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Empowering patients to link to care and treatment: qualitative findings about the role of a home-based HIV counselling, testing and linkage intervention in South Africa

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Abstract

To explore the barriers and facilitators of linkage to and retention in care amongst persons who tested positive for HIV, qualitative research was conducted in a home-based HIV counselling and testing (HBCT) project with interventions to facilitate linkages to HIV care in rural KwaZulu-Natal, South Africa. The intervention tested 1,272 adults for HIV in Vulindlela of whom 32% were HIV-positive, received point-of-care (POC) CD4 testing and referral to local HIV clinics. Those testing positive also received follow-up visits from a counsellor to evaluate linkages to care. The study employed a qualitative methodology collecting data through in-depth semi-structured interviews. Respondents included 25 HIV-positive persons who had tested as part of HBCT project, 4 intervention research counsellors who delivered the HBCT intervention and 9 government clinic staff who received referrals for care. The results show that HBCT helped to facilitate linkage to care through providing education and support to help overcome fears of stigma and discrimination. The results show the perceived value of receiving a POC CD4 result during post-test counselling, both for those newly diagnosed and those previously diagnosed as HIV positive. The results also demonstrate that in-depth counselling creates an 'educated

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consumer' facilitating engagement with clinical services. The study provides qualitative insights into the acceptability of confidential HBCT with same day POC CD4 testing and ART counselling as factors that influenced HIV-positive persons' decisions to link to care. This model warrants further evaluation in non-research settings to determine impact and cost-effectiveness relative to other HIV testing and referral strategies.

Keywords

barriers; facilitators; linkage to care; home-based counselling and testing; South Africa

Introduction

High coverage of HIV counselling and testing (HCT) followed by effective linkage to and retention in care is required for antiretroviral therapy (ART) to have clinical and public health benefits (Cohen et al., 2011; Karim & Karim, 2011). South Africa has over 2 million people on ART, boosted by a successful national HCT campaign in 2012 (Barron et al., 2013). Despite this, only about 46% of HIV-positive persons know their status and one-third of those eligible are receiving ART (Shisana et al., 2014).

The potential for loss to follow-up exists at all stages in the cascade of care (Kranzer et al., 2012; Rosen & Fox, 2011) potentially resulting in delayed ART initiation, greater risk of viremia and HIV transmission (Baeten et al., 2012; Granich et al., 2012). Given that only about 30% of HIV-positive persons are virally suppressed, identifying effective strategies for linkage to HIV care is paramount to maximize the impact of HIV testing (Mugglin et al., 2012).

South African research suggests that economic issues including working hours, travel costs or distances may hinder access to care (Govindasamy et al., 2011; Ingle et al., 2010; Losina et al., 2010). As do health system barriers, such as long queues and staff attitudes (Bogart et al., 2012). Fear of disclosure or stigma (Bogart et al., 2012) and drug toxicities (Govindasamy et al., 2011) are other potential barriers. Prospective studies suggest that being male and younger (Bassett et al., 2010; Ingle et al., 2010; Kaplan, Orrell, Zwane, & Bekker, 2009; Lessells, Mutevedzi, Cooke, & Newell, 2011), having advanced illness and the presence of a co-morbidity (Bassett et al., 2009), predict attrition.

Point-of-care (POC) CD4 at mobile HCT may reduce initial attrition and encourage ART initiation among those harder to engage in care, including men (Jani et al., 2011; Larson et al., 2012), and urban South African youth (Patten et al., 2013). Thus supporting linkage and removing a step in the cascade, thereby limiting losses (Faal, Naidoo, Glencross, Venter, & Osih, 2011).

Home-based testing has shown promise, resulting in high testing uptake in South African research, possibly because of overcoming accessibility barriers (Naik, Tabana, Doherty, Zembe, & Jackson, 2012; Sabapathy, Van den Bergh, Fidler, Hayes, & Ford, 2012). Drop off in the continuum of care persists after testing. This research enrolled respondents from a study in rural KwaZulu-Natal (KZN) that provided HBCT along with POC CD4

measurement, in-depth counselling and follow-up to improve linkage and retention in care. The study achieved 90% HCT uptake and the support package of services resulted in 90% linkage to care by 6 months (Barnabas et al., 2014; van Rooyen et al., 2013). In the context of this HBCT package, we explored barriers and facilitators to linkage to care.

Methodology

This qualitative study included in-depth semi-structured interviews with local government health providers, but this paper focuses on the responses of HIV-positive HBCT clients and HBCT staff, from Vulindlela, KZN during 2013 (Table 1). Clients were enrolled after the final 6-month HBCT follow-up visit at which stage linkage to care was established, it is notable at this stage only 3 of the 25 client respondents were not linked to care (Table 2).

Interviews were conducted by trained local research staff in *isiZulu* and took about one hour to complete, in the homes of clients and workplaces of providers. Interviews were recorded, then transcribed and translated into English. All respondents provided informed consent and permission for recording. Transcripts were coded by the first author in NVivo software using framework analysis. Three members of the research team developed the initial coding framework using the research questions about the reasons for, barriers to and factors motivating linkage to care and refined it during multiple coding iterations with emerging thematic areas. Data from the different respondents were analysed independently as cases, followed by a comparison between emerging themes in each.

Ethics approval was granted by the University of Washington Institutional Review Board and the Human Sciences Research Council's Research Ethics Committee. The KZN Department of Health provided permission for government service providers.

Results

The analysis revealed three categories of factors affecting linkage to care. The first are service related, the second are social factors (Ulett et al., 2009). The third relate to individuals' perceptions and experience (Roura et al., 2009).

Service-related factors

Clients' reception to the intervention was overwhelmingly positive with interactions described as personal, and providing sufficient time for questions and discussion. These service-related factors were closely linked with and influenced individual's experience. Respondents reported that HBCT facilitated a feeling of comfort and helped them to control the privacy of the HBCT interaction.

[Intervention staff] care, you don't get too nervous because they talk to you and you feel free. (Client)

Home-based delivery helped people to bypass barriers associated with testing and receiving results at the clinic, such as long queues, lost results and poor treatment, hence the significance of including those with previous testing experience. In general the clinic experience is described as like being on a conveyor belt and a noted contrast to HBCT.

At the clinic a person just tests you and the next person follows, you don't get any comfort. (Client)

Facility-based barriers to linkage were observed for those with higher CD4 counts (Table 1) who often failed to receive ongoing facility care following referral from HBCT.

...they do not get [anything] if the CD4 is still high, I don't see them getting attention because they are sent away and told to come back... (Intervention staff)

In this way facility-level barriers may influence individuals' perceptions and act as barriers to linkage.

Social factors

While relatively few clients mentioned fear of stigma and discrimination as a social factor influencing their decision to link to care, where it was reported, clients attributed the intervention's supportive counselling and information about treatment with helping them overcome these fears.

... I [worry] that someone will see me collecting ART and it's a person that likes to gossip... [But] I could still live a long life if I look after myself, which is what made me go to the clinic. (Client)

Despite the relative unimportance of stigma for clients, it was mentioned by many service providers as a perceived barrier, but comparatively few had actually encountered it.

...not a lot of [participants], just two or three...they are scared that people are going to see them in the clinic and realize the reason for them being there ... (Intervention staff)

Other social factors such as the support of family members and friends also encouraged linkage.

My family supports and encourages me, my sister-in-law was with me all the way, if there was something I didn't understand she helped me. (Client)

Individual-level factors

Individual-level knowledge and beliefs potentially influenced linkage to care. Counselling and follow-up influenced individual perceptions by encouraging access to care and facilitating an understanding of ART and its benefits. Thereby stimulating a positive perception of treatment and motivating access to care.

...if [the team] hadn't counselled or encouraged me I would have had problems. [They encouraged] me to go to the clinic and take pills... they tell me I will be well. (Client)

...[The intervention team] gave me referral letter to visit the clinic... it was useful to know my CD4 count, I was motivated to continue with ART from the clinic, it helped me a lot. (Client)

Access to POC CD4 testing and same day results provided clients with immediate information about their CD4 count.

...when I tested I found that my CD4 was low, that is what made me go to the clinic. (Client)

This was accompanied by counselling to ensure adequate understanding of the implications which encouraged linkage and retention.

I got really shocked when I got my CD4 results...that's the reasons I take [my ART] all the time, I can now see that [my CD4] is increasing. (Client)

Clinic providers also noted the benefits of information about CD4 count and ART eligibility, facilitating easy referrals and bypassing steps.

... for us here at the clinic [HBCT] cuts the load for the counsellors, [clients] come ready [for ART]. (Clinic staff)

Discussion

This study explored the factors associated with linkage to care, within an HBCT intervention study in KZN with very high rates of linkage (Barnabas et al., 2014; van Rooyen et al., 2013). These findings demonstrate high qualitatively assessed acceptability, supporting evidence for high uptake of HBCT in South Africa (Naik et al., 2012; Negin et al., 2012). Participants reported that HBCT avoided health service barriers and provided personalized counselling about their CD4 results based on the POC results, ART eligibility and benefits.

The quality and nature of HBCT made it preferable to facility-based services, providing a personal service, privacy, confidentiality and opportunities to ask questions. Explorations of perceptions of the quality of counselling and personal interaction by an HBCT intervention such as this are limited. Patients receiving guidance and support in a Tanzanian study (Nsigaye et al., 2009) and those receiving peer linkage support through a 'navigation model' in Kenya (Hatcher et al., 2012), were more likely to link to care than those not receiving the intervention. Our qualitative findings indicate that a similar model of navigation provided by a counsellor, incorporating support and information, and influencing personal motivation, is beneficial for care linkage.

In contrast to the positive role of HBCT for linkage, the results demonstrate that a failure to adequately cater for the needs of clients with a high CD4, a group with documented poor linkage to care (Lessells et al., 2011), may negatively influence community perceptions about HIV care and likelihood of linking to care. Services for this group, who are not yet eligible for ART, should be a priority for HIV programs, to encourage ongoing engagement with care and prevent loss to follow-up. The adoption of new WHO ART treatment guidelines (WHO, 2013) will reduce the proportion of people in this category, but the need to offer counselling and services to HIV persons not yet eligible for ART will remain, to maintain engagement in care.

The results suggest that HBCT and subsequent follow-up also helps to overcome social factors that may hinder linkage to care, such as discrimination and stigma (Bogart et al., 2012; Govindasamy et al., 2011). Counselling messages and support from family and friends were reported to help clients overcome fear of stigma and discrimination at the clinic.

The results demonstrate the benefits that information about CD4 count and counselling can have for linkage. Previous South African research suggests an increased likelihood to link following receipt of POC CD4 results (Faal et al., 2011; Larson et al., 2012). Our results show that those receiving POC CD4 were better prepared and able to negotiate the clinic, overcome service-related barriers and focus on the long-term benefits of engagement. Revealing that comprehensive counselling, POC CD4 and follow-up can potentially create motivated and empowered individual clients to assist linkage (Govindasamy, Ford, & Kranzer, 2012).

Three limitations to the study require consideration. Firstly, almost half of the clients enrolled had tested prior to HBCT, possibly biasing respondent's perception of the clinic services. To account for this, information was collected about prior HCT and service contact. This facilitated the analysis of comparisons between service quality, drawing on personal experience. Importantly, regardless of previous testing respondents appeared to hold similar views about both facility-based services and HBCT. Secondly, despite actively sampling for asymptomatic clients with low CD4 counts, for maximum variation, the available sample was smaller than desired. This was as a result of the third limitation which was the high linkage rates in the study population. These factors make it harder to explore barriers to linkage and care. Although these small-scale qualitative research results are unlikely to be generalizable beyond this study context they have important lessons for the design of policy to facilitate improved linkage to care within South Africa and similar contexts and may influence the design of future HBCT services.

Conclusion and Recommendations

This research qualitatively demonstrates high acceptability of this model of HBCT, showing that this service acts to facilitate linkage to care. While social factors such as stigma and discrimination may influence linkage, it is notable that the role of supportive family and friends, counselling and follow-up can counter these fears. Counselling, POC CD4 and follow-up can influence individuals' perceptions and empower clients to link to care, regardless of previous testing. Recent research demonstrating cost-effectiveness (Smith et al., 2015) suggests that this model of HBCT may encourage not just uptake of testing but also facilitate linkage to care.

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Table 1

Details of the sample characteristics

Sample characteristics	Sampling technique	Sample Size	Purpose of inclusion
HIV-positive HBCT clients from the larger intervention study,	Purposive sampling to represent varying CD4 counts among previous and first-time testers, both those with and without symptoms, and those who were and were not linked to care,	25	To understand the experience of HBCT, referral, support, POC CD4 testing and linkages
HBCT intervention research staff.	Randomly sampled from the small research team.	4	To provide insight into logistics of the intervention and perceptions about linkage to care
Government health providers from a local HIV referral clinic.	Purposively sampled to represent a range of providers (nurses, counsellors, management) involved in the delivery of HIV testing and care.	9	To provide their perceptions about HBCT and its impact on linkages to care and ART initiation.

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Table 2

Characteristics of the sample of HIV-positive respondents enrolled

Interview Type	Female	Male
Asymptomatic, CD4 > 350, unlinked* to care	2	0
Asymptomatic, CD4 < 350, linked*	3	0
Asymptomatic, CD4 > 350, linked*	12	1
Symptomatic, CD4 < 350, unlinked*	1	0
Symptomatic, CD4 < 350, linked*	2	2
Symptomatic, CD4 > 350, linked*	0	2
Total	25	

* Linkage to care was established at the 6 month follow-up interview

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