemu xa 3: nxopaxopo wa tibuku.

#### 1. Verbal Autopsy

##### (a) ndzhwalo wa mavabyi

Verbal autopsy (VA) I Ndlela ya ndzavisiso yak u pima swiyimo na swivangelo swa vutshunguri swa mafu hinkwawo endzeni na le handle ka switirhisiwa swa rihsnyo eka vaaki. Wits/Agincourt HDSS yi katsa vaaki va xifundzankulu lava seketelaka ku andlala. Hi kambisisile dathsa ya VA ku pimandzhwalo wa HIV/AIDS na TB hi ku famba ka nkarhi (Fig. 1).

- **Significant improvements** in HIV/TB burden over the period 2012-19
- **20-49-year-olds largely affected** - account for 61% HIV, 66% TB deaths (2019)
- **72% TB deaths in males** (2019). HIV-related deaths 42%: 58% (M:F) (2019)

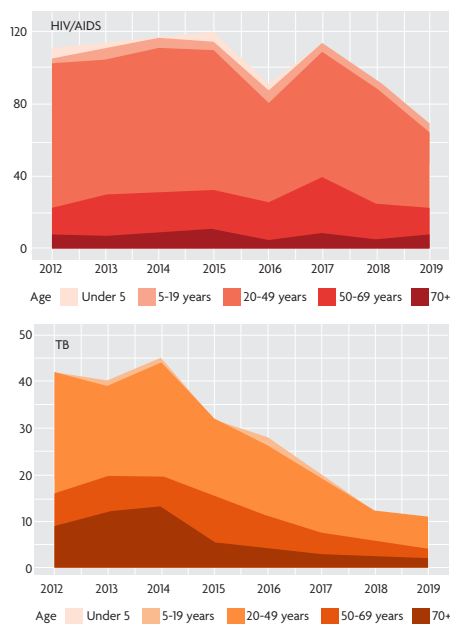


Figure 1: Number of HIV/AIDS and TB related deaths in Agincourt HDSS 2012-19

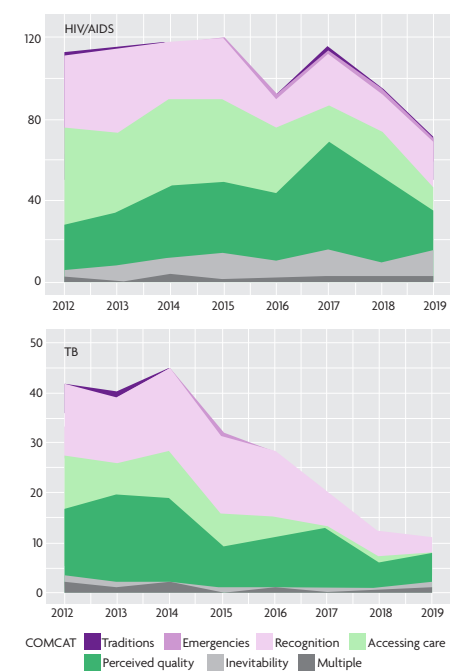


Figure 2: Circumstances of Mortality Categories (COMCATs) by year for HIV/AIDS and TB related deaths in Agincourt HDSS 2012-19

##### (b) swiyimo swa fu ka

Hi humesile ndlela yo kambela swilaveko swa munhu hi yexe na mahanyelo hi nkarhi wa rifu na le kusuhi na yena, na ku hlamula ka sisiteme ya rihanyo, ku katsa na datha ya ndzhwalo wa mavabyi. Swiyenge leswi kulu swa swiyimo leswi fambelanaka na ndzhwalo wa HIV/TB I : (Fig. 2).

#### HIV (2019)

- 32% reported failures to **recognise severity**
- 29% reported problems with **perceived quality**

#### TB (2019)

- 54% reported problems with **perceived quality**
- 28% reported failures to **recognise severity**

#### 2. Participatory Action Research

hi kumile swilo swa nkoka swa rihanyo ra laha kaya hi ku tirhisa ndzavisiso wa maendlelo yo ngehenelela ku seketela ku ngehenelela hi xihatla ka ma CHWs na ku aka vuswikoti eka tindlela ta ndzavisiso wa xihantla. Ma CHWs, na ti clinic committee members, clinic outreach team nurses xikan’we na community stakeholders, ku lemukiwile ku tsandzeka ku landzelela loko swi ta eka HIV/ TB defaulting ku twisisa timhaka ta mphakelo wa vukorhokeri: mavonelo yo biha lama kombeteliwaka eka mahanyelo yo pfumala xichavo eka vatirhi va swa rihanyo na vavabyi lava khumbaka miganga na sisiteme ya rihanyo.

**(a) swivangelo swaku tsandzeka ku landelela**

- General negative attitude towards the health system, by health workers and communities
- Disclosure and stigma
- Migration
- Missing medications and clinic appointments
- Long waiting time at facilities
- Lack of food due to poverty

**(b) switandzhaku swaku tsandzeka kulandzelela**

- Ku lwisana ni mirhi leswi tisaka nxungeto wun'wana wa rihanyo hi ku tsana ka fambiselo ra nsawutiso
- ku engetela tinhlayo ta ku tsandzeka ku landzelela swi voniwa swi fambelanisiwa na ku pfumala vuswikoi eka ma CHWs
- Vutihlamuleri byi n'wana lebyi honisiwaka hi ku ringeta ku landzelerisa ni ku sungula nakambe muvabyi un'wana ni u n'wana la nga landzeleriki

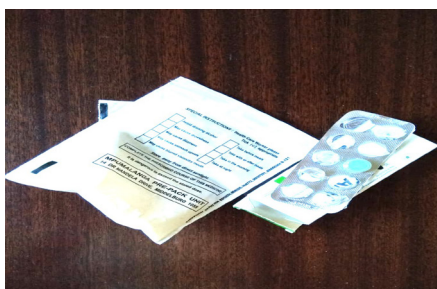


Figure 3: Skipping medication collection dates described as the cause of persons lost to follow up with HIV/TB treatment

Swin'we ni ti Ndlela tin'wana ta participatory action research(ku nghenelela), vakhomaxiave va leteriwiile eka photovoice laha ku tirhisiwaka tikhamera na ti foyini ku hlengeleta na ku vutisa vumbhoni lebyi voniwaka ku suka eka mbango wa ndhawu. Leswi a swi ri ntlhonthlo hikwalaho ka ku soriwa loku fambelanaka na swiyimo leswi na ku siveriwa ka ku tirhisiwa ka switirhisiwa swo rhekhoda hi ku vona swo fan ana ti khamera eka switirhisiwa swa rihanyo. Vatekaxiave van ga ri vangani va swi kotile ku tirhisa endlelo leri ku nga langutiwi mintlhonthlo (Figs. 3-4).

**(c) goza ra ndhawu**

Endzhaku ka ku lavisisa ku vilela ka rihanyo na vatlangi va nkoka, ajendaya maendlelo yi endliwile (see overleaf). Yi katsa swilo leswi rhangelaka hi ma CHWs (local awareness campaigns, drawing patients' medication schedules, establishing local support groups and encouraging patients to utilise local clinics) eka swi swi nga leka sisiteme ya rihanyoto (improving patient tracing systems, training CHWs, food supplementation, addressing employment of CHWs, and verifying patients' information).

**(d) Refections**

Ma CHWs ya vikile leswaku vuleteri bya ku hlengeleta vaaki (Fig. 5) yive ni vuyelo byo tala lebyinene.vuswikoti bya maendlelo ya ndzavisisoyo nghenelela byi kumiwile, vaengetele ku tshemba eka ku vulavula emahlweni ka vanhu na ku burisana na miganga na vatrhi va titlilini. Ma CHWs va kombiile leswaku va tiyimisele ngopfu ku nghenelela eka miganga tanihilaaha swi kombisiweke hakona hi ku tinyiketela ka vona ku rhangela mtshalatshala yo lemukisa vaakiindicated. Va fambisi va matirhelo ya titlilini na vaongori va ku fikelela titlilini a va



Figure 4: Long queues at health facilities described as causes of persons lost to follow up with HIV/ TB treatment

BETA VERSION REVIEWED FEB 2021

Mpumalanga Health Policy and Systems Learning Platform

Community Health Workers  
Community Mobilisation  
TRAINING MANUAL



Verbal Autopsy with Participatory Action Research (VAPAR)

Figure 5: CHW Community Mobilisation Training Manual



## Collective Local Action Agenda

ACTION	ACTORS	WHEN	MONITORING
<b>Community (including CHWs)</b>			
1. Drawing up patient medication schedules	<ul style="list-style-type: none"> <li>- CHWs</li> <li>- Patients</li> </ul>	Ongoing as of May	Increased in number adhering patients
2. Establishing community-based support groups for HIV/TB patients	<ul style="list-style-type: none"> <li>- CHWs</li> <li>- Lay counsellors</li> <li>- Induna</li> <li>- Nurses</li> </ul>	As soon as possible	Increased in number of people accessing and attending support group
3. Check clinic cards and regularly encourage patients to collect their medications during households	<ul style="list-style-type: none"> <li>- CHWs</li> <li>- Family members</li> </ul>	Ongoing as of May	Increase in number of patients whose medication schedule is up to date
4. Re-initiating and continuous monitoring of patients/persons lost to follow up HIV/TB	<ul style="list-style-type: none"> <li>- CHWs</li> <li>- Nurses</li> </ul>	As soon as possible	Improved patient adherence
5. Community awareness campaigns	<ul style="list-style-type: none"> <li>- CHWs</li> <li>- Induna</li> <li>- OTL</li> </ul>	As soon as possible	CHWs becoming more visible during community wanes campaigns
6. Encourage patients to collect their medications at their respective villages	<ul style="list-style-type: none"> <li>- Induna</li> <li>- Clinic health committee</li> <li>- Nurses</li> <li>- CHWs</li> </ul>	As soon as possible	Reduced number of persons lost to follow up
<b>Government Departments</b>			
7. Improving food supplement coverage for HIV/TB patients	<ul style="list-style-type: none"> <li>- Social workers</li> <li>- Nurses</li> <li>- CHWs</li> </ul>	As soon as possible	Increased in number of people receiving food parcels
8. Training of all CHW on CCMDD (Dablapmeds)	<ul style="list-style-type: none"> <li>- DoH</li> </ul>	As soon as possible	Clear understanding of the feasibility of water harvesting
9. Verify patient's information while they are still at the clinic premises	<ul style="list-style-type: none"> <li>- Clinic data captures</li> </ul>	As soon as possible	Improve tracing of persons lost to follow up for HIV/TB treatment
10. Linking patients to CHWs during treatment initiation while they are still at the clinic	<ul style="list-style-type: none"> <li>- Nurses</li> <li>- Lay counsellors</li> <li>- Family</li> </ul>	As soon as possible	Reduced number of of persons lost to follow up for HIV/TB treatment
11. Reducing waiting period that results in long ques at clinics	<ul style="list-style-type: none"> <li>- Clinic health committee</li> </ul>	As soon as possible	Reduced waiting times
12. Improving the tracing system of persons lost to follow up	<ul style="list-style-type: none"> <li>- DoH</li> <li>- OTLs</li> </ul>	As from August	Increase in number of traced patients
13. Permanent employment of CHWs	<ul style="list-style-type: none"> <li>- DoH</li> </ul>	End of 2022	Progress towards getting all CHWs permanently employment
<b>Researchers</b>			
14. Investigating why patients give wrong incorrect personal information at the clinic	<ul style="list-style-type: none"> <li>- Wits/Agincourt</li> </ul>	Anytime from now	Report illustrating why patients give incorrect information



### 3. Literature review on loss to follow up with HIV/TB treatment and role of CHWs

#### (a) Epidemiological and impact analysis

→ Afrika-Dzonga yina nhlayo leyikulu ya vanhu lava hanyaka na HIV, with 7.52 million of the estimated 36.9 million vanhu lava hanyaka na HIV na AIDS e Afrika-Dzonga (1). Furthermore, TB remains in the top causes of death in South Africa with an estimated incidence of 567 cases per 100,000 population in 2015 (2). The growing threat of multi-drug resistant TB are of concern and South Africa reported the second highest number of MDR-TB (4,5). Levels of HIV and TB co-infection are very high, with as many one third of people with HIV also infected with TB and TB accounting for 1 in 4 HIV deaths (4).

Afrika-Dzonga ri na nongonoko lowu wa vutshunguri bya antiretroviral lowu nga kwalomu ka 4.3 wa timilyoni ta vanhu lava nga eka vutshunguri (6, 7). Nkambisiso wun'wana wu hlamuserile kutlakuka ka nkarhi wa vutomi e KZN ku sukela hi 2003-14 HI 15.2 wa malimbe na 17.2 wa malimbe (vavanuna na vavasati hi ku landzelana), 79.7% na 90.7% ku tlakuka loku leswi vangiwaka hi ku hunguteka ka mafu lama fambelanaka na HIV na TB (9). Hi mayelana na vutshunguri bya TB, Afrika-Dzonga ri amukerile pfhumba ra “ku yimisa TB” leru kunguhataka ku tshungula hi Ndlela leyi humelelaka kwalomu ka 90% ta timhangu ta TB leti tivisiweke na ku fikelela xikongomelo xa WHO xo herisa TB hi 2035 (10).

#### → Uptake and adherence sub-optimal

Ku nga khathariseki ku antswisiwa ka vutshunguri, ku amukeriswa nak u namarhela swi tshama swiri ehansi ka kahle. Leswaku vutshunguri bya HIV na TB byi kota ku tirha kahle, vanhu va fanele va namarhela swiyimiso leswi tiyeke swa mirhi (11, 12). In 2018, ku ehleketiwa leswaku eva vanhu va 13.8 million lava hanyaka na HIV lava va kumekaka e East na Southern Africa, only 58% vav e nak u tshikeleriwa hi xitongwatsongwana (13), although official defaulting rates for HIV are not nationally documented. In 2018/19, Mpumalanga

Department of Health (MDoH) documented 6.6% of the population with TB are lost to follow up, (42). However, for those that test positive with TB and never initiate treatment, rates are expected to be between 15-18% (2).

#### → Defaulting linked to health systems and individual challenges

Kunamarhela swi vuriwa tani hi vanhu lava kotaka ku landzelela mfumo lowu vekiwake (14, 15). Kunamarhela l swilo swa nkoka loko swita eka ku tshungula HIV and TB, swi hunguta na tinxaka leti lwisanakana mirhi (3, 5). Ku nga namarhele swi hlamuseriwa tani hi xivangelo nkulu lexi tsandzekisaka ku tirha ka treatment ya HIV (16). Swi vangelo swa ku tshika treatment swi voniwa hi ndhawu leti anameke, ndhawu leyi hanyeke kahle na swipimelo swa munhu hi xiyexe. Although these often overlap, individual constraints are largely due to stigma, poor understanding of treatment and forgetfulness. Whereas health system constraints are problems associated with accessing care, such as having large distances to travel, long waiting times and inconvenient clinic operating hours (2). This is evidenced further by findings that adherence is greater in urban areas, in females and older populations, as these populations describe less barriers in accessing care and loss of time away from work (17, 18, 19, 20).

#### (b) Policy and strategy

#### → Defaulting recognised in policy and strategy

Mfumo wa Afrika-Dzonga wu lava ku yisa emahlweni ku tatisa kukumeka ka mimirhi ya HIV na TB. The National Strategic Plan for HIV, TB and STIs 2017-2022 states that of the R23 billion that funds the HIV and TB services, the South African Government pays for 80% (21).va ndzawulo ya rihanyo va lemuka xiphiquo lex inga kona lexi vangiwaka hi vanhu lava van ga landzeleriseki rihanyu ra vona hi ku teka treatment, this is reflected in key priorities; 'Improving long-term retention in care of both HIV positive and TB patients'; 'Integrated services to improve access to services'; and 'Community outreach' (21,22).

#### → CHWs critical service delivery mechanism

Tanihleswi vukorhokeri byi hluvukeke k uva lebyi simekiweke eka vaaki na swona ku kongomisiwa kamfikelelo nak u hlayisiwa eka nhlayiso swi andzile, ti CHWs ti vile xilotlelo eka ku ncinca loku (33, 37). CHWs, who in 2011 outnumbered nurses in primary health clinics by 7:1 (43) sweswi va endla mintirhi yo tala leyi khale a yi endlwiwa hi vatirhi va ri hanyo ku nga tinese (33). In South Africa, nseketelo lowu kulu lowu nyikiwaka vanhu lava hanyaka na HIV kumbe TB wu nyikiwa hi lava vuriwaka Ward-Based Primary health Care Outreach Teams (WBPHCOTs). A WBPHCOT yi katsa enrolled or professional nurse as outreach team leader, 6 to 10 CHWs and one data capturer (41). Ku ncinca loku ku vangwiwa hi leswaku eka matiko ya n'wana rihanyo a raha kumeki ntsena e tlininiki kambe ti tisiwa nale mugangeni laha vanhu va tshamaka kona (37). Ndzawulo ya rihanyo yi lava kuya mahlweni nak u tirhisa leswi vuliwaka WBPHCOT ku vuyisa vanhu lava ava ngaha landzelerisi rihanyu ra vona, vanhu lava va vabyaka hi mavabyi yo fana na TB and/ or HIV (42). Nseketelo lowu nyikiwaka hi ma CHWs wu nga vuriwa hi swiyenge swimbirhi: (i) va kota ku landzelerisa nak u landza vanhu emakaya va vuya tlininiki ku ta sungula ku nakekela rihanyu ra vona(ii) va nyika nseketelo nak u pfuneta eka lava va tekaka treatment ya HIV and / or TB.

#### → Stigma, trust and mobile populations challenges adherence

Ma CHWs ma endla ku landzelerisa eka lava tsandzekaka ku landzelerisa na ku nyika nseketelo ku hlayisa vanhu eka vutshunguri bya HIV na TB. 90% wa ku landzelerisa loku endlwiweke hi ma CHWs a ku ri vanhu lava va lahlekile eka ku landzelerisa ku suka eka vutshunguri bya HIV/TB (32). Ma CHWs va nyikiwa nxaxamelo wa vanhu lava nga tsandzeka ku kuma vutshunguri naswona va na vutihlamuleri byo endzela makaya ya vonadku va simeka nakambe endzeni ka vukorhokeri (2). Eka nkambisiso wa vanhu lava lahlekeke eka ku landzelerisa ku suka eka vutshunguri bya HIV lava ma CHWs va





koteke ku va landzelela hi 2016 ku ya eka 2017. In a study of individuals defaulting from HIV treatment whom CHWs were able to trace in 2016-17, 62% endzhaku va vikile etitliniki ku ya kuma vutshunguri endzhaku ka ku landzelerisa loku humeleleke na ku rhumeriwa nakambe ku suka eka ma CHWs. Leswi swi yile ehansi ku ya eka 51% hi 2018-2019(32). For TB, ya lava va tlheleke va rhumeriwa, 73% va vikiwile kuya etitliniki hi 2018-19, ku tlakuka ku suka eka 52% hi 2016-17(32). Hi tlhelo raku landzelerisa, xin'wana xa swiphiqu leswikulu xi voniwa xi ri eku kumeni ka lava tsandzekeke ku landzelerisa. Swiviko swa tiadirese ta mavunwa, mavito na vuxokoxoko byo tihlanganisawin'we na mhaka ya leswaku ku na nhlayo ya le henhla ya vahlampfa lava rhurhelakankarhi na nkarhi ku ya tirha swi vikiwa tanihi swihinga eka ku landzelerisa vanhu(32, 33).

→ 'Adherence clubs' a promising intervention to improve trust relationships and adherence

Hi 2007, ku sunguriwe mintlawa yo namarhela ekapa-vupeladyambu eka vanhu lava hanyaka na HIV, na swona endzhakunyana yi hangalaka ngopfu hi madokodela lama ng ariki na mindzelekano, nhlango lowu ng ariki na mfumo hi 2011 (23, 40). Xipano lexi fambisiwaka ngopfu hi ma CHWs xindlandlamuxa ku hlaysiwa ka muvabyi na ku namarhela ka vutshunguri. Vanhu va katsiwile eka swipano leswi endzhaku ka loko swiyimo swa vona swi hlamuseriwile tani hi leswi tiyeke, hi nhlayo ya vona ya xitsongwatsongwana yi tshikeleriwa ku ringana tin'hweti tinharhu (23). Ku katsa eka mintlawa yak u namarhela swi pfumelela mirhi ku nyikiwa hi nhlayo leyikulu, ku vekiwa tihlo loku nga tolovelekangiki na minkarhi ya nseketelo wa tintangha. Ku kamberwa ku kombisile ku antswisiwa ka mimpimp yak u hlaysiwa na ku namarhela vutshunguri eka 97% ku kanetana na 85% wa milawu na minongonoko ya ART ya ntolovelo (24, 25, 26). Ku humelela ku vuriwa leswaku ku vangwiwe hi ku olova ku kuma mirhi ni nseketelo wa risima swinene wa ntsamisano(27-29).

Vuxaka lebyi tshembhiwaka bya nseketelo byi fambelanisiwa na ku tifuma lokukulu ka muvabyi na ku antswisa ku tiyimela na ku hunguta ku soriwa na ku karhateka ka miehleketo hikwalaho ka vutshunguri bya vutlhari swinene(34-35). Ku ya emahlweni, vutshunguri emugangeni nale kaya byi hunguta swihinga swo fan ana minkarhi yo leha yo rindza, titliniki leti taleke ngopfu na ntshukelelo wa timali(35, 36). Leswi swi seketeriwa hi swikumiwa leswi kombisaka leswaku lava ng ana nseketelo wa vaaki va na mimbuyelo yo antswa ya rihanyo na swona va tala ku namarhela vutshunguri ku tlula lava nga eka nseketelo lowu simekiweke eka ndhawuya vutshunguri (12,33,35,37-39).

→ CHWs perform many vital roles, and in the face of many challenges

Ma CHWs ma endla mintirho eka vaaki leyi khale a yi endlwa hi vaongori eka titliniki, swo fan ana ku veka tihlo eka swikombiso, ku endla maendo ya le makaya na ku veka tihlo eka ku namarhela vutshunguri hi ku tirhisa ku hlaysiwa ka tiphilisi (33). Kutlula kwalani, hakanyingi va nyika nseketelo lowu engetelekeke hi ku tsundzuxa vanhu I mirhi ni ku hlangana ni ku hlengeleta swileriso swa dokodela (32, 33). CHWs e Gauteng na le Limpopo vahlamuserile ku endla vutshunguri lebyi langutiweke hi ku kongoma eka vavabyi va TB, laha vav eke tihlo eka vavabyi lava nwaka mirhi leyi lavekaka(40).eka swiyimo swin'wana, ma CHWs ma tlhela ma tlanga xiave xa nkoka eku seketeleni ka mindyangu ya vanhu hi ku sweka, ku basis ana ku endla mintirho ya siku na siku(33). Vuxaka lebyi bya nseketelo I bya nkoka eku hluleni ka swihinga leswi nga tisaka kulahlekeriwa eka ku landzelerisa eka vutshunguri.

Kasi ma CHWs hi ku tirhisa WBPHCOTs I swa noka swinene ku hunguta ku lahlekeriwacku landzelerisa eka vutshunguri bya HIV na TB, hinkwavo vav ula leswaku a hi seketeriwi ku mbe ku nyikiwa switirhisiwa hi Ndlela leyi faneleke naswona hi titshege hi vukahle na nsusumeto wa munhu hi xiyexe ku suka eka ti CHWs (43,44). Hambileswi mfumo wu ng ana matshalatshala yo veka ximfumo na ku hlanganisa ma CHWs eka sisteme ya rihanyo ra vaaki swihinga swo

tala swi kona. Ku tirhisiwa ka WBPHCOTs yi vile ma ku nonoka naswona yi nga ringani na swona ku na ku hlanganisiwa ka le hansi. Hi 2017, 42% ntsena ya swipano leswi lavekaka a swi simekiwile leswi ng ani swo tala leswi ng ariki na vatirhi lava ringaneke. Ku tlhela ku va na ku lemuka ka le hansi swinene ka mintirho na mintirho ya ti CHWs leti andlariweke eka miganga. Ku tlula kwalaho, hambileswi ku lemuka vuswikoti bya WBPHCOTs ku tlakusa goza ra laha kaya milawu leyi a yi hlamuseriwanga kahle yi ri ya nkoka kumbe ku seketeriwa(45).

### (c) Conclusion: CHWs "the backbone for accessible care and support"

Hambileswi ku ng ana nhluvuko HIV na TB swi tisa mintlhontlho leyikulu. Vutshunguri byi simekiwile kahle naswona bya kumeka. Hambiswiritano, kutiyisisa kunamahela I ntlhontlho, kuna vumbhoni lebyi nga erivaleni bya swiivangelo leswhlengeleta swileriso swa dokodela endlaka leswaku vanhu va tsandzeka ku landzelerisa eka vutshunguri bya HIV na TB. Ma CHWs va endla mintirho ya nkoka eku landzeleleni na ku simeka nakambe vanhu eka sisteme ya nhlaysi, xikan'we na ku nyika nseketelo wa matimba ek avanhu ku sivela ku lahlekeriwa eka ku landzelerisa ku humelela. Vuxaka lebyi tshembisiwaka bya ku nyika ku seketela ku lwisana na swiphiqu leswi fambelanaka na ku lahlekeriwa ku landzelerisa. Swi le rivaleni leswaku ti CHWs I buluho leri tshembhiwaka exikarhi ka vanhu na sisteme ya rihanyo, naxilotlelo xo hunguta ku lahlekeriwa ku landzelerisa, na ku endla leswaku vanhu lava nga sirhelelekangiki va fikelela vukorhokeri lebyikuly. Handle ka nseketelo lowu faneleke ku tshamiseka ka vuvekisi a swi tiyisiwi.

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