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Factors affecting linkage to HIV care and ART initiation following referral for ART by a mobile health clinic in South Africa: evidence from a multimethod study

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Abstract Linkage to care from mobile clinics is often poor and inadequately understood. This multimethod study assessed linkage to care and antiretroviral therapy (ART) uptake following ART-referral by a mobile clinic in Cape Town (2015/2016). Clinic record data (N = 86) indicated that 67% linked to care (i.e., attended a clinic) and 42% initiated ART within 3 months. Linkage to care was positively associated with HIV-status disclosure intentions (aOR: 2.99, 95% CI 1.13–7.91), and treatment readiness (aOR: 2.97, 95% CI 1.05–8.34); and negatively with good health (aOR: 0.35, 95% CI 0.13–0.99), weekly alcohol consumption (aOR: 0.35, 95% CI 0.12–0.98), and internalised stigma (aOR: 0.32, 95% CI 0.11–0.91). Following linkage, perceived stigma negatively affected ART-initiation. In-depth interviews (N = 41) elucidated fears about ART side-effects, HIV-status denial, and food insecurity as barriers to ART initiation; while awareness of positive ART-effects, follow-up telephone counselling, familial responsibilities, and maintaining health to avoid involuntary disclosure were motivating factors. Results indicate that an array of interventions are required to encourage rapid ART-initiation following mobile clinic HIV-testing services.

Keywords Linkage to care · HIV/AIDS · Barriers to ART initiation · Community-based HIV testing services · Mobile clinic · HIV care continuum · Qualitative · HIV treatment cascade

Introduction

Antiretroviral therapy (ART) for HIV reduces AIDS-related morbidity and mortality (Johnson et al., 2013), and is effective at preventing further HIV transmission (Cohen et al., 2011). Early HIV detection and rapid ART initiation post diagnosis can optimise the health benefits of treatment and prevent secondary transmission. Community-based HIV testing services are effective at reaching previously undiagnosed, asymptomatic people living with HIV (Sharma et al., 2015), and are accordingly important for early HIV detection. However, linkage to treatment subsequent to routine ART-referral from community-based HIV-testing services, such as mobile clinic and home-based testing services, is often poor (Parker et al., 2015; Ruzagira et al., 2017).

South Africa has the largest population living with HIV globally (UNAIDS, 2016). The country implemented a treat-all strategy for HIV in September 2016 and in 2017

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was providing ART to approximately 65% of people living with HIV (Motsoaledi, 2016; UNAIDS, 2017). Mobile clinic HIV testing services are crucial to strategies for increasing awareness of HIV-status (National Strategic Plan Steering Committee, 2017). These services have proven effective at providing HIV testing to individuals who historically are less likely to have been tested, in particular men, as well as younger and healthier populations (Bassett et al., 2014, 2015). However, in South Africa, there are low rates of subsequent linkage to care from mobile testing services. One study in Durban found that 10% of individuals diagnosed HIV-positive at a mobile health clinic linked to HIV care services within 90 days (Bassett et al., 2014). In Cape Town, 51% linked to care within the prescribed time-frame, which ranged from one to 6 months based on baseline CD4 count (Govindasamy et al., 2013). An improved understanding of factors affecting linkage to care from these services is important in ensuring that gains made in increasing awareness of HIV status result in improvements across the treatment continuum.

A pilot randomised controlled trial (the iLink Study) was conducted in an informal urban area in Cape Town, South Africa, from 2015 to 2016 to assess whether a cash incentive (R300, approximately $23) could improve rates of ART initiation among people living with HIV who were referred to a health facility by a mobile health clinic. The iLink Study found no effect of the incentive on ART initiation by the third month (Maughan-Brown et al., 2018a). This finding led to the further question of why a relatively large incentive among a population living in poverty did not result in better uptake of treatment. In subsequent analyses, in-depth interviews conducted as part of the iLink Study revealed significant clinic-related barriers to ART initiation (Maughan-Brown et al., 2018b), that may have rendered the incentive inadequate compensation for the effort required to commence treatment.

A systematic review of quantitative and qualitative studies in sub-Saharan Africa, primarily among patients enrolled at primary health care settings, shows that a range of health system, psychosocial (i.e., involving both psychological and social aspects), and structural (i.e., relating to economic, social, policy, organizational or other aspects of the environment) factors act as barriers to linkage and retention in care (Govindasamy et al., 2012). The main psychosocial barriers were found to be stigma, fear of disclosure, and fear of drug toxicities. Structural barriers included transport costs, distance to health facility, food shortage, and patient-related time constraints. Only a few studies from sub-Saharan Africa have assessed linkage to care among adults newly diagnosed with HIV through mobile health clinics (Sharma et al., 2015), or other community-based services such as home testing (Ruzagira et al., 2017). Studies among populations diagnosed HIV-positive at mobile clinics have focused mainly on the demographic and clinical determinants, with younger age ($\leq$ 30 vs. $>$ 40), being male, being employed, and having a higher CD4 count found to decrease the likelihood of linkage to care in South Africa (Dorward et al., 2017; Govindasamy et al., 2011). In terms of psychosocial factors, non-disclosure of HIV status was found in these studies to decrease the likelihood of linkage (Dorward et al., 2017; Govindasamy et al., 2011). In the context of home-based HIV testing, a broader range of psychosocial determinants of linkage to care was found in one study in South Africa. In this study, linkage to care was more likely among individuals believing that drugs were available at the health facility, being a caregiver for four or more people, and knowing someone who died of HIV/AIDS; and less likely among individuals unsure about the test results, and believing that ART can make you sick (Naik et al., 2015).

To build on the limited evidence to explain poor rates of linkage to care from community-based testing services, this study used multimethods data to elucidate factors that hindered or motivated ART initiation following referral from a mobile health clinic in South Africa. Specifically, prospective cohort data from the iLink Study were used to assess the association between linkage to care and a wide range of psychosocial and structural factors. Follow-up in-depth interviews were conducted to deepen our understanding of treatment decisions within the cohort.

Methods

Data

The iLink Study (April 2015 to August 2016) enrolled individuals diagnosed HIV-positive and referred for ART by a mobile health clinic in Cape Town. ART-referral was based on National Department of Health guidelines at that time: a CD4 count $\leq$ 500 cells/μL. The mobile clinic is operated by an organisation well-known to local communities and has been offering free screening for several health conditions since 2008. The clinic implements a patient-centred approach, including a focus on increasing access, using highly trained staff, situating itself in informal urban areas, and focusing on locations with high foot-traffic. Clinic services are advertised with banners and through the distribution of pamphlets to people passing by and to local residents.

Individuals were screened for study eligibility by the mobile clinic staff immediately after referral for ART. Study eligibility criteria included being 18 years or older; being ART-naïve; and owning a cell phone. Participants completed a baseline survey and were randomly assigned (1:1) to the control or intervention group. The control group received the standard of care: counselling on the benefits of early ART initiation, referral to an ART clinic, and follow-up telephone counselling by the mobile clinic staff (up to six calls over 6 weeks). The intervention group received the standard of care plus a voucher that could be exchanged for R300 cash if ART was started within 3 months. After ART initiation, participants in the intervention group met with the study staff to verify ART initiation and receive the incentive. Data on linkage to care and ART initiation were collected using the Western Cape Department of Health's provincial clinic record database. Data were available on dates of clinic visits, dates of CD4 count laboratory tests, and the dates on which antiretrovirals were dispensed.

The sample frame for the follow-up in-depth qualitative interviews included all iLink Study participants who received the incentive or were successfully contacted 3 months after baseline enrolment (N = 64). Forty-one of these 64 participants were successfully recruited for in-depth qualitative interviews. While sampling was not determined by saturation, no new data emerged from the final interviews, which indicated that saturation was reached. Participants in the intervention group who initiated ART within 3 months were interviewed immediately after they received the incentive. All other participants were interviewed as soon after the 3-month follow-up as possible. Interviews were conducted in Xhosa, the participants' home-language, in a safe and private location that was mutually agreed upon by the interviewer and participant. Interviews were typically conducted in participants' homes or in private rooms at public libraries, which were reserved for the purpose of our study. A semi-structured interview guide was designed to explore (1) ART decision making, (2) concerns and challenges with starting ART, and (3) factors that helped to encourage ART initiation. The interview was designed to elicit factors influencing linkage to care and treatment without interviewers specifically mentioning any potential barriers and motivators.

Measures

'Linkage to care' was defined as a visit to a health facility within 3 months from study enrolment, a common time-period used for linkage to care and treatment studies (Fox et al., 2012). Clinic records were used to create a binary variable identifying the date of first clinic visit post study enrolment. Individuals without any record of clinic attendance were assumed not to have linked to care. ART initiation was defined as receipt of ART within 3 months of referral for treatment. We used the date on which ART was first dispensed to create a binary variable for ART initiation.

Self-perceived barriers to linking to a clinic were assessed in the baseline survey by asking participants the reasons why they might not visit an HIV clinic in the next 30 days. Fieldworkers recorded responses using a predetermined checklist of possible reasons (e.g., I don't want anyone to see me at the clinic), and by adding other reasons to the list. Multiple options were allowed, with participants prompted to provide additional reasons until no other reason was given.

A wide range of demographic, health-related and psychosocial variables were created from the baseline survey for the assessment of factors associated with linkage to care. These variables reflected factors, determined prior to data analysis, that could theoretically influence linkage to care, or found to be associated with linkage to HIV services in previous studies. Potential demographic and socio-economic determinants of linkage to care included household income, employment status and marital status. Health-related variables included a self-perceived health measure, and an indicator of alcohol consumption. We assessed participants' 'discount rates' as temporal discounting—the tendency to give greater value to rewards in the present or near future than those in the more distant future—could impede treatment uptake if the future benefits of ART are undervalued in the present (Operario et al., 2013). Accordingly, many people, and especially asymptomatic individuals may perceive the benefits of ART to accrue in the future and decide to delay treatment uptake due to an undermined appreciation of the immediate value of ART. Participants were asked to imagine that they had won a prize and could choose how it was paid, with a binary variable identifying individuals who chose R200 now over R500 in 1 month's time, which was classified as representing a high discount rate.

ART-related measures included an indicator of ART readiness based on responses to questions designed to measure elements identified in the literature as essential for readiness (Fowler, 1998). Participants were considered 'ready' if they reported being very ready to start ART, very motivated to start ART, very confident that ART would have a positive health effect, and predicted they would visit a clinic and start ART within 30 days. The Cronbach's alpha for these four dichotomised variables used to assess readiness was 0.71. As being fully ready to start treatment potentially involves several additional unmeasured factors, we consider our binary indicator of readiness as a measure that differentiates individuals with a greater degree of readiness for ART, rather than a measure of who was completely ready for treatment. Beliefs about side-effects were measured by asking participants how likely they thought it was that they would experience any side-effects.

As subjective norms can influence behavioural intentions (Ajzen, 1991), we measured perceived norms around ART uptake by asking participants 'Thinking about people like yourself, with a similar CD4 count, how many do you think start treatment within 3 months?' A binary variable was created, taking the value one for individuals believing that most, or all people do. Denial of being HIV-positive has been identified as a barrier to ART initiation (Naik et al., 2015). As surprise or shock at a positive diagnosis to a medical condition can be associated with denial (Kubler-Ross, 1997), we used the question 'Before you were tested for HIV today, how likely did you think it was that you would have HIV?' to create a binary variable for individuals who thought that their HIV test would not show that they were infected (i.e., they responded ''not at all likely'' to this question). We also created a binary variable to identify individuals who reported that any of their friends or family were taking ART and believed ART had a positive effect on their health. We posited that first-hand knowledge of the benefits of ART would be positively associated with ART initiation.

Our last set of factors related to stigma and disclosure. Internalised stigma [i.e., the devaluation of one's own identity by oneself and/or internalisation of the devaluation by others (Crocker, 1999)] was assessed using two items common in the measurement of internalised stigma: (1) 'Do you feel at all guilty that you have HIV?' and (2) 'Do you feel at all ashamed that you have HIV?' We created a binary variable to represent individuals who reported either form of internalised stigma. Perceived stigma (i.e., perceptions on the part of individuals about the nature and level of stigma in the broader social environment) was measured by asking participants how likely it was that HIV-status disclosure would result in being treated unfairly or badly by (1) your spouse/partner, (2) family members, (3) friends, (4) community members, and (5) health professionals. A binary variable was created to identify individuals who thought it was somewhat or very likely that they would be treated unfairly or badly by any group. Disclosure was measured by asking participants how likely it was that they would tell (1) their primary sexual partner and (2) anyone else about their HIV status.

Analysis

For the quantitative analysis, we compared self-reported barriers to visiting a clinic among men and women using Chi squared tests as uptake of HIV services, including ART, is often gendered (Bassett et al., 2009; Maughan-Brown et al., 2016). Logistic regression analysis was then used to assess the association between outcome measures (linkage to care and ART initiation) and a wide range of demographic, health-related and psychosocial variables (described above). Multivariable models controlled for study group assignment and key demographic and socioeconomic characteristics identified a priori as factors demonstrated to influence linkage to care and ART initiation: gender (Hachfeld et al., 2015; Plazy et al., 2014), age (Naik et al., 2015; Patten et al., 2013), years of completed education (Alvarez-Uria et al., 2013; Bengtson et al., 2016).

The qualitative data were analysed using thematic analysis. Audio recordings of interviews were professionally translated and transcribed into English. Interview transcripts were imported into Nvivo (QSR International Pty Ltd.) for analysis. The initial codebook was generated by four team members through an iterative process of reading transcripts and refining the codes. Codes were based on emergent ideas, concepts and themes from the transcripts. Regular research meetings were held throughout this initial coding process with the aim to allow time for peer debriefing and to help the research team to examine how their thoughts and ideas were evolving as they became more immersed in the data. Two team members then independently coded the same sample of one-third of the transcripts, with discrepancies discussed and resolved to refine the codebook and coding. Using the final codebook, the principal investigator coded the remaining transcripts. An inductive, team-based approach was used to identify themes from the interviews, with the process being data driven. The study team then met regularly to review, define and name themes.

Results

A total of 147 participants were assessed for study eligibility, and 87 individuals were randomised to the study intervention or control group. Post randomisation, 1 participant was excluded due to an unmet inclusion criterion. The final baseline sample comprised 86 individuals, with 46 allocated to the study intervention and 40 to the control group (see Fig. 1). In-depth interviews were conducted with 25 participants in the intervention group (14 on ART, 11 ART-naïve), and 16 individuals in the control group (11 on ART, 5 ART-naïve). The majority of the baseline sample was female (64%), 18–39 years old (72%), had not completed Grade 12 (71%), and was poor (see Table 1). Approximately half the sample (51%) perceived themselves to be in good health, and 72% were classified as ART 'ready' at baseline. It was common for participants to believe that they would experience ART side-effects (35%), and to report internalised (59%), and perceived stigma (67%).

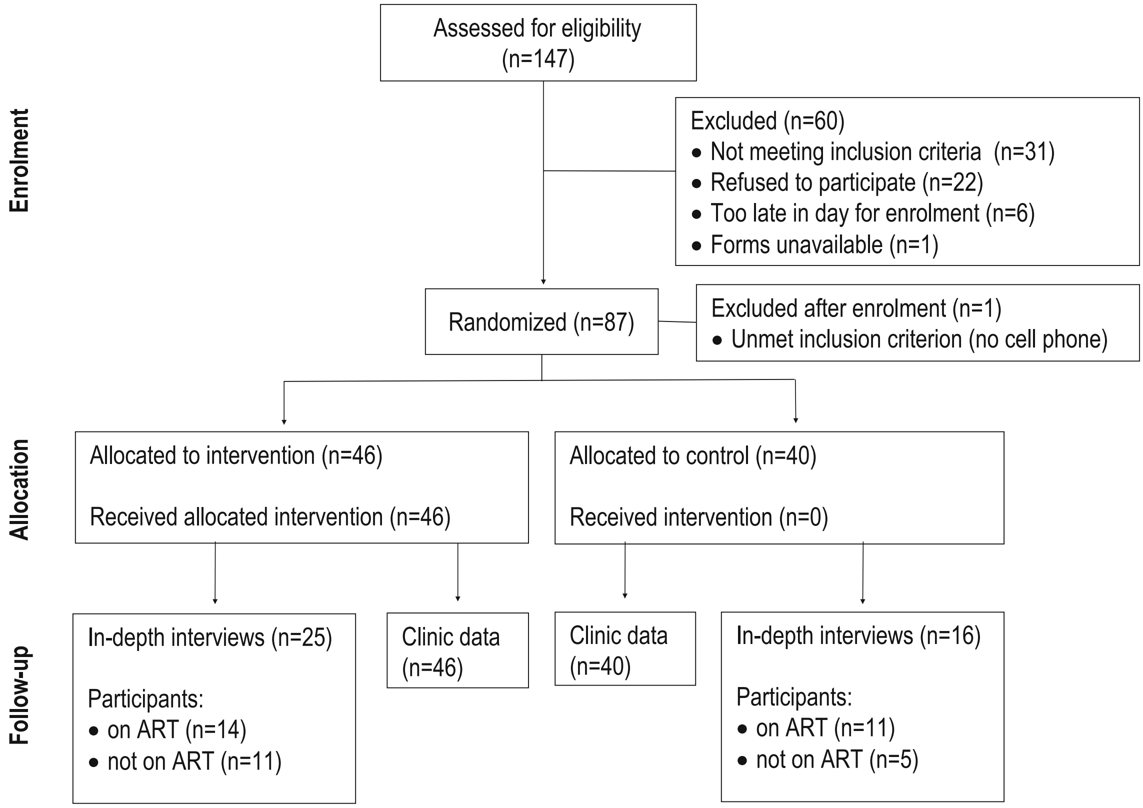

Fig. 1 iLink study profile

Self-reported barriers to visiting a clinic

The three most common reasons for why participants might not visit an HIV/ART clinic within 30 days were: (1) not wanting to be seen by others at the clinic (31%); (2) no money for transport (28%); and (3) not being able to get time off work (21%) (see Table 2). A larger proportion of women (33% vs. 19%, $p = 0.184$) reported not having money for transport as a potential barrier, while a larger proportion of men (42% vs. 25%, $p = 0.114$) reported not wanting to be seen at the clinic. Other factors mentioned were not being sick enough (6% of men), being too ill to go to the clinic (5% of women), and waiting lines being too long at the clinic (13% of women).

Factors from the baseline survey associated with linkage to care and ART initiation

Sixty-seven percent (95% CI 57–78) of participants linked to care within 3 months. Linkage to care was significantly more likely among individuals reporting a greater likelihood of HIV-status disclosure to someone other than their sexual partner (aOR: 2.99, 95% CI 1.13–7.91, $p = 0.03$); and among those who were classified as treatment ready (aOR: 2.97, 95% CI 1.05–8.34, $p = 0.04$). Linkage to care was significantly less likely among individuals who reported being in good health (aOR: 0.35, 95% CI 0.13–0.99, $p = 0.047$); those who drank alcohol at least once weekly (aOR: 0.35, 95% CI 0.12–0.98, $p = 0.045$); and participants who reported internalised stigma (aOR: 0.32, 95% CI 0.11–0.91, $p = 0.03$). Results are presented in Table 3.

Forty-two percent (95% CI 31–52) of all participants initiated ART within 3 months, and of those that linked to care within 3 months, 62% (36/58) started ART within that time period. Among all participants, multivariable regression analysis found a similar set of factors associated with ART initiation as those associated with linkage to care, which is intuitive as linkage to care is a prerequisite for ART. ART initiation was significantly more likely among individuals classified as treatment ready (aOR: 3.20, 95% CI 1.09–9.39, $p = 0.03$), and less likely among individuals who drank alcohol at least weekly (aOR: 0.24, 95% CI 0.08–0.73, $p = 0.01$). The negative association between ART initiation and two factors had a p value < 0.1, but 95% confidence intervals crossing one: internalised stigma (aOR: 0.44, 95% CI 0.17–1.12, $p = 0.09$), and perceived stigma (aOR: 0.38, 95% CI 0.14–1.01, $p = 0.06$). Among the sample that linked to care (n = 58) perceived stigma significantly reduced the likelihood of subsequent ART

Table 1 Baseline sample characteristics of study participants: individuals referred for ART by a mobile health clinic in Cape Town, South Africa (2015/2016)

	N	% or mean[a]
Demographics/SES		
Male	86	36
Age in years (mean)	86	33.02
Black African	86	97
Married	86	21
Years of education (mean)	86	9.977
Grade 12 completed	86	29
Household monthly income < R2000	79	68
Dwelling type: shack	86	77
Employed	86	33
Health		
CD4 count (mean)	86	313.77
Self-perceived health = good	86	51
Alcohol consumed ≥ once weekly	86	34
No previous HIV test	86	12
Psychosocial		
High discount rate	82	39
Believed unlikely to test HIV+	83	37
ART 'ready' (combined measure)	86	72
Knowledge of positive ART effect for others	86	65
Perceived norm of ART initiation < 3 months	82	40
Likely to experience side-effects	85	35
Internalised stigma (any)	85	59
Perceived stigma (any)	84	67
Very likely to disclose to partner	70	81
Very likely to disclose to someone else	86	56

SES socio-economic status, *ART* antiretroviral therapy

[a] All figures in the column represent percentages, unless otherwise stated

initiation (aOR: 0.20, 95% CI 0.05–0.89, $p = 0.035$). Other important determinants may not have been detected due to the sample size. These regression results are presented in Electronic Supplementary Material 1, Tables S1 and S2.

In-depth interviews: factors motivating linkage to care and ART initiation

Awareness of other people's experience with ART and AIDS

Participants were highly motivated to seek and initiate ART treatment when they knew someone on ART and in good health.

> The people that I had seen over time that are on ARVs; those are the people that encouraged me to also start with my treatment…. I noticed that they looked good. Instead of them going thin, I saw them looking good and seemingly in good health. [male, 30, intervention group, on ART]

Furthermore, participants were motivated to initiate treatment when they heard stories about the positive health effects of ART via media or from friends. The mobile clinic counsellors were aware that knowledge of a positive ART-effect can be motivating for patients and used this information effectively to encourage treatment uptake:

> What encouraged me…, oh they asked me is there anyone that I know who is taking treatment, I said yes. They asked me if she was sick or well? I said she is fine she doesn't look like someone who is taking treatment. [Female, 25, intervention group, on ART]

Participants described how they were initially anxious about waiting in an area of the clinic designated for HIV-services due to fears of being identified as HIV-positive and subsequently stigmatised. Unexpectedly for many, the interaction with other patients on ART at the clinic provided another source of motivation to initiate treatment:

> When I am in the queue at the clinic, I would talk to someone and ask what they are in line for and they would say that I should not worry because they are there for the same reason that they were there for.…Whoever I would be talking to would be telling me that they have been HIV for years and I would be encouraged because it meant I could still have a life too. [female, 29, control group, on ART]

Another strong motivating factor for initiating ART was the experience of witnessing the devastating consequences of AIDS. In one example, a woman recalled 'this HIV and AIDS, it is all around; I have seen people die from it, I have seen young people even; how they deteriorate, I would not want that for myself.' [female, 46, control, on ART].

Telephone counselling

The mobile clinic staff make follow-up calls to each patient to provide support and encourage ART initiation as part of routine care. Several participants, including the woman below, indicated that these calls were instrumental in their treatment decision.

> They used to call me each and every time to encourage that this is not the end of life, so they always wanted to know how I am doing with my treatment. So I told myself that let me stand up to get the treatment…If I did not get tested at [mobile

Table 2 Perceived barriers to visiting a clinic within 30 days among patients referred for ART by a mobile health clinic in Cape Town, South Africa (2015/2016)

	Total N = 86 % (n)	Female N = 55 % (n)	Male N = 31 % (n)	Difference female–male[a]
Don't want to start ART ever	2 (2)	4 (2)	0 (0)	4 ($p = 0.283$)
Can't get time off work	21 (18)	22 (12)	19 (6)	2 ($p = 0.788$)
Don't know where to go	1 (1)	0 (0)	3 (1)	3 ($p = 0.180$)
No money for transport	28 (24)	33 (18)	19 (6)	13 ($p = 0.184$)
Clinic staff will not keep my status confidential	1 (1)	0 (0)	3 (1)	3 ($p = 0.180$)
Clinic staff won't treat me with respect	1 (1)	2 (1)	0 (0)	2 ($p = 0.450$)
Don't want to be seen at the clinic	31 (27)	25 (14)	42 (13)	16 ($p = 0.114$)
I'm not sick enough	3 (3)	2 (1)	6 (2)	5 ($p = 0.261$)
Too ill to go to the clinic	3 (3)	5 (3)	0 (0)	5 ($p = 0.186$)
Waiting lines will be too long	9 (8)	13 (7)	3 (1)	10 ($p = 0.145$)
Fear of ART side-effects	2 (2)	4 (2)	0 (0)	4 ($p = 0.283$)

n refers to the size of the subset of the sample; N refers to total sample size without missing data

p values based on standard two group difference in proportions tests

[a] All percentages presented are rounded to the nearest integer. The difference was calculated prior to rounding values to the nearest integer

> clinic] I don't want to lie, I would not have visited the clinic by now. [female, 37, control group, on ART]

Participants described how the calls helped to reduce general stress and anxiety, and that they made them feel cared for. The telephone support was also valuable in helping participants overcome specific fears and concerns about starting ART, such as medication side-effects. In one case, a man who had not yet started treatment described how he had been uncertain for a long time about whether or not to start ART, and the follow-up calls had convinced him to go to the clinic and initiate ART as quickly as possible:

> The [mobile clinic] also called to ask and I told them too that I had not yet gone. But they called again and I thought that these people do not know me but they have taken it upon themselves to call and check up on me. So I decided to go…to receive a call from people who do not know you to ask about your health means that they care and it makes me feel encouraged. [male, 30, intervention group, ART-naïve]

In general, the follow-up telephone calls made participants feel as though they were "part of a family" and, especially for those who had not yet disclosed their HIV-status, that they were not alone.

Motivation to live because of children

The desire to stay healthy in order to care for and provide love to children was a common sentiment among participants, with children cited as a chief motivating factor in overcoming fears relating to ART and in initiating treatment.

> Okay, the most important reason…I have two children so I had to live for them if not for myself. [female, 32, control group, on ART]
>
> I have a young child and I have every intention to be with my child; I want to be there to ensure that I raise my child. [male, 30, intervention group, on ART]

Remaining healthy to avoid stigma and involuntary disclosure

Several participants thought that as soon as they looked sick people would presume they were HIV-positive. They feared involuntary disclosure because of the stigma they believed they would experience if certain people knew their status. For these individuals, a key motivating factor in starting ART was to stay looking healthy and thereby remain in control of disclosure of their HIV status. One man, for example, stated:

> There is a reason that made me start the ARVs; I wanted the same life I had before and be like everybody because I found out that there is no difference between the person who is using ARVs and the person who is not. And if you are using them none will know [your HIV status] without your knowledge. [male, 49, intervention group, on ART]

Table 3 Factors associated with linkage to care within 3 months after ART referral by a mobile health clinic in Cape Town, South Africa (2015/2016)

	% (n/N)	Unadjusted logistic regression OR (95% CI)	Multiple logistic regression aOR (95% CI)
Gender			
Female	67 (37/55)	1.00	1.00
Male	68 (21/31)	1.02 (0.39–2.63)	0.97 (0.36–2.59)
Age			
18–29	58 (21/36)	1.00	1.00
30–39	78 (21/27)	2.50 (0.81–7.74)	2.46 (0.79–7.71)
40+	70 (16/23)	1.63 (0.54–4.98)	1.74 (0.49–6.12)
Education			
< Grade 10	67 (18/27)	1.00	1.00
Grade 10 or 11	74 (25/34)	1.39 (0.46–4.22)	1.44 (0.43–4.89)
Grade 12	60 (15/25)	0.75 (0.24–2.34)	0.80 (0.24–2.72)
Assignment to intervention			
No	73 (29/40)	1.00	1.00
Yes	63 (29/46)	0.65 (0.26–1.63)	0.65 (0.25–1.70)
Household monthly income			
≥ R2000^	64 (16/25)	1.00	1.00
< R2000	67 (36/54)	1.13 (0.41–3.05)	1.19 (0.41–3.41)
Working			
No	67 (39/58)	1.00	1.00
Yes	68 (19/28)	1.03 (0.39–2.71)	0.80 (0.27–2.35)
Married			
No	66 (45/68)	1.00	1.00
Yes	72 (13/18)	1.33 (0.42–4.21)	1.21 (0.37–3.91)
Health			
Poor health	79 (33/42)	1.00	1.00
Good health	57 (25/44)	0.36 (0.14–0.93)**	0.35 (0.13–0.99)**
Alcohol consumption			
< once weekly	74 (42/57)	1.00	1.00
≥ once weekly	55 (16/29)	0.44 (0.17–1.13)*	0.35 (0.12–0.98)**
Discount rate[a]			
Low	62 (31/50)	1.00	1.00
High	75 (24/32)	1.83 (0.68–4.94)	2.22 (0.68–7.25)
Likelihood of testing HIV-positive[b]			
Likely	69 (36/52)	1.00	1.00
Unlikely	61 (19/31)	0.70 (0.27–1.79)	0.61 (0.23–1.66)
ART ‘ready’[c]			
Not ready	50 (12/24)	1.00	1.00
Ready	74 (46/62)	2.88 (1.07–7.71)**	2.97 (1.05–8.34)**
Knowledge of positive ART effect for others[d]			
No	60 (18/30)	1.00	1.00
Yes	71 (40/56)	1.66 (0.65–4.25)	1.68 (0.612–4.58)
Likelihood of experiencing side effects			
Not likely	79 (11/14)	1.00	1.00
Don’t know	68 (28/41)	0.58 (0.13–2.49)	0.63 (0.13–2.91)
Somewhat/very likely	60 (18/30)	0.40 (0.09–1.79)	0.33 (0.07–1.59)

Table 3 continued

	% (n/N)	Unadjusted logistic regression OR (95% CI)	Multiple logistic regression aOR (95% CI)
Most people start ARVs within 3 months[e]			
No	63 (31/49)	1.00	1.00
Yes	70 (23/33)	1.33 (0.51–3.44)	1.03 (0.38–2.87)
Internalised stigma[f]			
None	77 (27/35)	1.00	1.00
Yes	60 (30/50)	0.44 (0.16–1.18)	0.32 (0.11–0.91)**
Perceived stigma			
None	67 (20/30)	1.00	1.00
Yes	68 (38/56)	1.05 (0.40–2.72)	0.95 (0.35–2.59)
Likelihood of disclosure to partner			
Unlikely/don't know	54 (7/13)	1.00	1.00
Likely	67 (38/57)	1.71 (0.50–5.86)	1.90 (0.50–7.27)
Likelihood of disclosure to others			
Unlikely/don't know	55 (21/38)	1.00	1.00
Likely	77 (37/48)	2.72 (1.07–6.93)**	2.99 (1.13–7.91)**

OR unadjusted odds ratio, *aOR* adjusted odds ratio from multivariable models including the control variables age, gender, education, and assignment to the intervention versus control group. OR > 1 implies more likely to link to care compared to reference, *CI* confidence interval

^R2000 was equivalent to $145 on 31 October 2015 (approximately the mid-point of study enrolment)

***$p < 0.01$; **$p < 0.05$; *$p < 0.1$

[a] To assess discount rates, participants were asked to imagine that they had won a prize and could choose how it was paid, with the choice of R200 now over R500 in 1 month's time representing a high discount rate

[b] The question 'Before you were tested for HIV today, how likely did you think it was that you would have HIV?' was used to create a binary variable to identify individuals who thought it unlikely that their HIV test would show that they were infected

[c] Participants were deemed to be ART 'ready' if they reported being very ready, very motivated and very confident regarding ART, and predicted they would visit a clinic and start ART within 30 days

[d] This binary variable identified individuals who reported that any of their friends or family were taking ART and believed ART to have had a positive effect on their health

[e] The perceived norm around ART uptake was assessed by asking participants 'Thinking about people like yourself, with a similar CD4 count, how many do you think start treatment within 3 months?'

[f] Internalised stigma was assessed using two questions: (1) 'Do you feel at all guilty that you have HIV?' and (2) 'Do you feel at all ashamed that you have HIV?'

In another example, a woman said 'I already see some of the people who are sick of this thing that are getting ugly, so I decided to go while no one can realise that I am in this situation and worse. [female, 26, intervention group, on ART]

In-depth interviews: psychosocial barriers to ART initiation

Fear of ART-related side-effects

Fear of ART side-effects was the predominant psychosocial concern regarding ART, and was often cited as a reason for delayed treatment. Participants believed that starting ART would make them sicker and 'ugly'. One woman, for example, reported:

> I am afraid. I don't know what the medication will do to me. I used to see others, maybe someone change the shape to something else. … I have my cousin whose shape was not normal. She has a twisted shape [female, 35, intervention group, ART-naïve]

It was common for participants to believe that side-effects were a matter of course, with uncertainty around which ones they would experience rather than whether they would experience side-effects, as in the following man's example:

> Yes, the side effects that I was going to get because they named a number of possible side effects and I did not know which one I would get.…Sometimes you might not hear, you might lose your hearing, sometimes you might have problems with your feet, sometimes stomach, sometimes vomit and sometimes you might feel dizzy or exhausted. [male, 44, intervention group, on ART]

Many participants were under the impression that the side-effects could be extreme, possibly even fatal. Several participants also spoke about a link between mental illness and ART:

> I was very scared to take them. … there is a lady that I know that went insane and would shout at people on the street; [female, 48, intervention group, ART-naïve]
>
> I have heard that people hallucinate and they see things like snakes. [female, 38, intervention group, ART-naïve]

Three common sources of their concern about side-effects were mentioned by participants. First, participants feared side-effects following discussions during counselling sessions. It appeared that in some cases ART-counsellors had not considered potential fears regarding side-effects and had even fostered such fear in an attempt to stress the importance of returning for clinical care in the event of side-effects. One participant recalled the fear resulting from counseling about ART side-effects: 'I was afraid when they said that it also damages your face' [female, 32, intervention group, ART-naïve].

Second, having been told of individuals who experienced dramatic side-effects from ART, some participants expected and feared this for themselves. One participant referred to hallucinations of zombies caused by ART, and dreams involving unwanted sexual experiences. Third, participants also feared side-effects because they had witnessed people attending the clinic with visible disfigurements, such as sores on their faces, which were assumed to have been side-effects of ART. In addition to health-related concerns regarding ART side-effects, participants believed that experiencing side-effects could have negative social ramifications. For example, participants believed that side-effects would lead to people guessing their HIV-status and result in the loss of control they had over disclosure decisions:

> This medication is going to change my shape and everyone could see that I am taking HIV treatment [female, 37, control group, on ART]

Denial of HIV status

Denial of HIV status was also a common reason for delayed linkage to care and ART initiation. The perception that they could not be HIV-positive was linked to factors such as feeling healthy, and that people like themselves could not get HIV.

> I felt okay and I did not feel like I was sick. Even when I looked at the letter that I received, I did not feel like I was sick at all and I was quite convinced that I was not sick even though I had the letter in front of me. [male, 25, intervention group, ART-naïve]

In some cases, individuals struggled to come to terms with their diagnosis because it indicated that their sexual partner had had other partners. Distrust of the diagnostic service was also a source of uncertainty regarding their HIV-status. One man (48, control group, ART-naïve), for example, recalled hearing stories about inconsistent test results and reading an article in the most widely distributed local newspaper, which reported on faulty HIV tests. As a result of awareness among mobile clinic staff that denial is a common response to HIV diagnosis, some of the counsellors adopted the strategy of conducting a third and 'final' test to address participants' doubts about the accuracy of the diagnosis:

> I just could not believe it, they tested me three times and I only believed it the third time because all these tests were saying the same thing. [female, 29, control group, on ART]

HIV-related stigma

HIV-related stigma was also a common concern raised by participants regarding ART initiation. Participants perceived that they could experience a stigmatising response from a wide-range of people including family, friends, people in the community and health care providers. In one example a man described what he thought would happen if others knew his HIV-status:

> I was scared to go to the clinic. Sometimes people make fun and laugh about a disease such as this so I was scared of being part of the people who are teased. I was also scared of telling them at home. Some parents do not accept it. I am very stressed because I do not want people knowing that I have HIV. [male, 25, intervention group, ART-naïve]

In addition to perceiving that stigmatisation is common, participants also reported internalised stigma, reporting feelings of worthlessness or not having lived up to their own and others' expectations, or 'feeling like a half corpse' as one woman (29, intervention group, ART-naïve) described.

In-depth interviews: structural barriers to ART initiation

Insufficient money for transport and food

The inability to afford public transport to the clinic was a significant barrier to ART uptake. Given the perception that seeking HIV care would typically require a full day at the clinic, participants often raised the concern of being hungry at the clinic and included food in the cost of visiting a clinic:

> I don't want to lie, sometimes I don't have money.… So if I go there I need money for transport also some cents so as to buy fruit while I am waiting. [female, 45, control group, ART-naïve]

In addition to distance to the clinic, some participants did not think it was safe to walk to the clinic in their area.

> I stay home because I was struggling with transport money. It's dangerous in that section I am living in because there are people who are armed and … robbers. [female, 21, intervention group, on ART]

The association between food and ART emerged as a dominant theme in the interviews. There was a strong perception that food was required in order to take ART. The perceived ramifications of not taking ART with food ranged from a reduction in the efficacy of treatment to an increased risk of experiencing ART side-effects:

> … to be able to take the tablets there has to be food because the tablets won't be effective on an empty stomach. [male, 24, control group, ART-naïve]
> Because you can't take tablets without food … tablets end up being a poison for people who don't have food. [male, 27, control group, on ART]

For many participants, the relationship between food and ART also ran in the opposite direction, with participants believing that ART would make them hungry and delaying ART initiation in response:

> There is none other [factor in delaying ART initiation] than what I have already mentioned like having to eat all the time because they will make me hungry. The treatment makes one really hungry. [female, 48, intervention group, ART-naïve]

Insufficient time for clinic visits

Availability of time to visit the clinic was another major factor that reportedly delayed ART initiation. For many, work commitments and the fear of losing their jobs as a result of the many days required at the clinic in order to start treatment delayed linkage to care or resulted in patients not completing the ART initiation process:

> …we have these jobs that we are doing and it's not that easy to stay or ask for days off every week, because they would have a concern about abusing sick leave. [female, 45, control group, ART-naïve]

The problem of finding enough time to complete the ART initiation process was compounded by other life events, including the death of family members and the termination of abusive relationships, and by fears about being seen at the local clinic, which sometimes resulted in participants travelling to clinics far from home.

Discussion

Study results demonstrate low rates of rapid ART initiation (42% of participants started ART within 3 months) following ART referral from a mobile clinic operating in an informal urban area in South Africa. These findings are consistent with those from other mobile clinic based studies in Lesotho (Labhardt et al., 2014), which found that 25% of individuals diagnosed HIV-positive linked to care within 28 days, and South Africa (Bassett et al., 2014), where 10% linked to care within 90 days. They are also consistent with results from a previous study conducted in partnership with the same mobile health clinic in 2010/2011 showing that 53% of individuals with a CD4 count between 201 and 350 cells/μL linked to care within 3 months (Govindasamy et al., 2013). Our results therefore suggest a persistent problem of poor rates of early ART initiation among populations diagnosed HIV-positive by mobile health services.

A range of factors was identified that could delay treatment initiation. These identified barriers to ART initiation have the potential to be addressed in future interventions, for example, by incorporating the use of brief screening tools at the time of HIV diagnosis to help triage individuals into differentiated care services that aim to encourage ART uptake. Consistent with other studies (Katz et al., 2011), individuals perceiving themselves to be in good health were more likely to delay clinic visits. In a context characterised by high perceived and actual costs to ART initiation—including high levels of perceived stigma, fears regarding treatment side-effects, and financial and time constraints to clinic access—initiating treatment may well be perceived as a greater cost than benefit to one's immediate quality of life. Because community-based HIV testing services aim to diagnose asymptomatic people living with HIV who will often not perceive the need for testing services, our findings highlight the particular importance of interventions that increase the perceived benefits and reduce the perceived costs of ART, and corresponding linkage to care, among healthier populations living with HIV.

Assessing and managing fears regarding ART side-effects may be particularly important for encouraging rapid ART initiation. Study findings align with other evidence that side-effects are a major psychosocial barrier to treatment uptake (Fox et al., 2010; Govindasamy et al., 2012; Katz & Maughan-Brown, 2017; Naik et al., 2015). Concerns about side-effects were deep-seated, with many participants fearing severe or life-threatening side-effects, such as insanity and dreams about snakes, which in the Xhosa culture are closely associated with witchcraft and bad omens (Ashforth, 2005). Asymptomatic participants described concerns that even relatively minor side-effects could lead to visible signs of HIV-infection and result in involuntary HIV-status disclosure. This suggests that there could be an important interplay between fears about being stigmatised and concerns regarding side-effects.

Conversely, concerns about being stigmatised and the associated fear of losing control of disclosure decisions due to AIDS-related illness was, for some participants, a motivating factor for starting ART while still in apparent good health. The finding that the perception of living in a highly stigmatising environment may actually encourage ART initiation is consistent with a recent qualitative study conducted in Cape Town (Lambert et al., 2018). As long as fears about involuntary HIV-status disclosure as a result of being seen at a clinic remain common, it is unlikely that perceived stigma would prove to be more of a motivating than deterrent factor when it comes to treatment uptake. However, if differentiated models of ART initiation were designed that alleviated concerns about being seen at a clinic, there is the potential for perceived stigma to have a positive effect on treatment uptake.

Another barrier to ART initiation identified by our study was denial of HIV-diagnosis. This is likely to be associated with perceptions of health and related inaccuracies in perceived HIV risk (Maughan-Brown & Venkataramani, 2018). These findings add to the growing evidence that initial HIV-status denial requires assessment and targeted intervention (Naik et al., 2015). Further research is warranted as it is likely that denial in response to HIV-diagnosis will remain relevant, or even become more common, as additional efforts are made to increase the proportion of individuals, and especially men, who are diagnosed early. A potential intervention, which helped some participants in our study to overcome doubt about their diagnosis is to provide patients with additional evidence of HIV infection.

ART-readiness has been shown to improve adherence to ART (Balfour et al., 2007) and, in Uganda, treatment uptake (Amuron et al., 2009). Adding to this evidence, our study found evidence of a positive association between ART-readiness at baseline and subsequent ART uptake in a country in Southern Africa, the epicentre of the HIV epidemic. Our findings suggest that a brief ART-readiness assessment could be effective in identifying individuals in need of additional encouragement to initiate treatment. As ART-readiness in our study sample has been shown to be lower among individuals in good health and those who did not expect an HIV-positive diagnosis (Maughan-Brown et al., 2018c), our findings further underscore the need for interventions to encourage treatment among otherwise healthy populations, and those who respond to HIV-diagnosis with denial.

Uncertainty exists regarding the relationship between internalised stigma and ART initiation. Previous evidence indicates that internalised stigma negatively impacts various behaviours along the HIV care continuum including ART adherence (Earnshaw et al., 2013) and health care visits among individuals on ART (Rice et al., 2017). In terms of ART initiation, one study conducted in India found that internalised stigma was associated with delays in seeking HIV care (Steward et al., 2012), while another found no evidence that internalised stigma was linked to ART initiation during late stages of HIV-infection in Ethiopia (Nash et al., 2016). Our study results provide the first evidence in Southern Africa that internalised stigma reduces the likelihood of rapid ART initiation. Our findings align with those of studies showing high levels of internalised stigma among people living with HIV in general in South Africa (Simbayi et al., 2015), and highlight the importance of rapidly identifying and addressing internalised stigma.

The results from this study point towards the value of additional research on several interventions that show potential to improve treatment outcomes. Follow-up telephone counselling appeared to be effective in encouraging linkage to care and ART initiation by, among other things, helping participants to overcome denial of their HIV status and their fears regarding treatment side-effects. Several studies have demonstrated a positive effect from intensive support through home visits and peer navigators (Van Rooyen et al., 2013), and the cost effectiveness of telephone counselling in comparison with these other interventions warrants investigation. Telephone support could be particularly effective among individuals who do not have a social support network to which they feel comfortable about disclosure, a group identified in our study as being at risk of delayed ART uptake.

Awareness of the positive long-term health effects of ART that came through knowing, or learning about, people on treatment appeared to motivate many to start treatment quickly. Previous research has also indicated that there is a positive association between such awareness and ART-readiness (Maughan-Brown et al., 2018c). The strategy adopted by counsellors at this mobile clinic of drawing the patients' attention to people who have been living happily on ART for several years could be tested more broadly. Furthermore, our results indicate the value of role models in communities and in the media who demonstrate the benefits of ART.

Finally, the belief that ART must be taken with food to be effective and safe (Fox et al., 2010) was again found in our study. In addition, our findings highlight the bi-directionality of the relationship between ART and food, with a great deal of concern being raised regarding the belief that ART makes people hungry. This perception could have a very significant impact among populations facing food insecurity, and particularly among healthy-feeling individuals. The fact that HIV prevalence and incidence is highest among urban informal residents in South Africa highlights the potential importance of these beliefs for ART programmes (Shisana et al., 2014). Accordingly, interventions to improve access to food specifically targeted towards resource-poor patients may be effective at improving treatment outcomes. Livelihood programmes for people living with HIV, for example, may help to address food insecurity and its adverse effects (Masa et al., 2018).

Study results should be interpreted in the context of the study limitations. While the use of clinic data reduces the potential for social desirability bias on the key dependent variables, it is possible that incomplete matching of study participants to clinic records could have resulted in error in the measurement of linkage to care and ART initiation. Inconsistencies in the provision, or data capture of names and dates of birth between study and clinic records could have resulted in failure to match participants and an underestimation of the outcomes. However, we believe the potential for such bias is limited given an assessment of the completeness of matching using clinic record outcomes for study participants who had met with the study team and verified ART initiation by presenting their ART medication. Among these individuals, 94% (17/18) had initiated ART according to the clinic records, thus suggesting a high degree of accuracy in data matching. In addition, recruiting a population at the moment of ART referral is difficult and quantitative analyses of this nature are often limited, as in our case, by relatively small sample sizes. Small sample bias might have resulted in spurious associations, or a failure to detect statistical significance on associations between linkage to care and factors that did affect health seeking behaviour. Regarding evidence from in-depth interviews, it is possible that individuals who were not interviewed (n = 23) faced challenges to linkage to care that differed from those among interview participants, and these would not have been captured. Last, it is unclear whether results can be generalized to other populations.

Overall, our study adds to the evidence that interventions are required to encourage rapid ART initiation among individuals who receive an HIV-positive diagnosis from community-based HIV testing services (Labhardt et al., 2014). This is especially the case among healthier populations. Key barriers to early treatment uptake include self-perceived good health, concerns about side-effects, HIV-status denial, hesitancy to disclose one's HIV status, internalised stigma, perceived stigma, feeling unready for ART, and lack of money for transport and food. Brief screening tools could potentially be used to identify individuals with these characteristics and in need of additional services to ensure ART initiation. Potential interventions meriting further exploration include the provision of additional evidence of HIV infection for those doubting their diagnosis, follow-up telephone support, food security programs, and ways of increasing awareness of the positive experiences of others on treatment.

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Compliance with ethical standards

Conflict of interest Brendan Maughan-Brown, Abigail Harrison, Omar Galárraga, Caroline Kuo, Philip Smith, Linda-Gail Bekker and Mark N. Lurie declare that they have no conflict of interest.

Human and animal rights and Informed consent The Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town provided study approval (Ref: 849/2014). The Western Cape Government Department of Health approved access to provincial health data (Ref: WC_2015RP1_270). Written informed consent was obtained from all study participants.

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