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## Engaging HIV-positive clients in care: acceptability and mechanisms of action of a peer navigation program in South Africa

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### ABSTRACT

Antiretroviral therapy (ART) could curtail the HIV epidemic, but its impact is diminished by low uptake. We developed a peer navigation program to enhance engagement in HIV care, ART adherence, and behavioral prevention. In preparation for a randomized controlled trial, the program was piloted over four months at two primary health clinics in South Africa's North West Province. Newly diagnosed, HIV-positive clients met regularly with navigators to address barriers to care, adherence, and prevention. To assess program acceptability and feasibility and characterize the mechanisms of action, we surveyed 25 clients who completed navigation services and conducted interviews with 10 clients, four navigators, and five clinic providers. Clients expressed near universal approval for the program and were satisfied with the frequency of contact with navigators. HIV stigma emerged as a primary driver of barriers to care. Navigators helped clients overcome feelings of shame through education and by modeling how to live successfully with HIV. They addressed discrimination fears by helping clients disclose to trusted individuals. These actions, in turn, facilitated clients' care engagement, ART adherence, and HIV prevention efforts. The findings suggest peer navigation is a feasible approach with potential to maximize the impact of ART-based HIV treatment and prevention strategies.

### ARTICLE HISTORY

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### KEYWORDS

Peer navigation; South Africa; engagement in care; retention; HIV prevention

### Background

Antiretroviral therapy (ART) could curtail the HIV epidemic by preventing onward transmission (Cohen et al., 2011; Padian et al., 2011; Quinn et al., 2000). To that end, UNAIDS included initiation of ART as a goal in its 90-90-90 campaign to enhance HIV diagnoses, ART provision, and viral suppression (*90-90-90: An Ambitious Treatment Target to Help End the AIDS epidemic*, 2014). Unfortunately, insufficient uptake continues to diminish the medications' preventive impact (Cheever, 2007; Fox & Rosen, 2015; Gardner, McLees, Steiner, Del Rio, & Burman, 2011; Rosen & Fox, 2011). After testing HIV-positive, large proportions of people do not initiate treatment or eventually fall out of care (Fox & Rosen, 2015; Rosen & Fox, 2011). These losses create a care cascade (Gardner et al., 2011; Kranzer, Govindasamy, Ford, Johnston, & Lawn, 2012), in which fewer than half of all individuals qualifying for ART are actively receiving it (Johnson, 2012; Kranzer et al., 2011).

Intervening to enhance care engagement and ART adherence in resource poor settings requires action on multiple fronts (Okeke, Ostermann, & Thielman, 2014;

Thompson et al., 2012). At a structural level, countries have altered their healthcare systems to facilitate utilization (Barnabas et al., 2014; Fatti, Grimwood, & Bock, 2010; Humphreys et al., 2010; Jani et al., 2011; Larson et al., 2012). For example, South Africa expanded eligibility for its public ART program and decentralized medication delivery (Brennan et al., 2011; *National Consolidated Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults*, 2014). These changes have not eliminated care cascade challenges, however (Gilvydis et al., 2015). Additional efforts thus focus on enhancing interpersonal support for individual clients facing barriers to care and ART use, such as home-based care services (Fatti, Meintjes, Shea, Eley, & Grimwood, 2012; Torpey et al., 2008) and the identification of a "treatment supporter" within a client's social network (Kunutsor et al., 2012).

To enhance engagement in care, adherence, and behavioral prevention efforts among recently HIV diagnosed clients in South African community-based primary health facilities, we developed a peer navigation

program. It offered interpersonal support, similar to other interventions (Fatti et al., 2012; Kunutsor et al., 2012; Torpey et al., 2008), but placed greater emphasis on social modeling (Bandura, 1994). We used HIV-positive individuals as navigators because we anticipated that the common experiences of navigators and clients would foster rapport (Figure 1), which in turn would facilitate navigators becoming trusted sources of support to guide clients' efforts to address barriers to HIV care and prevention. Peer-based intervention models have been shown to improve linkage to care and ART adherence while reducing burdens on the healthcare system (Hatcher et al., 2012; Richter et al., 2014; Selke et al., 2010), although such outcomes are not observed universally (Chang et al., 2010; Genberg et al., 2016).

We structured our research to establish the program's acceptability and feasibility, characterize its effects, and assess efficacy. Data on efficacy are being obtained in a cluster randomized controlled trial (Registration #NCT02417233) (Lippman et al., 2016). In this paper, we focus on the former two goals, drawing on qualitative interview data that accompanied pilot implementation of the navigation program. We seek to understand how peer navigation exerts influence on care engagement outcomes and how the approach can be optimized and targeted.

## Methods

### Navigation program overview

We implemented the program in the rural Moses Kotane Sub-district of South Africa's North West Province. In consultation with sub-district officials, four government-run clinics were identified, two of which were randomly assigned to implement the navigator program. The others implemented an intervention limited to Short Message Service (SMS) communications (Lippman et al., 2016) and are not discussed here. As reflected in Figure 2, navigators held an initial visit with each client to establish rapport; identify barriers to care, adherence, and prevention; and develop action plans meeting SMART (Doran, 1981) criteria (specific, measurable, attainable, relevant, and time-bound), which were documented on forms kept by the navigators. In each subsequent month, navigators held at least one in-person meeting and one check-in by SMS or phone with each client, during which progress was assessed and new action plans developed. In addition, scripted SMS were sent weekly to clients encouraging care engagement, adherence, and prevention (Lippman et al., 2016). SMS reminders were also sent for scheduled clinic visits. Additional contacts were encouraged when needed.

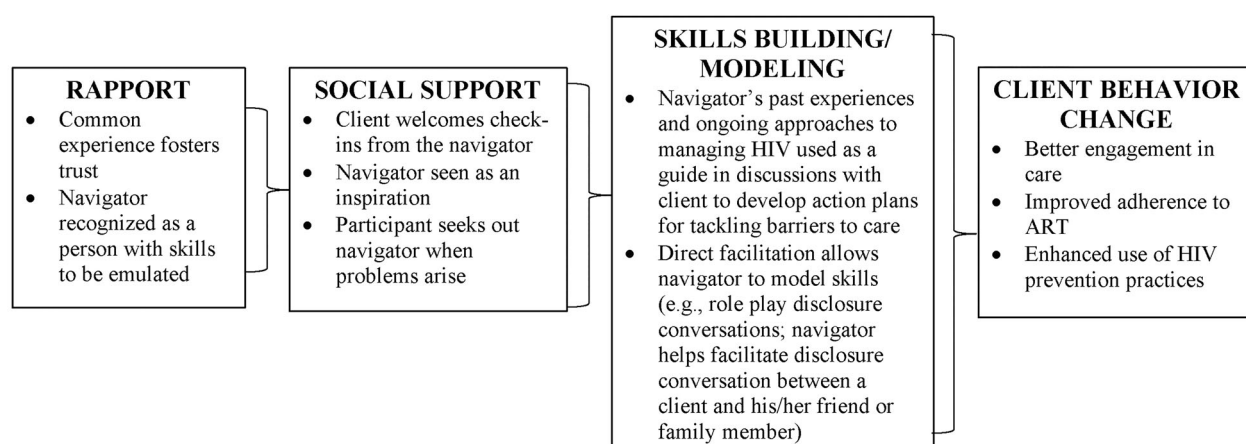
The program lasted four months. During the final month, navigators prepared each client for "graduation" by focusing on support systems within the client's social network and on longer-term plans for remaining in care, adherent to ART, and utilizing HIV prevention strategies.

Because navigators' own experiences were intended to guide client work, we did not prescribe specific activities for particular barriers. Rather, we provided general guidance that navigators could consider when responding to barriers. For example, they were told that strategies for addressing stigma included encouraging a client to meet other HIV positive individuals and supporting disclosure to trusted friends and family.

Navigators had to be receiving care at the local clinic and demonstrate commitment to medication adherence and clinical monitoring. We hired one male and one female navigator per facility. They received a small stipend and signed a statement acknowledging potential risks of the work (e.g., serostatus disclosure beyond the study). The navigators completed a one-week training that focused on developing and maintaining rapport, listening skills, identifying barriers to care and prevention, and working with clients to set behavior change goals. Navigators also learned about potential strategies for addressing specific barriers. Training content and study protocols were organized into a manual given to each navigator. After completing the initial training, navigators delivered services under supervision, with additional training provided to augment skills or address observed deficiencies. Navigators met weekly with supervisors and biweekly with the larger study team to monitor their fidelity to program protocols, provide feedback on recent client interactions, and offer guidance for dealing with complex barriers. Onsite supervisors met weekly with investigators to discuss particularly complex challenges facing navigators or clients. At each site, navigators also had access to a clinical provider liaison to facilitate client referrals.

### Study procedures

The primary participants were newly diagnosed clients identified during HIV testing. Clinic personnel referred eligible individuals to research staff who obtained consent and assigned them to a navigator. We aimed to enroll a maximum of 10 clients per navigator (20 per clinic) to maintain manageable workloads. Clients responded to surveys at enrollment and the end of navigation services. Surveys were developed in English and translated into Setswana, and captured demographics and health behaviors. Follow-up surveys included questions about program satisfaction and adequacy of



**Figure 1.** Pathway by Which Peer Navigation Was Expected to Influence Client Behavior.

navigation contact. Surveys were conducted by trained personnel who entered responses directly into tablets securely linked to an electronic database. To monitor contact frequency, navigators logged all interactions with clients on paper forms that were then entered into the database.

After completing pilot implementation of the program, we conducted individual interviews, lasting 30–60 min, with navigators and subsets of clients and clinic providers. Each interview was held in a private clinic room and led by an investigator and field supervisor. Most conversations moved between English and Setswana, with the field supervisor providing translation when needed.

Clients talked about barriers to care, adherence, and prevention; described the services they received; and

identified what they liked and disliked about the program. Navigators characterized their clients' barriers, assessed the degree to which clients had overcome the barriers, and described why the work was more or less successful. Providers were asked about navigation's impact on clients and about the program's integration with other clinic work. Interviews were recorded and subsequently transcribed, at which time the Setswana portions of the conversation were translated into English.

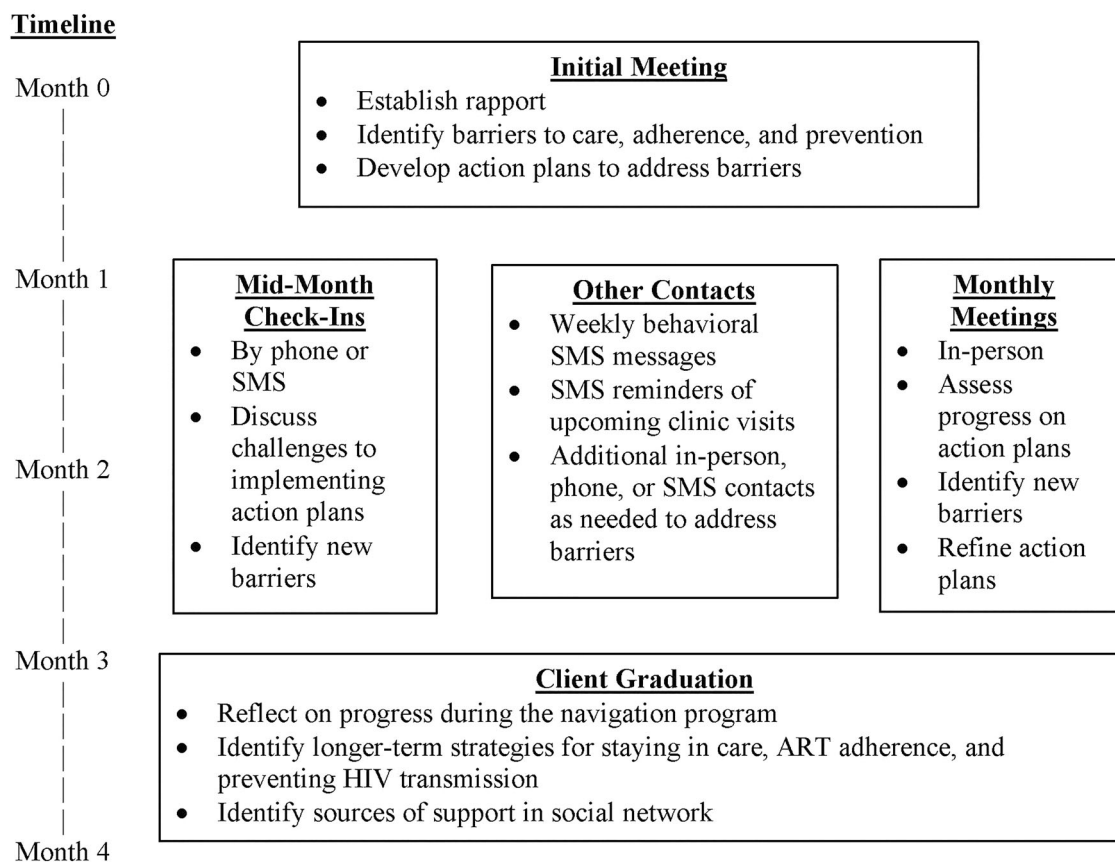
Participants provided written informed consent. Clients received 20 South African Rand (approximately \$2 US) to reimburse the costs of study-related SMS and phone communications. Otherwise, participants were not compensated. All procedures were approved by the institutional review boards at the University of California San Francisco (Study #12-10482), the University of Washington (Study #44313), and the Human Sciences Research Council in South Africa (REC 9/20/02/13). The study was also approved by the Policy, Planning, Research, Monitoring and Evaluation Committee for the North West Provincial Department of Health.

### Analysis

Survey and contact log data were exported into Stata (Release 13, College Station, TX) and frequencies run on demographics, program acceptability and feasibility, and number of contacts. Interview data were analyzed using Framework Analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie & Spencer, 1994). Investigators developed and refined codes reflecting the interview topics and emergent themes. The codes were applied to transcripts via Atlas.ti (Version 7, Berlin), after which we compared and contrasted themes across interviews.

**Table 1.** Demographic characteristics among navigation participants who completed baseline and follow-up surveys ( $N = 25$ ).

	<i>N</i>	Percent
Gender		
Female	17	68.0
Male	8	32.0
Currently in a relationship		
Yes	15	60.0
No	9	36.0
Unknown/not reported	1	4.0
Education		
Less than primary school	8	32.0
Completed primary school	10	40.0
Completed secondary school	4	16.0
Post-secondary school	1	4.0
Unknown/not reported	2	8.0
Employment		
Full time	1	4.0
Part time	11	44.0
Unemployed	11	44.0
Student	1	4.0
Unknown/not reported	1	4.0
Age at enrollment (range: 18–57)	Mean 34.2	Std. Dev. 10.7



**Figure 2.** Schematic Overview of the Peer Navigation Program.

## Results

Twenty-eight clients enrolled in navigation services. This total was lower than our original target because one clinic had few HIV diagnoses during the recruitment period. Of those enrolled, three (two women, one man) could not be reached for follow-up surveys, leaving a

final sample of 25. [Table 1](#) provides client demographic information. We conducted 19 qualitative interviews: 10 with clients (six women, four men), four with navigators (two women, two men), and five with providers (four women, one man; two nurses, two counselors, one operations manager).

**Table 2.** Program acceptability, as assessed during the follow-up survey ( $N = 25$ ).

	Mean	Interquartile range (IQR)
Contact with navigator		
In-person meetings	5.0	1.5–7.0
Phone calls	8.9	3.5–13.5
SMS (text message)	6.3	0–14.5
	<i>N</i>	Percent
Helpfulness of navigation		
Very helpful	25	100.0
Somewhat helpful	0	0.0
Not at all helpful	0	0.0
Adequacy of contact		
Not enough	3	12.0
Just about right	20	80.0
Too much	2	8.0
	Number of participants reporting topic discussion	Percentage of participants reporting topic discussion
Topics discussed with navigator		
Staying in care	25	100.0
Appointment reminders	24	96.0
Taking ART on time	24	96.0
Disclosing HIV status	25	100.0
Practicing safer sex	25	100.0
Drinking in moderation	24	96.0

**Table 3.** Quotes from qualitative interviews with clients ( $n = 10$ ), navigators ( $n = 4$ ), and clinic providers ( $n = 5$ ).

<i>Impact on the navigator program on engagement in care, adherence, and prevention</i>	
Q1	The thing is when I started [taking ART], it felt like I would vomit. At other times, they would make me sleepy. ... After about five days, that's when I got used to them. ... [My navigator] is the one I have been sending SMSs. They said if I have a problem I should call them, they explained that I should just keep taking [my ART medications], because that's how they are when you're starting, don't even stop. –Male Client 1
Q2	<i>Interviewer:</i> What are the things [the navigator] is advising you about or the things she asks you to do for you to stay safe? What are those? <i>Participant:</i> Like, I was drinking alcohol, [my navigator] told me that – she did not say “leave it” – but I must try to leave. I think that is being safe. Then, even when I have a boyfriend, I have to be fair to him and explain to him, to be friendly to him, to explain to him [i.e., disclose that she has HIV]. –Female Client 1
Q3	We have the problem of the forgotten appointment. But because of the peer navigators, they remind [clients] with an SMS to come. And then others [navigation clients] were able to disclose. Because, unlike professional nurses, they [the navigators] can tell you, “Like you, I'm also taking treatment” ... It [the medication] is working and it's good, so it means if I take it myself, it doesn't mean I'm dying. So if you see somebody who is a role model of an HIV person and they are talking to you, it is something that is good. –Provider 1
<i>Client shame and blame (stigma manifestation)</i>	
Q4	She has not been able to tell [her mother], has not told anyone about what is going on with her life. So she is always stressed, she is always crying. She is always blaming herself, [asking] why should this disease infect her. –Navigator 1
Q5	The hardest thing was the blame. Even when they talk he would be like, “I blame her.” The hardest thing was he was not focused. He left everything now to blaming the partner. –Navigator 2
<i>Addressing shame in the navigation program</i>	
Q6	[My client said], “I feel I have accepted myself. Even when I am sometimes lying on the bed and think of you and see the way you are, and thinking of your story you told me, how you were and even when you found out you were positive and pregnant. The situation you were in is the one I am currently in, so ... I was picturing you when I am home. I was now healed emotionally.” –Navigator 1
<i>Client disclosure fears (stigma manifestation)</i>	
Q7	[Some patients] will tell you, “In my family I will never disclose to anybody.” Some will tell you, “When our parents, maybe my mother has taken alcohol, she will tell other people, so I don't [tell her].” –Provider 2
<i>Addressing disclosure fears in the navigation program</i>	
Q8	I was not able to tell them at home that I am sick now, [but] I feel like there is someone [the navigator] who will support me; they are the one who [is] always by my side. –Female Client 3
Q9	I encouraged her to disclose to someone because I saw it was important cause she was always talking alone. When you look at her you could see that this person is talking in her heart [thinking too much] ... Then she told her aunt that I am like this and that [disclosed she has HIV] and her aunt said, “You see how beautiful I am, I am also there drinking those things [Aunt is also taking ART]. If you are going to drink them, you are going to be like me.” –Navigator 3
<i>Navigators' own stigma fears and effect of the program on them</i>	
Q10	[When a new client is recruited], maybe she knows me and [the study recruiter] has already told her about my status. At the end she withdraws from the study, how will it be when we meet? The lady is not in the study and yet she knows what my status is. –Navigator 1
Q11	But now, on the streets, even my friends, they know I am on treatment, and it happened that way after I became a [peer navigator]. ... I can talk even if I am with them or on the streets with my friends, I can tell them that this type of a pill does so and so, that is we talk and it's nice. –Navigator 1

### **Findings from the survey and contact log: program acceptability and feasibility**

All participants felt that navigation services were very helpful and most described the amount of contact as being “just about right” (Table 2). Nearly all reported having discussions about remaining in care, adhering to ART, serostatus disclosure, and practicing safer sex. Navigators logged 456 client contacts, of which 104 (23%) were in person, 131 (29%) were by phone, and 221 (48%) were by SMS.

### **Findings from the interviews: characterizing the achievements of the program**

To illustrate interview themes, we have placed quotes in Table 3, with each assigned a number. In this section, we reference specific quotes by placing quote numbers in brackets (e.g., [Q1]).

Clients described the navigation program as influencing their engagement in care and ART adherence. For some, support was as simple as a reminder, but others relied heavily on navigators for advice and encouragement [Q1]. Clients faced varied barriers, including medication stock-outs at clinics, concerns that keeping

medications at home would reveal one's HIV status, and a lack of food to take with the pills. Navigators responded by helping clients communicate with providers, disclose their status, and connect to government grant services to receive food subsidies.

Some clients entered the study with a poor understanding of HIV prevention, which their navigators rectified. For example, one (Male Client 2) stated that he previously believed that ejaculating into a condom would make him sick. His navigator disabused him of this notion. Another client spoke of learning of the importance of HIV disclosure and reducing alcohol use from her navigator [Q2].

Among providers, there were similar assessments of success [Q3]. They described navigation clients as missing fewer appointments and not requiring extensive clinic staff efforts to track them down.

### **Mechanisms of action**

Navigation impact was achieved through rapport building, social support, education, and disclosure assistance. Considering these mechanisms requires a focus on stigma, which emerged as a driver of many client barriers. An early stigma-related challenge was shame following diagnosis [Q4], which occasionally turned to

blame against those perceived to have caused the infection [Q5]. To address these feelings, navigators provided education about HIV and ART and helped clients develop plans for healthy living. The approaches were useful for giving clients an understanding of how to combat the effects of HIV. But the most important mechanism of action was navigators' ability to model living a happy, healthy life. It helped forge the bond between clients and navigators. The dynamic is reflected in the story of one woman (Female Client 2) who reported isolation after diagnosis. She had been left by her partner and wanted someone "to be on this journey together." The navigator discussed her own experiences living with HIV. The client said the conversations helped her trust the navigator and feel less lonely. She had found someone to whom she could relate. Similarly, the value of a peer connection was evident in the story a navigator heard from a different client [Q6], who described being "healed emotionally" by thinking of how the navigator had persevered through similar challenges.

The impact of stigma was also reflected in clients' worries about being rejected for having HIV. They feared being blamed for infecting others and that, by telling anyone, they would lose control of who knew they had HIV [Q7]. Participants described how attending clinic, keeping medical documentation and medications at home, regularly taking pills, and experiencing side-effects presented risks of being discovered. These concerns made disclosure a priority. In fact, agreeing to be in the study brought up concerns about disclosure. Some participants worried that navigator home visits would make neighbors suspicious. Interestingly, these same stigma-related fears turned into facilitators of navigation once the client was enrolled. The navigators became trusted sources of comfort, a dynamic reinforced by clients' reluctance to reveal their HIV status to anyone else [Q8].

Until clients were able to disclose to a few trusted individuals, they found it difficult to engage in care, adhere to ART, and practice prevention behaviors. These challenges were reflected in the observations of one participant (Provider 2) who noted that there were HIV-positive individuals so afraid of being rejected that they would not seek care in their home village. This provider felt that the navigators' stories about their own experiences gave the clients the confidence to seek services locally. Navigators worked with clients to identify individuals to whom they could or should disclose, such as sexual partners [Q9]. They also helped the clients work through situational barriers to disclosure and, in some cases, mediated disclosing conversations in person. With this support, most clients were able to tell at least one person about their HIV status.

We also found that navigators had to confront their own fears and discomfort around stigma [Q10]. Importantly, the program helped navigators become more comfortable with being open about their HIV status [Q11].

## Discussion

Our research establishes a peer navigation program's acceptability and feasibility, and characterizes how it influenced engagement in care, ART adherence, and prevention practices among newly diagnosed HIV-positive clients in South African primary health clinics. The program was well regarded by clients, navigators, and clinic providers as a means to identify barriers to care and solutions to overcome them. Peer navigation offered tailored support that, if implemented widely, could enhance the number of clients engaged with South Africa's expanded HIV services (Brennan et al., 2011; *National Consolidated Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults*, 2014) and bring the country closer to meeting UNAIDS' 90-90-90 campaign targets (90-90-90: *An Ambitious Treatment Target to Help End the AIDS epidemic*, 2014). Interventions that provide interpersonal support, such as our program, complement structural interventions by helping to overcome individuals' barriers to care and ART adherence (Okeke et al., 2014).

Our research suggests that peer navigation is particularly well-suited for offering support because it successfully responds to stigma. Clients' engagement in care, adherence, and prevention practices were hindered by shame at being infected and fears of how others would treat them for having HIV, which aligns with prior findings (Treves-Kagan et al., 2015). Consistent with the program model (Figure 1) and its theoretical basis (Bandura, 1994), navigators were able to respond to the barriers because they came to be seen as models for living with HIV. They were a trusted source of support for individuals otherwise isolated by stigma. Navigators' support helped clients overcome feelings of shame and disclose to members of their social network.

Because pilot implementation of the program lasted four months, we are unable to draw inferences about the longer-term impact on stigma and other barriers. A navigation program ideally should foster self-sufficiency by reducing clients' reliance on navigators over time. We have little data to suggest that our navigators imparted independent problem-solving skills. The successes of the current program are already challenging to reproduce because they rely on navigator-client bonding and



on appropriate tailoring of support to client needs, rather than on delivery of specific content. Teaching problem-solving skills is even more complicated and would require greater supervision and more highly-skilled navigators. Such demands could exceed the capacities of busy clinics. Alternately, the program could be tailored so that navigation services are directed more extensively and quickly to those clients who most need help at any given time. Such an adaptive program could also prove more economical and lead to greater impact for its investment.

Our findings reflect only clients who were newly diagnosed and therefore cannot be generalized to those who have known of their HIV-positive status for longer periods of time. We focused on newly diagnosed clients because they had not yet established care routines. But they also were experiencing strong emotional reactions to learning they had HIV. There is research in other settings that shows that the longer-term impact of hidden stigmatized conditions continues to be distress from isolation and rumination (Hatzenbuehler, Nolen-Hoeksema, & Dovidio, 2009). This finding suggests that our program's mechanisms of action could look similar even when dealing with clients who enroll years after diagnosis. It is also worth noting that the program is designed for flexibility: it targets the barriers that a person is currently facing. Therefore, we do not have reason to believe that the program's architecture would need to change, even if clients faced barriers different than those observed among our participants.

Peer navigation offers an acceptable, feasible, and promising strategy for enhancing engagement in HIV care, ART adherence, and prevention practices among newly diagnosed HIV positive clients in resource-limited, sub-Saharan African settings. It may be a particularly useful complement to efforts to expand access to treatment. Research is now needed to determine whether navigation services are able to sufficiently change care outcomes in order to have a cost-effective impact on the HIV epidemic.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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