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## “Life is so easy on ART, once you accept it”: Acceptance, denial and linkage to HIV care in Shiselweni, Swaziland



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### ABSTRACT

**Background:** Timely uptake of antiretroviral therapy, adherence and retention in care for people living with HIV (PLHIV) can improve health outcomes and reduce transmission. Médecins Sans Frontières and the Swaziland Ministry of Health provide community-based HIV testing services (HTS) in Shiselweni, Swaziland, with high HTS coverage but sub-optimal linkage to HIV care. This qualitative study examined factors influencing linkage to HIV care for PLHIV diagnosed by community-based HTS.

**Methods:** Participants were sampled purposively, exploring linkage experiences among both genders and different age groups. Interviews were conducted with 28 PLHIV (linked and not linked) and 11 health practitioners. Data were thematically analysed to identify emergent patterns and categories using NVivo 10. Principles of grounded theory were applied, including constant comparison of findings, raising codes to a conceptual level, and inductively generating theory from participant accounts.

**Results:** The process of HIV status acceptance or denial influenced the accounts of patients' health seeking and linkage to care. This process was non-linear and varied temporally, with some experiencing non-acceptance for an extended period of time. Non-acceptance was linked to perceptions of HIV risk, with those not identifying as at risk less likely to expect and therefore be prepared for a positive result. Status disclosure was seen to support linkage, reportedly occurring after the acceptance of HIV status. HIV status acceptance motivated health seeking and tended to be accompanied by a perceived need for, and positive value placed on, HIV health care.

**Conclusions:** The manner in which PLHIV process a positive result can influence their engagement with HIV treatment and care. Thus, there is a need for individually tailored approaches to HTS, including the potential for counselling over multiple sessions if required, supporting status acceptance, and disclosure. This is particularly relevant considering 90-90-90 targets and the need to better support PLHIV to engage with HIV treatment and care following diagnosis.

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## 1. Introduction

Timely uptake of antiretroviral therapy (ART) has a considerable effect on individual HIV-related health outcomes and on reducing the likelihood of HIV transmission (Cohen et al., 2011; Gardner et al., 2011; INSIGHT START Study Group, 2015; Jenness et al., 2012; The TEMPRANO ANRS 12136 Study Group, 2015). The UNAIDS 90-90-90 targets propose that with 90% of people living with HIV (PLHIV) knowing their status, 90% ART initiation

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for those diagnosed and 90% viral suppression for those on ART, HIV could be eliminated by 2030 (UNAIDS, 2014). Several countries are now adopting 'Test and Start' approaches in light of recent WHO guidelines (World Health Organisation, 2015), whereby providers offer ART for all individuals diagnosed HIV positive, irrespective of CD4 count. High coverage and uptake of HIV testing, linkage to HIV care, treatment initiation, retention in care, and maintained adherence to ART are required for Test and Start to reduce HIV incidence successfully (Gardner et al., 2011; Gardner and Young, 2014; Hayes et al., 2015). However, shortfalls exist at each of these stages (Gardner et al., 2011; Kilmarx and Mutasa-Apollo, 2013; Nachega et al., 2014).

Community-based HIV testing services (HTS) can achieve high uptake, particularly among first time testers, underrepresented groups such as men, and those in early stages of disease (Bassett et al., 2014; Mills and Ford, 2012; Negin et al., 2009; Parker et al., 2015; Tumwebaze et al., 2012; Tumwesigye et al., 2010; van Rooyen et al., 2013; Wachira et al., 2012). Yet, reported rates of linkage to HIV care following diagnosis can be low. Recent findings from the ANRS 12249 TasP trial in South Africa demonstrated just 36.9% linkage to care within three months, among those tested HIV positive by home-based HTS and not in HIV care at the time of referral (Plazy et al., 2016), compared to linkage rates found in Kenya, which were 42% following home-based HTS (Medley et al., 2013).

Factors that can support or undermine linkage to HIV care have been documented, including access barriers such as transport costs and distance to health services (Mills and Ford, 2012), and the perception that medical care is not required in the absence of symptoms (Braunstein et al., 2011; Nachega et al., 2014; Rosen and Fox, 2011). The reasons for patients' clinic non-attendance may be complex and unintentional, including competing time demands and anticipated harsh provider attitudes (Ware et al., 2013). Authors argue that how people process an HIV-positive result, their subsequent actions and their support needs remain insufficiently understood (Gerdtts et al., 2014; Mills and Ford, 2012; Wachira et al., 2012). The need for more research on this topic is increasingly pertinent in light of the move towards Test and Start, with linkage to care presenting a critical gap that could undermine its effectiveness in reducing HIV incidence (Iwujii et al., 2016). Swaziland is one of the first countries in sub-Saharan Africa to pilot Test and Start amongst the general population, with a Médecins Sans Frontières (MSF) and Swaziland Ministry of Health (MoH) implementation study in Shiselweni since 2014 and plans for national adoption imminently.

Swaziland has the highest reported HIV prevalence worldwide (31% of 18–49 year olds; Swaziland Ministry of Health (2012)). As part of a MSF/MoH decentralised HIV and TB care project in the Shiselweni region of southern Swaziland, community-based HTS is one of the services provided. These HTS approaches were recently evaluated and found to have achieved high levels of HIV testing (e.g., 86% uptake reported by a home-based HTS campaign) but with just 34% of those testing HIV positive then recorded as linked to pre-ART care at an HIV care facility within six months of the test date (Parker et al., 2015). Project data suggest that these rates of linkage to care have improved to around 50% since 2015, following the implementation of a range of linkage support strategies. These strategies include individual case management with intensive counsellor follow-up, point-of-care CD4 count, and a buddying scheme, which connects newly diagnosed HIV-positive individuals with a Rural Health Motivator in their community. Yet, it is not exactly known why linkage to care rates improved (or which strategies had the greatest effect), and the factors supporting or hindering individuals' from linking to care following HIV diagnosis are not well understood. It was therefore pertinent to examine

individuals' experiences with HIV testing and linkage to HIV care to inform potential adaptation of support strategies to meet identified needs satisfactorily.

## 2. Methods

In early 2015, qualitative research was conducted in Swaziland to examine community member and health practitioner experiences with MSF/MoH-provided community-based HTS in the Shiselweni region, in particular exploring factors influencing linkage to care for those testing HIV positive. Data were collected through semi-structured interviews and focus group discussions.

For the purposes of this study, linkage to care refers to attendance at a specified referral facility and registration in the pre-ART or ART register within six months of the HIV test date as this information is recorded and available through the project linkage to care database. The study area was Shiselweni, southern Swaziland, which includes three health zones: Nhlanguano, Hlatikhulu and Matsanjani.

Full ethics approval was granted by the Swaziland Scientific and Ethics Committee and the MSF Ethics Review Board before study commencement.

### 2.1. Sampling strategy and participant recruitment

A stratified purposive sampling strategy was adopted to identify and recruit those able to provide insight into community-based HTS and linkage to HIV care (Marshall, 1996). The study sample included three participant groups (Table 1): Patients who tested HIV positive by community-based HTS interventions (group 1), including those who had linked to care (group 1a) and those who had not (group 1b); health practitioners with knowledge and experience of community-based testing and/or linkage to HIV care (group 2); and members of the communities where the HTS interventions were delivered (group 3, HIV status unknown).

Group 1 participants were selected from a larger cohort of patients in the project's community-based testing and linkage database, including those who had tested HIV positive by community-based HTS between June and November 2014 and either linked to care (using the pre-ART or ART enrolment date) or not (no pre-ART or ART registration recorded) within six months, to explore their experiences with HIV diagnosis and subsequent health seeking. The research team selected patients to include a gender balance and a range of ages, those from each of the three health zones, and a mix of urban and rural dwellings. A team member contacted identified participants with information about the study, requesting their participation. Interviews were arranged with those who agreed at a time, date and location of their choice, which was either in the patient's home, a private room within the health clinic, or a private room within the project office.

Group 2 participants were recruited to include health practitioners from the community-based HTS team, clinic-based HTS staff, expert clients (HIV positive lay counsellors) and nurses responsible for pre-ART and ART enrolment to explore their views and experiences working with patients during HIV diagnosis and linkage to care. Recruitment of this participant group aimed to give insight into provider perspectives on their rapport with HIV patients and to understand how their views on the social and cultural factors influencing linkage to care may confer or differ from patient accounts.

Finally, group 3 participants (community members from the community-based HTS sites) were recruited for focus group discussions to explore their views on HIV testing and access to HIV services, providing important contextual information through insight into shared perspectives and commonly held views.

**Table 1**  
Characteristics of study sample participants and methods adopted for each.

Participant group	Participants	Data collection method
Group 1	Patients diagnosed HIV positive by community-based HTS	Semi-structured interviews ( $n = 28$ )
Group 1a	Who are linked to care	$n = 14$
Group 1b	Who are not recorded as having linked to care	$n = 14$
Group 2	Health practitioners (with knowledge/experience of HTS and linkage to care)	Semi-structured interviews ( $n = 11$ )
Group 3	General community members (HIV status unknown)	Focus group discussions ( $n = 3$ , 6–7 participants per group, 19 participants total; 2 with women aged 17–39 years, 1 with men aged 16–30 years)

Community members were identified through community-based expert clients who recruited six to eight members of their community with unknown HIV status and of the same gender and a similar age.

## 2.2. Data generation and analysis

Data were generated through semi-structured interviews with patients and health practitioners and focus group discussions with community members in Shiselweni from March to May 2015. Interviews with female patients were conducted by a female research assistant (RA). All interviews with male patients were conducted by a male RA save one, which was conducted by the female RA, and all were in siSwati language. The principal investigator (PI; SH) conducted interviews with health practitioners, with most being in English and two a combination of English and siSwati, with the assistance of an interpreter. Interviews averaged 50 min. An RA facilitated focus group discussions in siSwati, with an interpreter and the PI co-facilitating and taking notes, averaging one hour and 40 min. Interviews and focus group discussions were conducted according to topic guides following written informed consent. The consent process included an informed consent form (discussed verbally), with provisions for confidentiality, data storage and requesting consent for audio recording. All interviews were transcribed verbatim or transcribed and translated equivalently to maintain meaning and integrity of data.

Data generation and analysis followed an iterative process, with analysis beginning at the point of data generation and participants being recruited until evidence of data saturation, when adding further participants generated no new findings (Green and Thorogood, 2009; O'Reilly and Parker, 2013). Data were analysed thematically using coding to identify emergent patterns, categories, and concepts from participant accounts. Principles of grounded theory were drawn upon including constant comparison of codes within and between cases to raise codes to a conceptual level and generate theory inductively from participant accounts, and through actively seeking discrepancies from majority themes (Bradley et al., 2007; Glaser, 1999; Glaser and Strauss, 1967).

To ensure analytic rigour, interview transcripts were initially analysed by three researchers independently to identify patterns and descriptive codes from participant narratives. These patterns were discussed, results were checked, and an initial coding framework was developed. Full analysis was conducted by the PI with NVivo 10 as an analytic aid, with the initial coding framework being adapted as analysis progressed. Attention was paid to the role of the researcher in shaping data analysis and interpretation, emergent themes were tested by examining exceptions and counter examples, and findings were triangulated by comparing participant groups. Finally, a fourth researcher (BS) reviewed the NVivo project data and coding to enhance validity and minimise researcher bias.

## 3. Results

Thirty-nine interviews were conducted, with 28 patients who tested HIV positive through community-based HTS initiatives and 11 health practitioners (online supplement Tables 2 and 3). Half of the patients were female and ages ranged from 16 to 69 years. Among the patients identified for recruitment from the project patient database, 52% were contactable, and for those who were non-contactable, there was no telephone number listed on their testing form, the number listed was incorrect, or they are now living outside the study area. For the patients who were contactable ( $n = 31$ ), 100% agreed to be interviewed; of these, 90% completed the interview, obtaining a final sample of 28. Three focus group discussions were conducted with 19 community members in total.

Of the 28 patients who were interviewed, half of them were recorded as having linked to HIV care and half as not. It is noteworthy that during interview 8 of the 14 'not linked' participants reported having actually linked to care, either to the clinic they were referred to or another clinic elsewhere.

Data analysis led to the identification of several key themes as influencing individuals' linkage to HIV care: (1) processing an HIV-positive result and status acceptance and (2) value placed on health care and the perceived need for HIV care services. Fig. 1 depicts these themes, as elaborated in this section.

### 3.1. Processing an HIV-Positive result: shock, doubt and disbelief

Many participants reported experiencing shock after receiving an HIV-positive test result, feeling distressed, and questioning how they were infected and the source of HIV infection. Many struggled to accept the diagnosis, with several doubting or disbelieving the test result.

'I was refusing to accept the result when they were telling me ... I'm still asking myself how I got infected'. P06

'I really cried, I felt pain and was shocked that "oh my word"'. P02

'When sisi [HTC] told me that I am positive, I just did not believe it. So I stayed for two years, and some people would come to do testing, and I would not test because I was like these people tell lies ... '. P05

Periods of non-acceptance that were described ranged from months to years and had marked consequences for many individuals' mental and physical health, seen as a significant barrier to accessing care.

'It is what can make someone ill, the fact that they do not accept'. C06

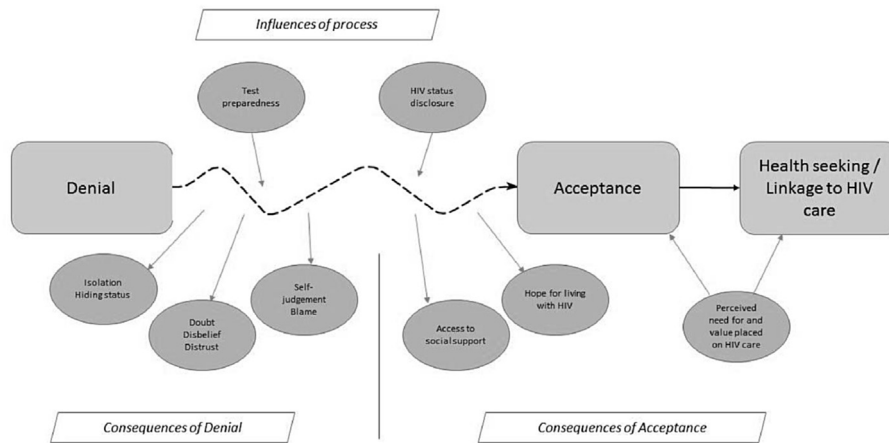


Fig. 1. The process of HIV status acceptance or non-acceptance: influencing factors and consequences.

'I came back and stayed here at home for almost a year, and I would go to Nhletjeni and get some pills [not ART], and then it later got worse and I lay down'. C04

Non-acceptance of HIV status was particularly evident among those who had not felt unwell or were not experiencing symptoms, which was reiterated by health practitioner participants. Participants reported confusion over receiving an HIV-positive result and not identifying themselves as being HIV positive because of their expectation that HIV infection comes with common symptoms.

'If I had got it from him, there would be a difference by now. I would have gotten sick and bedridden, but I just think that I do not know'. C01

'I stayed for the year telling myself that they are lying. It means that my mind was acting childish because I would tell myself, how come I am not sick and I do not have any pain'. P05

Many participants reported undergoing re-testing for HIV to confirm whether the result they had received was true. Re-testing and verifying the HIV-positive result appeared to be an important step in accessing HIV treatment and care and 'taking the necessary steps':

'I wanted to see if the test was for real. I wanted to see if what we did last time was realistic, and I found that it was realistic ... I found that I am really HIV positive, and that is when I accepted that I am really HIV positive and when I started the ART'. C08

'I was tested, and the result was the same as the one I got before ... and then I decided that I should then go to the clinic ... because I have heard two different people sharing that information with me ...'. P11

Still, this could potentially add to participants' confusion, as one participant described receiving discordant results on re-testing:

'I did not believe that they say now I am positive because you see I had tested just that week, and I tested again, I found it positive, and I tested again the last time and found it negative. It made me think, what is happening. That is what is making me question'. C06

### 3.2. Perceptions of HIV risk

Non-acceptance of HIV status was exacerbated by not associating oneself with HIV through judgements about who gets HIV, which shaped a sense of personal risk of infection. The reflections individuals made about their perception of risk for HIV included the described introduction of HIV in Swaziland linked to 'prostitution'; therefore, those who reported few sexual partners felt they were not at risk. Perception of HIV risk continues to have associations with the concepts of morality or social standards despite the generalised HIV prevalence.

'The way in which HIV was first introduced, that HIV is in those who go sleeping around, so for those who know that they take care of themselves, they are far away from thinking of being HIV positive'. HP 02.

'I can say I never got to accept it. What came to me was that I questioned "me and HIV? But I am well behaved"'. P05.

Certain men presented as not identifying themselves with risk of HIV infection, as having multiple partners was seen as a positive and celebrated achievement for men, which they did not associate with the negative connotations of 'promiscuity'. Many men described living a life of Christianity and not believing in sex before marriage, which could be at odds with the reality of their sexual practices, thereby creating misalignment of their beliefs, religious practices, and HIV risk.

'I live a life of Christianity. I was very shocked to find that it is there ... when it comes to sex ... [pause] hmm let me say it is possible for me to have gotten it through that because it does not mean that I am this old and I have never, never had sex without a condom'. C13, male

Those who expected that a positive result could be possible and perceived themselves to be at risk of HIV could accept their status. This was particularly apparent in the accounts of some of the women who suspected HIV exposure through their partner's refusal of condom use or their partner's infidelity, which they felt put them at risk of HIV infection:

'I found my boyfriend's treatment, and he had not told me that he is HIV positive ... I went to get tested and found that I am HIV

positive ... I was expecting it because my boyfriend is HIV positive'. C08, female

### 3.3. Readiness to test and acceptance

Preparedness for the chance of receiving a positive result and pre-test information appeared to be vital for acceptance of one's HIV status. Participants described their feeling of being able to exert choice in testing as influencing their preparedness for dealing with the result and therefore their likelihood of accepting it. Testing incentives were said to undermine this process, and participants described instances where individuals' motivation to test was the incentive (e.g., a t-shirt), rather than to know their health status, which caused them to go into shock on receiving a positive result.

'Testing when you want to test and you wish to test, it is better in your spirit because you initiated it, so the results will also not be so hard to accept emotionally'. C06

'At the tents sometimes, they give incentives. And because as Swazis, we are hungry, so if there is some incentive, I will not stay behind, but that is not good ... because they want to receive those things but will they accept after that? I do not know'. FGD 02–P3

HIV-related counselling and information were seen to be crucial in providing support and reassurance that there is life after HIV diagnosis. Some participants reported needing time to process and come to terms with their result.

'I ended up going for counselling and accepting it. What helped me the most and what I can advise that every person does is to go for counselling because counselling helps a lot; it soothes the soul and makes you able to accept the status you have'. C08

Individuals' acceptance of their HIV diagnosis and their sense of hope and belief for living with HIV was emphasised through social support and encouragement (which was achieved through disclosure). Participants had seen others with HIV surviving, realised that they were not alone or the minority affected by HIV, and had seen the transformative effects of ART, compared to the past when many had seen people around them dying due to HIV-related illnesses. These experiences enabled individuals to move from questioning where HIV could have come from to accepting and looking towards the future.

'I accepted my situation because I have seen others surviving with the virus'. C03

'I was not scared because there are others I know that are living with HIV ... That is what made me not be nervous, as well as looking at other relatives who have passed on because of it and not being educated about it'. C06

### 3.4. HIV status disclosure and linkage to care

Non-acceptance was described as a barrier to disclosure of HIV status as the disbelief, perceived stigma, and fear of negative judgement may force the HIV-infected individuals to hide their positive result. Disclosure was seen to help the process of acceptance and support engagement in care and receiving treatment. It enabled access to social support, reassurance, and encouragement, including for treatment initiation decisions, clinic visits, and

treatment reminders.

'I was able to [disclose] after I had accepted ... I told them that I am now someone who is like this. If you see me taking pills, do remind me to take the pills when it is time'. C08

'I accepted and decided to let them know because I'm going to need their help and I want them to remind me when it's time to take the treatment and also when going to the facility'. P01

Disclosure could influence linkage to care, with some participants who had not accessed care stating that they were waiting to disclose before going to the health clinic. Participants described how those who feared inadvertent disclosure of their status would struggle to take their treatment consistently because they did not want to be seen taking their treatment. This concern was considered significant enough to deter people from even seeking treatment.

'I'm waiting to talk to her first before I can go to the clinic'. C12

'Some people die because of not telling their relatives. You find that a male person has his friend but is unable to tell them that they are taking treatment, so he ends up hiding the treatment ... they stop taking them because they are scared to tell the lover ... that is what kills them'. P03

### 3.5. Perceived need for and value placed on health services

The perceived need for and belief in the benefits of health care were seen to influence whether individuals would link to care or not. This was particularly evident where individuals did not feel unwell, they had not experienced symptoms that they associated with HIV, and where they did not accept their HIV status. This belief therefore created the sense that seeking health care was not urgent, and other life needs, such as work, household activities, and responsibilities, have higher priority.

'I have not gone because I have not even had that cold. I am someone who is working, and I have not felt that I was sick and I cannot even work'. C01

'Some would feel strong, see themselves very good, very healthy, so they wouldn't see the reason for coming to the clinic'. HP 01

For some, avoiding potential imminent health deterioration motivated them to access services even in the absence of symptoms because of the perceived benefits of accessing early care to avoid reaching a 'bedridden state'.

'Going there when you're bit healthy is better than going there when you're already lying down. This way you can live longer, as if you don't have this thing'. C09

'We want life ... it is better to go to the clinic while you still can walk there unlike when you're already sick and bedridden. That is what motivated us'. P08

Avoiding a 'bedridden state' was not only associated with health benefits including avoiding risk of death, but was also seen in terms of stigma reduction. Participants felt they would be able to maintain good physical health with early access to treatment, thereby preventing them from developing symptoms and being identifiable as HIV positive.



'I do not want to fall sick and get bedridden ... and be a written book for anyone to read'. P07

Though ART was described as enabling stigma reduction, some participants felt reluctant to visit health clinics for fear that doing so could reveal their HIV status. They feared confidentiality breaches by health practitioners or of being seen queuing for ART-related services, which could instil feelings of shame. These fears could be particularly influential for those who had not fully accepted their HIV status and who described them as deterring these individuals from accessing HIV care.

'The minute you sit on the bench, you are engulfed with embarrassment and you feel ashamed, but then you must accept yourself and not worry yourself about whether you see your neighbour or anybody. We are all there to get the treatment'. P14

Seemingly, socio-cultural norms and expectations relating to men could create difficulties for their accessing health services, which was mainly described by health practitioner participants who stated that males are less involved in all aspects of health services. Furthermore, men were perceived as not wanting to go to the clinic due to its association as being a woman's place, and the expectation that men should be strong and not seek health care.

'Going to the clinic is something I wouldn't have done except when I'm being driven there in a wheel barrow'. P06 (male)

'They are afraid to use hospitals ... Mainly Swazi men ... They don't believe that much in hospitals. They prefer to do something else'. HP 04

Counsellor attitudes and the approach taken with linkage follow-up were important to patients. When patients felt as though the health practitioner valued their life and wanted them to seek care for their own well-being, it tapped into their sense of valuing and prioritising healthcare. On the contrary, more aggressive approaches when patients felt they were being followed up for the sole purpose of getting them to go to the clinic could undermine their motivation and could cause feelings of disappointment and distrust.

'She really followed up on me, and called me and called me to ask me and said she loved me very much. She stopped once I went there, and I usually say, aw I thought she loved me but she stopped calling me. She stopped once I went there'. P05

#### 4. Discussion

Our study findings suggest that HIV status acceptance is important for a person's engagement with HIV care and access to social support, quality counselling, knowledge, attitudes, and practices regarding health care. The process of status acceptance was influenced by an individual's awareness that there was a heightened probability they would receive an HIV-positive result. Although past studies describe linkage to care and HIV status denial, as far as we are aware, our study is the first to portray acceptance as a longitudinal process in which supporters can intervene to facilitate individuals' acceptance of an HIV-positive result.

While the exact way in which someone processes an HIV-positive result is heterogeneous and individually defined, certain factors could influence the transition towards acceptance. These

include the perception of risk for potential HIV infection, including judgements about HIV; an association of self with images of HIV positivity; and counsellor support offering reassurance, encouragement, and hope for life after diagnosis. Although Swaziland has the highest reported HIV prevalence rate in the world with a generalised epidemic, an association of HIV with 'promiscuity' and 'prostitution' persists. Most participants did not identify themselves with these behaviours and therefore did not perceive themselves to be at risk. This non-association with HIV risk led many to experience shock and disbelief on being diagnosed HIV positive and made accepting the diagnosis particularly challenging.

Other studies have found non-acceptance of HIV status, often termed as denial, to negatively affect individuals' access to HIV care, ART initiation and adherence (Beer et al., 2009; Jenness et al., 2012; Lindkvist et al., 2015; Manirankunda et al., 2009; Nakigozi et al., 2013; Nam et al., 2008; Otieno et al., 2010; Stinson and Myer, 2012; Wringe et al., 2009). Reiterating our findings, doubt and disbelief on receiving a positive HIV result are associated with a lack of HIV-related symptoms (Beer et al., 2009; Nakigozi et al., 2013; Raveis et al., 1998; Wringe et al., 2009), and time can be required to process, come to terms with, and accept an HIV-positive result (Gilbert and Walker, 2010; Raveis et al., 1998). In our study, many reported re-testing for HIV to verify if their result was true, and HIV testing incentives were seen to undermine status acceptance. Denial of HIV status has been linked to poor mental and physical health (Kamen et al., 2012; Moitra et al., 2011). Still, our findings are unexpected, given that shock and disbelief can prevail and prevent PLHIV from accessing HIV care in a setting where HIV knowledge and familiarity is high and where HIV is perceived to be increasingly 'normalised' through increased access to ART, transforming it to a chronic manageable condition (Bernays et al., 2015; Russell and Seeley, 2010).

How individuals respond to chronic diseases, including HIV, are varied and contextual (Bernays et al., 2015; Harris, 2009). Various theories can be applied in understanding individuals' reactions to health and illness, and an HIV diagnosis has been described as a transition (Russell and Seeley, 2010) and biographical reinforcement (Bernays et al., 2015; Carricaburu and Pierret, 1995; Williams, 2000) through reinforcing components of identity and lifetime illness experiences or struggles. Yet, because of commonly held views related to morality and behaviour, an HIV diagnosis in this context appeared to disrupt the 'socially set standards and cultural prescriptions of normality' (Bury, 1982), with a reaction of disbelief and anxiety thus being more common, in line with Bury's (1982) theory of biographical disruption. The reactions to an HIV-positive result described in our study echo some of the stages of grief that Kübler-Ross described by following a patient's diagnosis with a terminal illness, which include shock, denial, anger, bargaining, depression, and acceptance (Kübler-Ross et al., 1972). As individuals progressed towards acceptance, elements of transition appeared, with active adaptation to incorporate illness and its treatment to daily life, developing approaches for self-management of HIV and feeling 'normal' again (Kralik et al., 2004, 2003; Russell and Seeley, 2010; Telford et al., 2006). We found that acceptance, disclosure of HIV status, and linkage to HIV care appeared connected. Disclosure enabled support and reassurance, which aided accessing care and cultivated hope (Gilbert and Walker, 2010; Nakigozi et al., 2013; Nam et al., 2008).

The perceived need for and value placed on health services increased individuals' motivation for seeking HIV care. This could be challenged in the absence of symptoms, where the need for health care was less evident, a factor that has been reported previously (Jenness et al., 2012; Nachega et al., 2014; Nakigozi et al., 2013; Rosen and Fox, 2011). However, some participants described learning about the benefits of early access to treatment

and care through receiving HIV information linked to the Test and Start pilot and through seeing others with HIV experience health deterioration in the absence of treatment. The avoidance of a 'bedridden state', which could render an individual identifiable as HIV positive, had the potential to be a powerful motivator for accessing care. Yet, fear of health practitioner confidentiality breaches and experiencing stigma on being seen attending a health clinic for HIV-related care were reported, as found by others (Beer et al., 2009; Nakigozi et al., 2013; Raveis et al., 1998; Tumwebaze et al., 2012; Wringe et al., 2009). In our study, this was particularly prevalent among those who had not fully accepted their HIV status and appeared to be more vulnerable to self-stigma.

#### 4.1. Limitations

During initial patient interviews, it was clear that the interviewer was being associated with the medical programme, which subsequently improved following adaptations to the study introduction, such as reiterating the non-association of the researchers with medical teams. Interviews conducted with male patients recorded as not linked to care were shorter and less in-depth (including less participant open narrative) than those with females (average interview length: 30 min for males vs. 55 min for females, with the exception of one 72-min interview conducted by a female RA). Interviewer technique is likely to have influenced the narratives of these participants, although this could also reflect characteristics of the participant group.

Nearly half of the identified participants for study recruitment were non-contactable because of a missing or incorrect phone number captured during HTS. This reflects the operational challenges with linkage follow-up and may have affected the results, with these participants potentially having different experiences with testing and linkage to HIV care. In addition, two patients (one recorded as not linked and one linked) did not attend the agreed interview appointment, with unknown reasons for non-participation. However, it appears that the themes that emerged were robust and reiterated sufficiently to evidence data saturation. Furthermore, the general participation response rate was good. Although we had requested that focus group discussions be held with community members who were similar in age, two of the groups had a large age range. These differences may have influenced the group dynamics, as younger participants were quieter than older participants, which reflects the social interactions that can be found within wider Swazi society. The generalisability of the study's findings is limited to the concepts presented, which also may not apply in different contexts or settings.

#### 5. Conclusions

This research shows that how individuals process an HIV-positive result can fundamentally affect their engagement with health services. Status acceptance enabled access to social support and increased a sense of need for and value placed on HIV services, thus influencing individuals' linkage to HIV care. Although situated within a generalised high-prevalence epidemic setting, many participants in our study did not perceive themselves to be at risk of HIV and struggled to accept a positive result. Being asymptomatic could pose particular challenges for accepting an HIV diagnosis and could create less sense of urgency regarding the need for health services. Still, there were also perceived benefits from accessing treatment and care early.

Our findings indicate the need to develop and test linkage support strategies that address individuals' needs and facilitate progression to HIV status acceptance. These could include supporting diagnosis preparedness (e.g., through pre-test

information), exploring individuals' perceptions relating to HIV risk, and expectations for the chance of receiving an HIV-positive result. Counselling with clear goals is important within programmes to support status acceptance and disclosure. A flexible approach to patient follow-up should be considered, with varied intensity and types of support provided depending on the needs of each individual and with the opportunity for multiple sessions beyond the point of HIV testing if required. For example, certain individuals may require more time to process and come to terms with an HIV diagnosis before engaging in HIV care or initiating ART than others. HIV prevention programmes should consider our finding that HIV testing incentives undermined status acceptance as individuals may be less prepared for a potential positive result.

These findings are particularly important in light of the move towards the adoption of Test and Start approaches in many settings, including in Swaziland. Engaging with how people respond to an HIV test result is critical to the success of these initiatives, given how crucial the processes of HIV diagnosis and follow-up are for patients' access to HIV care. Without addressing specific patient support needs and improving linkage to HIV care, these approaches risk being ineffective in reducing HIV incidence and improving the quality of care to PLHIV.

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#### Appendix A Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2017.01.006>.

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