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Information, Motivation, and Behavioral Skills for Early Pre-ART Engagement in HIV Care among Patients Entering Clinical Care in KwaZulu-Natal, South Africa

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Abstract

Little is known regarding factors implicated in early engagement and retention in HIV-care among individuals not yet eligible for antiretroviral therapy (pre-ART) in sub-Saharan Africa. Identifying such factors is critical for supporting retention in pre-ART clinical care to ensure timely ART initiation and optimize long-term health outcomes. We assessed patients' pre-ART HIV-care related information, motivation, and behavioral skills among newly diagnosed ART-ineligible patients initiating care in KwaZulu-Natal, South Africa. The survey was interviewer-administered to eligible patients who were 18 years of age or older, newly entering care (diagnosed within the last 6-months), and ineligible for ART (CD4 count >200 cells/mm³) in one of four primary care clinical sites. Self-reported information, motivation and behavioral skills specific to retention in pre-ART HIV-care were characterized by categorizing responses into those reflecting potential

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strengths and those reflective of potential deficits. Information, motivation, and behavioral skills deficits sufficiently prevalent in the overall sample (i.e., 30% prevalent) were identified as areas in need of specific attention through intervention efforts adapted to the clinic level. Gender-based differences were also evaluated. A total of 288 patients (75% female) completed structured interviews. Across the sample, 8 information, 8 motivation, and 8 behavioral skills deficit areas were identified as sufficiently prevalent to warrant specific targeted attention. Gender differences did not emerge. The deficits in pre-ART HIV-care related information, motivation and behavioral skills that were identified suggest that efforts to improve accurate information on immune function and HIV disease are needed, as is accurate information regarding HIV treatment and transmission risk prior to ART initiation. Additional efforts to facilitate the development of social support, including positive interactions with clinic staff and decreasing community-level stigma, and to decrease structural and resource-depleting demands of HIV-care may be particularly valuable to facilitate retention in pre-ART HIV-care.

Keywords

Retention in HIV-care; early engagement in HIV-care; IMB; pre-ART; South Africa

INTRODUCTION

South Africa is home to an estimated 5.6 million people living with HIV (PLWH) (UNAIDS, 2010), with an estimated 380,500 new infections in 2011 (Statistics South Africa, 2011). To address the needs of this epidemic, national policies to enhance HIV testing and treatment efforts have been implemented (South African National AIDS Council (SANAC), 2011). During the current study, national antiretroviral therapy (ART) treatment guidelines recommend ART for all adult and adolescent PLWH with treatment resistant Tuberculosis (TB), WHO stage IV HIV infection or a CD4 count < 200 cells/mm³; which had been recently expanded to < 350 cells/mm³ for pregnant women and TB co-infected PLWH (National Department of Health: Republic of South Africa, 2010). Over 1 million adults have been successfully enrolled in ART treatment in South Africa, although approximately 1.1 million remain in need of treatment (SANAC, 2011). In April 2010, South Africa initiated a massive national HIV Counseling and Testing program (Motsoaledi, 2010); testing 14 million South Africans and referring 2 million newly diagnosed PLWH to care by August 2011 (SANAC, 2011).

Clearly, these expanded testing efforts aim to identify PLWH at earlier stages of HIV. Thus, a larger number of people testing positive are likely not yet eligible for ART. As the number of ART-ineligible PLWH increases, efforts to engage and retain them in pre-ART HIV clinical care are essential to ensure optimal health outcomes through ongoing treatment and prevention of comorbidities (e.g., tuberculosis, STIs, diabetes), CD4 monitoring every 6-months, and timely initiation of ART (National Department of Health: Republic of South Africa, 2010). Additionally, pre-ART care offers opportunities to reinforce secondary prevention efforts (J. D. Fisher, Smith, & Lenz, 2010; National Department of Health: Republic of South Africa, 2010). With fewer than one-third of ART-ineligible PLWH successfully retained in pre-ART care across sub-Saharan Africa (Rosen & Fox, 2011),

gaining an understanding of factors that influence retention in care that could guide targeted interventions is critical.

As part of a study evaluating an intervention to increase engagement and retention in pre-ART clinical care, we conducted a preliminary assessment of retention-related facilitators and barriers among ART-ineligible patients newly enrolled in HIV-care in two health districts in KwaZulu-Natal, South Africa. Based on the Information, Motivation, Behavioral Skills (IMB) model of health behavior change (W. A. Fisher, Fisher, & Harman, 2003; J. D. Fisher & Fisher, 1992) and its application to engagement in HIV-care (Amico, 2011; Smith, Fisher, Cunningham, & Amico, 2012), pre-ART care-related information, personal and social motivation to remain engaged in pre-ART care, and behavioral skills to manage living with HIV and routine use of pre-ART care were evaluated to identify potential intervention targets.

METHODS

Participants were recruited from patients initiating care during April-July 2011 at four HIV-care sites in KwaZulu-Natal, South Africa. Eligible participants were at least 18-years of age, had first tested HIV-positive within the last 6-months, and had chart-confirmed CD4 counts above the eligibility criteria for ART initiation. All referred patients agreed to participate, completed an IRB-approved consent, and were provided with ~\$10USD for their participation in this baseline interview. Study procedures were approved by the Institutional Review Boards of University of Connecticut (USA), The Centre for Addiction and Mental Health (Canada), and University of KwaZulu-Natal (South Africa).

The interviewer-administered survey created for this study (survey items available at:<http://www.chip.uconn.edu/chipweb/supplemental/PreARTRetention.pdf>) took an average of 45-60 minutes to complete in a private location within the clinic, and included demography (e.g., age, sex, date of HIV diagnosis, education, income) and items targeting experiences with HIV-care (e.g., travel cost and distance to care, clinic wait-times). Additionally, care-related **information** (12 items, e.g., 'Regular health checks by a nurse or doctor help to keep patients with HIV more healthy'), **personal motivation** (8 items, e.g., 'Going to clinic for your HIV-care when you are feeling sick is important') and **social motivation** (15 items, e.g., 'Most people from your community think that you should go to the clinic regularly'), and **behavioral skills** (18 items, e.g., 'Ease or difficulty of asking clinic staff or providers questions about your HIV or treatment') were assessed; based on the IMB model of health behavior (W. A. Fisher et al., 2003; J. D. Fisher & Fisher, 1992) and recent applications of it to initiation and retention in HIV-care (Amico, 2011; Smith et al., 2012). This theory-based survey was implemented to guide a subsequent IMB-model based intervention to promote retention in pre-ART care, and the current baseline responses are evaluated to identify IMB areas most in need of targeted intervention. Individual responses to retention in HIV-care-related IMB items were dichotomized into strengths (responses that reflected being well-informed, motivated, or skilled) and deficits (responses that reflected being misinformed, less motivated or skilled). Any deficit present in 30% or more of the sample was identified as sufficiently prevalent to warrant specific attention through intervention efforts. We also evaluated whether deficits varied by gender via chi-square test for differences in proportion

falling in the deficit-region among women and among men, using Fisher's exact to determine significance levels where cell sizes contained 5 or less respondents. All analyses used PASW v18.0 with two-sided alpha.

RESULTS

A total of 288 PLWH (75% female, average 31 years of age) were interviewed. Almost a quarter (24%) reported having earned a diploma or work certificate and 33% reported experiencing food insecurity in the past three months. Chart notes indicate an average CD4 count of 539 (SD=238, 252 to 1977), and that 17% of participants were told by clinic staff to return to pre-ART care monthly for repeat CD4-monitoring, 26% every 3-months, 42% every 6-months, and 13% had no documented instructions for when to return.

In terms of accessing HIV-care, participants traveled to clinic most often by foot (55%) or taxi/bus (44%); travel to the clinic one-way took an average of 41 minutes (SD=29 minutes), and cost an average of \$1-2USD. Average reported clinic wait time was 2 hours 15 minutes. In terms of recall of instructions for return to care, 10% recalled being asked by clinic staff to return monthly, 45% every 3-months, 32% every 6-months, and 9% reported not having been given any specific instructions on when they should return to clinic.

Pre-ART Retention Related Information, Motivation and Skills

Overall, participants demonstrated a number of notable pre-ART related strengths and deficits. As depicted in Figure 1, the range with which participants reported pre-ART HIV-care strengths and deficits varied across the specific information, motivation, and behavioral skills items.

Information—Across all participants, 8 of the 12 information items suggested a potential lack of accurate information about pre-ART HIV-care (see Figure 1a) sufficiently prevalent (e.g., 30%) to suggest sample-wide relevance. Most notably, there was the misconception that those reporting alcohol or drug use would be denied ART access, that the only function of HIV-care is to check for ART eligibility, that CD4 counts change very slowly so that attendance in care could be delayed over long periods, and that getting treatment for TB or an STI would not definitively help one's immune functioning. The misconception that individuals not qualifying for ART could not infect others via unprotected sex was reported by 27% of the sample, with an additional 7% who were unsure about the accuracy of this statement.

Motivation—The sample appeared to have numerous strengths (15 of 23 items), particularly in terms of positive attitudes towards pre-ART HIV-care (see Figure 1b). Deficits that were flagged as sufficiently prevalent in the overall sample to warrant specific intervention attention (8 items) included items reflecting social motivational aspects of negotiating HIV-care. These involved worrying about community suspicions invoked by frequent travel to a clinic, lacking support from friends/family, concerns about clinic staff disclosing the HIV-status of patients, and having disclosed to few or no family members or friends.

Behavioral Skills—The sample reported strengths (10 of 18 items) in most of the behavioral skills areas assessed (see Figure 1c). Within the 8 behavioral skills items reflecting areas in potential need of intervention, the most common was difficulty managing the long wait times at the clinic, followed by transportation costs, getting away from work or household duties, overall costs associated with coming to care, and skills to maintain privacy while still accessing HIV-care. Most of the factors that the sample identified as particularly difficult to negotiate were either systems generated (wait time) or resulting from limited personal resources (costs associated with care) common in the communities serviced by the participating clinics.

Group Differences—No significant differences by gender emerged across any pre-ART information, motivation, or behavioral skills items. Though not statistically significant, there were slight differences in the proportion of men and women endorsing several of the HIV care IMB deficits. For example, a statistical trend ($p=.06$) was observed in social motivational deficits, with men (54.9 %) more frequently reporting they were lacking support from family members for coming in for HIV-care than women (42.4%). More men than women also reported perceiving less support from friends (64.3% male vs. 54.6% female) for attending clinic, perceived greater difficulty finding time to come in for clinic visits (45.1% males vs. 34.1% females), or getting permission from work to attend clinic (56.3% male vs. 46.1% female). Similarly there were slight differences in the proportion of men and women endorsing some of the HIV care IMB strengths. Though these differences were not statistically significant, more women than men reported that it was easy for them to find a clinic that was within a reasonable travel distance (77.0% female vs. 67.6% male); whereas more men than women report greater ease finding their way around the clinic (87.3% male vs. 77.0% female).

DISCUSSION

In an effort to better understand the needs of pre-ART patients for retention in HIV-care, this study examined the information, motivation, and behavioral skills strengths and deficits of patients linked to care but ineligible for ART attending several clinics in KwaZulu-Natal, South Africa. Results suggested a number of informational, motivational, and behavioral skills factors that could be targeted for improvement through individual, community-based, and structural interventions.

Information deficits largely centered on *misinformation*, with over 46% of the sample reporting that pre-ART HIV-care is solely focused on evaluating people for ART initiation. Many also did not associate treatment for STIs or TB as being beneficial to the health of PLWH. Importantly, 34% of the sample reported PLWH not yet eligible for ART could have unprotected sex without risk of infecting their partners. Motivational deficits predominantly centered on attitudes about privacy, confidentiality, interactions with care providers, and other kinds of social support. Skills-related deficits centered on difficulties managing aspects of HIV-care that were either related to the care-delivery system (e.g., long wait times) or resources (e.g., costs of coming to care), as well as negotiating the maintenance of privacy and competing priorities. Significant gender differences were not identified among the current sample. However, there may be potential for gender differences

in some areas, such as perceived social support for attending HIV visits or perceived ability to locate HIV care that is easily accessible, to emerge as significant when generalized across the larger pre-ART population.

While the profile of results obtained provides much needed guidance for targeted intervention development, limitations include potential self-report bias and limited abilities to generalize the results beyond PLWH already linked to care within the first six months of their initial HIV diagnosis. With most participants reporting several areas of difficulty, self-report bias towards reporting only strengths did not appear to limit the results. The current research focuses on factors that may support retention among those already linked to HIV-care, and cannot speak to factors that may limit or promote linkage to care. Future work is needed to assess if gender differences might be more pronounced across larger samples of PLWH or among those with delayed entry to care. It is also important to caution that the deficits we identified drew from participant responses across four clinical care sites; intervention development for a particular clinic would need to focus on the factors relevant to that specific population in light of clinic resources, environment and community level factors.

Conclusion

The critical deficits and strengths identified in this research suggest that individuals in pre-ART HIV-care may benefit from education and counseling focused on providing more accurate information about pre-ART treatment and infectivity. Strengthened personal or social motivation could result from individual and/or group opportunities to build positive attitudes and perceived and actual social support, clinic-level intervention to promote more positive interactions with the care team and system of care, and community-level campaigns continuing efforts to decrease community-level HIV stigma. Finally, deficits in behavioral skills could be addressed through both working with the individual in increasing their negotiation and management skills and overall confidence in applying these skills to their HIV-care, as well as efforts to decrease barriers produced within the structural systems providing HIV-care.

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a

b

FIGURE 1. Pre-ART HIV-care related Information, Motivation, and Behavioral Skills Deficits and Strengths

(a) Information: Proportion of Participants Responding with Inaccurate (deficits) vs. Accurate (strengths) Pre-ART HIV Care Knowledge; (T): True response defines 'strength' category, (F): False response defines 'strength' category. (b) Motivation: Proportion of Participants Responding with Negative/Ambivalent (deficits) vs. Positive (strengths) Pre-ART HIV Care Attitudes; (A): Agree to Strongly Agree responses defines 'strength' category, (D): Disagree to Strongly Disagree responses defines 'strength' category. (c) Behavioral Skills: Proportion of Participants Responding with Low (deficits) vs. High (strengths) of Pre-ART HIV Care Perceived Self-efficacy; (E): Easy to Very Easy responses defined 'strength' category.