# Understanding the Behavioral Determinants of Retention in HIV Care: A Qualitative Evaluation of the Situated Information, Motivation, Behavioral Skills model of Care Initiation and Maintenance

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This thesis is dedicated to the participants, who gave **voice** to this project, and to Richard Davis, who survived with HIV until 2006 working within the HIV-positive community for unity and equal access to treatment.

**Abstract**

The goal of this study is to identify the content and context of critical informational, motivational, and behavioral skills related facilitators and barriers influencing retention in HIV care in an inner-city clinic population receiving clinic- and outreach-based HIV care services. Elicitation of retention-relevant factors was guided by the Situated Information-Motivation-Behavioral Skills model of Care Initiation and Maintenance, using qualitative in-depth semi-structured interviews. Deductive and inductive content coding were used to identify important theory-based dynamics of retention in HIV care and to identify factors discussed as important to retention in HIV-care that were not well specified by the model. Participants' experiences with retention in HIV care were well characterized by the proposed information, motivation, and behavioral skill model components. Findings indicate a need to attend to multiple determinants of self-directed care attendance, including information, motivation, and behavioral skills, as critical to sustaining retention in care over time. Contextual factors related to living with HIV including acceptance of diagnosis, HIV stigma and HIV-related physical and cognitive impairments; as well as those highly relevant to a marginalized inner-city population, such as care attendance and patient-provider relationships in the context of ongoing depression or active substance use additionally comprise aspects of these IMB-based determinants of retention in HIV care.

**Key Words:** HIV care, retention, health behavior models

# Understanding the Behavioral Determinants of Retention in HIV Care: A Qualitative Evaluation of the Situated Information, Motivation, Behavioral Skills Model of Care Initiation and Maintenance

The current standards of HIV-clinical care in the US recommend one clinical exam (including CD4 and viral load evaluation) with a primary care provider every three to four months for asymptomatic patients responding to treatment (Aberg et al., 2009). More frequent evaluations may be needed for patients initiating new treatments, with increased disease progression, or in need of ancillary support services (Aberg et al., 2009; Department of Health and Human Services, 2011). Timely initiation of HIV care post- diagnosis and sustained attendance in routine HIV care over time (i.e., retention in care), is critical to achieving positive clinical outcomes for persons living with HIV ( PLWH; Aberg et al., 2009; Berg et al., 2005; Giordano et al., 2007; Horstmann, Brown, Islam, Buck, & Agins, 2010; M. J. Mugavero, Lin, Allison et al., 2009; M. J. Mugavero, Lin, Willig et al., 2009; Park et al., 2007). The dramatic association between improved clinical prognosis, and early receipt of HIV care post -diagnosis, has facilitated a number of national efforts in the US to identify and effectively link (cf. Antiretroviral Treatment and Access Study (ARTAS), Gardner et al., 2005; and ARTAS II Studies, Craw et al., 2008) and reengage (cf – SPNS Outreach Initiative; Tobias et al., 2007) PLWH in HIV care (Cheever, 2007). Such efforts are reflective of increased emphasis on test and treat strategies (Mayer, 2011; M. J. Mugavero, Norton, & Saag, 2011).

Nevertheless, the research available to date suggest that once linked to HIV care a substantial portion of PLWH, approximately 30% (M. J. Mugavero, 2008) to 41% (Marks, Gardner, Craw, & Crepaz, 2010), do not adequately attend care services in the recommended intervals (i.e., do not adequately adhere to HIV care). Poor adherence to HIV care has been associated with increased odds of mortality and poorer viral suppression (Berg et al., 2005; Giordano et al., 2007; M. J. Mugavero, Lin, Allison et al., 2009; M. J. Mugavero, Lin, Willig et al., 2009; Park et al., 2007).

Increasingly, poor retention in HIV care is recognized as a substantial threat to individual and public health (Horstmann et al., 2010; Mayer, 2011). The severe negative outcomes associated with poor retention in HIV care for individual health (Berg et al., 2005; Giordano et al., 2007; M. J. Mugavero, Lin, Allison et al., 2009; M. J. Mugavero, Lin, Willig et al., 2009; Park et al., 2007), and its implications for compromising the key component in test-and-treat strategies (Mayer, 2011; M. J. Mugavero et al., 2011), and reducing community level viral burden (Das et al., 2010; Granich, Gilks, Dye, De Cock, & Williams, 2009; Montaner et al., 2010) warrant attention. Gaining an in-depth understanding of the core facilitators and barriers to self-sustained retention in HIV care is desperately needed to inform effective intervention efforts (Cheever, 2007; Horstmann et al., 2010; Mkanta & Uphold, 2006; Uphold & Mkanta, 2005).

Despite the recognized need for targeted interventions to improve retention in care, the literature exploring factors influencing retention in HIV care is largely dominated by the identification of demographic correlates of retention (Horstmann et al., 2010). Such correlates suggest poorer retention is more likely to occur with PLWH who are: younger, female, racial/ethnic minorities, heterosexual, those with a history of substance use or active current use, and those with lower SES (e.g., lower educational attainment, lower income, lack of insurance). Poor retention is also associated with structural factors (e.g., unstable housing, greater distances to quality HIV care; (Horstmann et al., 2010; Moore, 2011; N. L. Sohler et al., 2009). More recent efforts have sought to identify individual-level factors that may be more amenable to behavioral change efforts (e.g., health beliefs, acceptance of HIV status, abilities to overcome practical barriers to care) through the use of qualitative methodology (Beer, Fagan, Valverde, & Bertolli, 2009; Kempf et al., 2010; Mallinson et al., 2005; Mallinson, Rajabiun, & Coleman, 2007; Moneyham et al., 2010; Nunn et al., 2010; Rajabiun et al., 2007). The identification of discrete correlates, particularly those that are in fact malleable, is critical in building behavioral models that more comprehensively attend to the underlying dynamics of sustained retention in

HIV care, which can be understood as a self-directed health promotion behavior (Cheever, 2007; Horstmann et al., 2010; Marks et al., 2010; Rajabiun et al., 2007).

Several comprehensive models of health behavior adoption and maintenance have been applied individually and as a systems-level approach to accessing HIV-care, including: Andersen's Behavioral model of Health Service Utilization (Andersen, 1995; Christopoulos, Das, & Colfax, 2011; Gelberg, Andersen, & Leake, 2000; Mkanta & Uphold, 2006; Moneyham et al., 2010; M. J. Mugavero, 2008; Ulett et al., 2009), the Chronic Care Disease Model (Gifford & Groessl, 2002; Health Resources and Services Administration, 2006; Wagner, 1998), the Health Belief Model (Mkanta & Uphold, 2006; Rosenstock, 1966), and the Socio-ecological Framework (McLeroy, Bibeau, Steckler, & Glanz, 1988; M. J. Mugavero et al., 2011). However, models that provide both a good characterization of underlying determinants of retention in HIV care and lead to actionable intervention approaches are lacking. Partly in response to this gap in the literature, Amico and colleagues (K. R. Amico, Smith, Urso, Odesina, Diaz, Kwon, & Dieckhaus, 2010a; 2011) proposed an application and extension of the Information, Motivation, Behavioral Skills (IMB) model (J. D. Fisher & Fisher, 1992) as an explanatory model of initiation and maintenance in clinical care for chronic medical conditions that has immediate application for retention-related intervention approaches.

This situated Information, Motivation, Behavioral Skills (sIMB) model of Care Initiation and Maintenance for chronic diseases provides a detailed exploration of how an IMB model framework could apply to understanding the behavioral dynamics of self-sustained retention in HIV care. Also identified by the sIMB are specific contextual factors, related to engagement in care for chronic conditions that may shape the information, motivation, and behavioral skills components of the model. These factors reflect the affective (i.e., acceptance of diagnosis or disease stigma) and socio-cultural-environmental contexts (i.e., community or cultural norms about engaging in medical care for non-acute conditions or availability of trusted care providers),

within which the individual experiences living with and obtaining care for their chronic condition condition(s). The current research sought to examine this articulation of an IMB model to retention in HIV care (K. R. Amico, Smith, Urso, Odesina, Diaz, Kwon, & Dieckhaus, 2010a; K. R. Amico, 2011) through a highly nuanced exploration of perceived facilitators and barriers to retention in HIV care, both generally and in relation to the situated IMB model's s hypotheses, through richly detailed key informant interviews. As such, the current research aims to provide the first qualitative evaluation of the sIMB model of retention in HIV care (K. R. Amico, 2011). This evaluation examines experiences of PLWH and their perceptions of engagement and retention in HIV care in terms of (1) the content proposed as critical in each of the core theoretical determinants (i.e., information, motivation, and behavioral skills) of the sIMB model, and (2) the relative fit of the sIMB model of retention in HIV care to participants' self-reflected experiences.

**An IMB-based Model Situated to Retention in HIV Care**

The sIMB model of Care Initiation and Maintenance for chronic medical conditions, as articulated to retention in HIV care (K. R. Amico, 2011) and used in the current study, is a proposed application and extension of the Information- Motivation- Behavioral Skills (IMB) model (Fisher & Fisher, 1992), and more specifically the IMB model of ART adherence (J. D. Fisher, Fisher, Amico, & Harman, 2006). The sIMB model draws support for this new application of the IMB model from the successful application of the IMB model across a host of diverse health behaviors where information, motivation, and behavioral skills are well supported "drivers" of self-directed health promotion behaviors (e.g., J. D. Fisher, Fisher, & Shuper, 2009; J. D. Fisher & Fisher, 1992). Of relevance to the current study is substantial support for the IMB model's clinic-based application with HIV-infected populations such as its use in HIV-prevention with positives (J. D. Fisher et al., 2004; J. D. Fisher et al., 2006; J. D. Fisher & Smith, 2009), and enhancing ART medication adherence (K. R. Amico, Toro-Alfonso, & Fisher, 2005; J. D. Fisher

et al., 2006; J. D. Fisher et al., 2011; Kalichman, Cherry, & Cain, 2005; Parsons, Golub, Rosof, & Holder, 2007). Drawing from literatures across chronic medical conditions and HIV more specifically, Amico (2011) provides support for the role of information, motivation, and behavioral skills in retention in HIV care, as well as critical contextual factors (e.g., the role of affect towards and acceptance of one's diagnosis, one's position on the continuum of care, and other socio-cultural-environmental- contextual factors) proposed to contextualize each of the core IMB determinants in terms of chronic disease self-management.

As a situated application of the IMB model, "situatedness" essentially refers to articulating the core IMB determinants to attend to the critical contextual factors from which patients initiate and continue to negotiate care for chronic conditions over time, that characterize one's inter and intra-personal interactions with care, their condition, and their communities. For example, *affect towards and acceptance of one's chronic condition* can involve one's awareness of an adjustment process post- diagnosis (information), as well as the impact of acceptance/denial of the condition on one's motivation and requisite skills for attending medical appointments. One's *position on the continuum of care* has important implications as to which the types of information, motivation, and behavioral skills may be situationally- relevant to initiation of care, maintaining care over time, or reengaging in care following a prolonged absence. Other *socio-cultural-environmental factors* are also implicated, such as available social support and prevailing cultural beliefs regarding care for highly stigmatized versus moderately stigmatized chronic conditions (e.g., HIV versus diabetes), the availability/arduousness of traveling to a clinical care site, and the types of available systems in place to provide ancillary support for negotiating medical care across various life circumstances and financial constraints. The process of "situating" the information, motivation, and behavioral skills constructs of the IMB model squarely in relation to these factors results in a situated IMB approach to chronic disease care initiation and maintenance that is strongly aligned with the core IMB model tenets and structural hypotheses, as discussed below.

Similarly, the Network-Individual-Resource Model (NIR) (Johnson et al., 2010) has suggested that intervention efforts that attend to such socio-cultural-environmental factors (e.g., types of available ancillary support services) at the intersection of the individual and their important social networks (e.g., community trust in and social norms for accessing services, tangible availability of and structural barriers to such services) may enhance the sustainability of the health behavior (e.g., accessing care) over time.

Consistent with IMB models across diverse health behaviors (J. D. Fisher et al., 2009; W. A. Fisher, Fisher, & Harman, 2003) retention-relevant information, motivation and behavioral skills are assumed to be the fundamental behavioral determinants of adherence to HIV-care attendance, with specific areas within each of these core determinants further specified (see Figure 1). The IMB model of health behavior predicts that well-informed, highly-motivated individuals who possess adequate skills for enacting complex patterns of the health behavior in question (in this case, retention-related behavior) will engage in the behavior optimally over time with feedback from execution of the behavior further influencing each of the core determinants. Individuals who are less, poorly, or inaccurately informed, less motivated or insufficiently skilled will exhibit inadequate levels of the health behavior in question. Articulated to retention in HIV-care, the situated approach suggested by Amico (K. R. Amico, Smith, Urso, Odesina, Diaz, Kwon, & Dieckhaus, 2010a; K. R. Amico, 2011) depicts this feedback process with the ellipse encircling the core determinants of the IMB model.

The hypotheses of the IMB model (W. A. Fisher et al., 2003; J. D. Fisher & Fisher, 1992) have received considerable support. As noted above, it has been found that relevant Information, Motivation, and Behavioral Skills have critical impact on the performance of a broad array of health behaviors (J. D. Fisher et al., 2009). Moreover, as predicted by the IMB model, for complex health behaviors, the effects of information and motivation on behavior generally “work through,” and are limited by an individual’s level of behavioral skills (J. D. Fisher et al., 2009).

Thus, if the health behavior in question were difficult and/or complex, even well informed and highly motivated individuals would still require sufficient behavioral skills to actually implement the behavior. Applied to retention in HIV-care, it is expected that sustained, regular attendance is influenced by information and motivation through their effects on behavioral skills. However, when the behavior at focus is easy to perform, which is typically not the case for initiation and maintenance in care, the IMB model proposes that there may be direct effects from Information or Motivation to behavior.

In addition to identifying the critical role of information, motivation and behavioral skills in health behavior and health behavior change, and specifying their structural interrelations, Fisher and Fisher (1992) provided a clear process for developing interventions to change unhealthy behaviors. First, it is critical to elicit the particular information, motivation and behavioral skills dynamics that drive the unhealthy behavior at focus, and which must be addressed to modify it. Careful elicitation work will provide critical insights into the nuanced and contextualized manner in which a target group experiences retention in HIV-care. Based on the elicitation research, one then designs an intervention to increase critical information, motivation and behavioral skills elements, and in so doing, change unhealthy behavior. Finally, it is critical to evaluate the intervention, using randomized, controlled designs whenever possible, to ascertain if it has been effective.

In applying the sIMB model to retention in HIV-care, IMB model based hypotheses regarding the core determinants of health behavior and health behavior change, the structural relations among these constructs and retention in HIV-care behavior, and the recommended process of developing targeted interventions, are all leveraged without modification. Where the proposed situated approach diverges from previous applications of the IMB model is in the hypotheses regarding moderation. Whereas a situated approach to applying an IMB model to retention in HIV care suggests that factors such as acute depression, homelessness, drug use, and

other such factors contextualize the core constructs, other applications of the IMB model have suggested that these factors are likely to moderate the relations among determinants. While the relations between IMB model constructs and behavior have been shown to be robust for populations with high levels of depression, homelessness, drug use, etc., at extreme levels of these variables, unless directly addressed through intervention (e.g., for drug use, through drug treatment, or harm reduction), these conditions may potentially affect the impact of IMB-model based interventions. It is important to note that in the applications of an IMB model, e.g., to adherence, Fisher et al.(2006) suggest that such moderating factors can operate *through* the core IMB model constructs (e.g., the intervention would address information regarding the interaction of ARVs and hazardous drinking, and motivational barriers and behavioral skills specific to adherence in this context). The situated application of the IMB model to retention in HIV-care adopts this conceptualization specifically (K. R. Amico, Smith, Urso, Odesina, Diaz, Kwon, & Dieckhaus, 2010a; K. R. Amico, 2011) and uses the term "situated" to qualify the application of the IMB model to retention in HIV-care to reflect this, as well as to call increased attention to the need to account for how the affective, social, and cultural contexts surrounding the negotiation of HIV-care must be included in defining relevant information, motivation, and skills (see K. R. Amico, 2011).

The situated IMB model offers a particular manner of applying the IMB model to a behavior that is self-directed but largely influenced by the multiple systems contextualizing one's negotiation of care for chronic conditions. To date, only one small sample study has used this sIMB approach (K. R. Amico, Smith, Urso, Odesina, Diaz, Kwon, & Dieckhaus, 2010b) to characterizing self-reported retention in HIV care quantitatively. This study demonstrated support for the roles of motivation and behavioral skills with behavioral skills significantly mediating the relation between motivation and retention in HIV care, but did not find support for information as it was measured by the brief survey used. As such, it is important to consider the evidence drawn

from the available literature on retention in HIV care (provided below in the discussion of each of the core IMB constructs), as well as support of the role of affective adjustment processes within each core construct. The aim of the current research is to provide the first detailed exploration and qualitative test of this situated IMB approach through in-depth key informant interviews. Analysis of patient discourse will characterize patient's experiences with retention in HIV care, in terms of perceived facilitators and barriers to retention in HIV care, and results will offer theory-based insights into the types of information, motivation, and behavioral skills important for targeting in future intervention development and implementation efforts.

## Information, Motivation, Behavioral Skills of Retention in HIV Care

**Information.** The first determinant of an IMB model, information, reflects objective information (and misinformation) held by an individual regarding the specific health behavior in question. The information construct also contains cognitive heuristics (e.g., implicit theories) held by an individual about the health behavior that are used as simple decision rules permitting the individual to make decisions (often incorrect ones) about engaging or not engaging in the specific health behavior that are relatively automatic and which require limited cognitive effort. The use of inaccurate heuristics typically occurs without recognition of the cognitive process associated with the behavioral decision in question (J. D. Fisher et al., 2004; J. D. Fisher & Fisher, 1992). The specific kinds of information identified in the situated application of the IMB model in the context of retention in HIV care (K. R. Amico, 2011) include: information about available treatment(s), their purpose and typical procedures; information on the disease itself (HIV), including the process of adjusting life with HIV and changes in the disease course; and information about the available system(s) of care, including interrelated ancillary services and patients' rights). Misinformation or inaccurate heuristics may reflect perceived ineffectiveness of HIV treatments or non-medically based rationale for when treatment is needed/not needed. Several correlates reflecting retention-relevant information and heuristics identified across

previous quantitative and qualitative work are anticipated to be present in patients' experiences of retention in care in the current study. These include: general knowledge of HIV disease and treatment (Brewer et al., 2007; Marx, Hirozawa, Soskolne, Liu, & Katz, 2001; Rajabiun et al., 2007), information on the benefits of treatment (Burns et al., 2008), awareness of ancillary services available to facilitate access to and use of HIV treatments (e.g., case management, AIDS drug assistance programs; Nunn et al., 2010; Whetten et al., 2004), as well as health beliefs specific to HIV that are often used as heuristics to guide health behaviors (e.g., absence of HIV symptoms means one does not need medical care; Beer et al., 2009; Rajabuin et al., 2008; Rumptz et al., 2007; Tobias et al., 2007).

**Motivation.** Motivation to engage in the health behavior is the second element in the IMB model, impacting an individuals' inclination to act on what they know about the behavior. Motivation is comprised of an individual's personal motivation (i.e., attitudes and beliefs about engaging or not engaging in the behavior), as well as his or her social motivation (i.e., perceptions of social norms regarding the appropriateness of the behavior and of the social support or social consequences for engaging in the behavior; Fisher & Fisher, 1992; Fisher et al., 2004). The specific kinds of personal motivation identified in the situated application of the IMB model as critical to retention in HIV care (K. R. Amico, 2011) include the attitudes and beliefs about the positive and negative consequences of attending HIV care in terms of (1) prioritizing self-care in the face of competing priorities, (2) obtaining results of viral load, CD4 monitoring and disease progression, (3) managing affect related to living with HIV such as HIV stigma, acceptance of diagnosis or the long term effects of HIV, and HIV treatment). Social norms and degree of support for navigating care are reflected in social motivation in terms of (1) degree of perceived social support for attending care from important others (including navigating HIV stigma or cultural beliefs about the relevance of routine medical care); (2) perceptions of patient-provider interactions including anticipated consequences of disclosing substance use or non-adherence to

medications or other proscribed treatments; (3) social pressures and norms to prioritize/not prioritize care appointments).

Motivation-related correlates identified in the extant literature and anticipated to be of relevance to patients' experiences of retention in care in the current study reflect: personal attitudes and beliefs regarding HIV and HIV-care (Beer et al., 2009; Brewer et al., 2007), perceived vulnerability (including subjective health status) to the positive consequences of attending care or negative consequences of non-attendance (Anthony et al., 2007; Bakken & Holzemer, 2000; Burns et al., 2008; Catz, McClure, Jones, & Brantley, 1999; Gordon et al., 2006; Lo, MacGovern, & Bradford, 2002; Marx et al., 2001), trust in one's provider and the healthcare system (Beer et al., 2009; Bodenlos et al., 2007; C. O. Cunningham, Sohler, Korin, Gao, & Anastos, 2007; N. L. Sohler, Li, & Cunningham, 2009; Whetten, Reif, Lowe, & Eldred, 2004), and attitudes towards living with HIV (e.g., HIV-stigma and acceptance of diagnosis; Bakken et al., 2000; Beer et al., 2009; Kempf et al., 2010; Mallison et al., 2005; Moneyham et al., 2010; Rajabuin et al., 2007, 2008). In addition to personal motivation, social motivation factors such as perceived social norms and social support surrounding HIV and healthcare-related cultural beliefs (Coleman et al., 2007; Kempf et al., 2010; Moneyham et al., 2010), perceived engagement of one's provider in patient-provider interactions (Bakken & Holzemer, 2000; C. Cunningham et al., 2007; Kempf et al., 2010; Mallinson et al., 2007; Rajabiun et al., 2007), and the presence of personal external support systems (e.g., family, friends, mental health treatment, transportation and other support services; Bodenlos et al., 2007; Burgoyne & Saunders, 2000; Catz et al., 1999; C. Cunningham et al., 2007; Kempf et al., 2010; Rajabiun et al., 2007) for obtaining care over time may be important to consider.

**Behavioral skills.** Behavioral skills for engaging in the health behavior is the third critical behavioral determinant of the IMB model, and comprises an individual's objective abilities and perceived self-efficacy to enact a series of coordinated behaviors involved in the execution of the

health behavior, *per se* (J. D. Fisher et al., 2004; J. D. Fisher & Fisher, 1992). The specific kinds of behavioral skills identified in the situated application of the IMB model as critical to retention in HIV care (K. R. Amico, 2011) include objective skills and perceived self-efficacy across three distinct skill sets for systems navigation, overcoming practical barriers to care, and enhancing sustained care attendance over time. *Systems navigation skills* reflect perceived and actual abilities to access available HIV care and arrange resources for attending care (including navigation of ancillary care services to aid in care attendance). *Functional Skills* (organizing/planning), are used to overcome practical barriers to care attendance, such as skills to integrate appointments into one's schedule (including execution of reminder strategies) and arranging to attend care visits (including transportation) in the context of competing demands from daily hassles, such as employment and child care, to more pressing comorbidities, such as active substance use or depression. *Activation Skills* are intend to minimize perceived negative consequences of care attendance and maximize perceived positive consequences of care attendance important to sustaining care over time (i.e., skills to increase/maintain HIV health literacy, invest in affective adjustment to HIV diagnosis and long term outcomes, garner instrumental and emotional social support for attending care appointments regularly, and sustain prioritization of self-care in the face of competing demands and barriers such as mental health issues, substance use, and housing instability).

Correlates reflecting such behavioral skills noted in previous work and anticipated to be present across patients' experiences of retention in care in the current study include: perceived and objective ability to overcome practical barriers to care (e.g., transportation, competing priorities; Kempf et al., 2010; Moneyham et al., 2010; Rajabuin et al., 2007), ability to access ancillary and support services (e.g., case management, mental health treatment; C. Cunningham et al., 2007; Lo et al., 2002; Rumptz et al., 2007; C. Tobias et al., 2007), as well as the ability to negotiate care in the context of living with HIV (e.g., coping with diagnosis, maintaining a sense

of ‘normalcy’, HIV stigma; Kempf et al., 2010; Moneyham et al., 2010; Mallison et al., 2005; Rajabuin et al., 2007) and other comorbidities (e.g., substance use, depression; Rajabuin et al., 2007).

Though the known correlates of retention in HIV care can be aptly characterized by the sIMB model (K. R. Amico, Smith, Urso, Odesina, Diaz, Kwon, & Dieckhaus, 2010b; K. R. Amico, 2011), the utility of behavioral models in informing intervention development are greatly enhanced by evaluating the model’s specific content through in-depth elicitation work, involving, questionnaires, focus groups, and key informant interviews (J. D. Fisher & Fisher, 1992). Such efforts additionally allow the proposed model to be evaluated in terms of the degree to which individual’s experiences with the health behavior at focus (i.e., retention in HIV care) overlap or extend beyond the existing model concepts (Ware, Wyatt, & Bangsberg, 2006). In providing the first qualitative evaluation of the sIMB model to retention in HIV care in the current study, we utilize data garnered from the patient’s perspective to assess the degree to which the sIMB model’s core theoretical determinants are represented in participant’s discourse, and identify any potential important content not well accounted for by the model. In doing so, the current study aims to evaluate the utility and validity of applying the sIMB model to a new behavioral and sociocultural setting (i.e., retention in HIV care among marginalized inner-city PLWH); identifying the types of theoretical content (i.e., types of information, motivation, behavioral skills, and other important affective/socio-cultural-environmental contextual factors) underlying retention in HIV care to address in future intervention development for this target population.

## Method

### Participants and Study Design

Between February and May 2009, twenty HIV-infected men ($n$ = 12) and women ($n$ = 8) residing in the Bronx, NY, and accessing either traditional HIV-primary care services at a

community clinic or non-traditional services through providers and staff comprising a mobile medical outreach team (see C. O. Cunningham, Sanchez, Heller, & Sohler, 2007; C. Cunningham et al., 2005 for more information on the medical outreach team) were recruited to participate in an in-depth semi-structured interview about their HIV-care experiences since being diagnosed with HIV. Participants were recruited at point of contact with their HIV-care services. Eligibility criteria included being diagnosed HIV-positive, linked to one of the care services noted above, English speaking and first initiating HIV-care a minimum of 24 months prior to recruitment. To ensure that a range of HIV-care experiences were represented, sampling was stratified between the community clinic ($n$ = 10) and medical outreach venues ($n$ = 10). Where participants recruited from the community clinic may more likely have intermittent lapses in care followed by reengagement in care, the non-traditional medical outreach service was developed specifically to address the medical care needs of patients who are at higher risk for loss to follow up or have had a history of poor engagement and retention in care. Both the community clinic (Comprehensive Community Health Center) and the medical outreach team are affiliated with Montefiore Medical Center. The study protocol and procedures were approved by University of Connecticut and Montefiore Medical Center's institutional review boards.

The community clinic provides adult primary care, and integrated HIV- and specialty- care services, to a predominantly low-income ethnic minority population. Participants recruited from the community clinic were interviewed the same day in a private or semi-private area at the clinic either just prior to or immediately following a visit with their primary care provider. Note that the medical outreach team serves the same local area as the community clinic, providing mobile HIV-care primary care services to HIV-infected clients residing in single room occupancy (SRO) hotels which provide temporary housing to persons living with HIV/AIDS located throughout the Bronx, New York. As a non-traditional service, medical outreach provides mobile HIV primary care services delivered by a team of providers and staff affiliated with the community clinic and a

local harm reduction agency to a predominantly minority, low-income, unstably housed clients with past or current histories of substance use (C. O. Cunningham et al., 2007; C. Cunningham et al., 2005). Participants recruited through the medical outreach team were interviewed 2-3 days post recruitment at semi-private public venues (i.e., a local park, or the lobby of a nearby hospital not affiliated with the community clinic). All participants consented to their interview being audio taped, however, due to an equipment failure, only 18 of the 20 interviews were successfully recorded for further transcription and analysis. Recorded interviews averaged 27 minutes in length and all participants were compensated $15 cash for their participation in the study.

## Measures

**Socio-demographic and HIV-treatment variables.** Prior to the interview questions, participants were asked a series of structured questions with closed-ended response options (Appendix C). Included in these items were socio-demographic questions (i.e., age, gender, race/ethnicity, sexual orientation, income, housing status); self-reported histories related to their HIV diagnosis and receipt of HIV care (i.e., route of HIV transmission, year of initial HIV diagnosis, year HIV care was first initiated, year ART was first initiated (if ever); as well as items regarding general frequency of attending HIV clinical care [Less than once every 6 months to At least once a month with never coming into care also an option] and the last time, if ever, the participant was absent from care for 6 months or more [Within the past year to More than 5 years ago, with the option of never]. Finally, items concerning past or current histories with known correlates of poor retention in care included stability of housing [Living in a house, apartment or room you rent or own, with a friend/family member, in a residential program, or residing in a shelter, abandon building or on the street] most recent incarceration [Within the past year to More than 5 years ago, with the option of never], mental health diagnosis or treatment [Within the past year to More than 5 years ago, with the option of never], injection and non-injection drug use [Within the past year to More than 5 years ago, with the option of never]. See Appendix B

(eligibility screener) and Appendix C (socio-demographic and HIV-treatment histories measure) for these quantitative items and response options. Perceived difficulties overcoming access-related barriers to HIV-care (i.e., lack of availability of convenient appointments, lack of ability to arrange adult and/or child care if needed, costs associated with travel and clinic appointments) were assessed by the interviewer utilizing a 7-point Likert- type scale [0 = not at all difficult, 6 = very difficult]. Participants' travel time to clinic, in terms of minutes, was assessed by the interviewer via open-ended response. The quantitative items and response options were read aloud to the participant and participant responses were recorded by the interviewer. All items were created for the current study, and used to characterize individuals in the participant sample.

**Interview guide.** The qualitative interview guide was designed to elicit participants' experiences with HIV-care utilization, since diagnosis, with an emphasis on experiences related to participant retention in care (see Appendix D for the semi-structured patient interview guide). The interview guide was created specifically for the current research using queries into one's general experiences with care as well as queries that were theory- based. The general HIV care queries used a series of open-ended questions to elicit spontaneous responses (Bernard, 2006) about experiences *initiating* HIV care post- diagnosis and *maintaining* themselves in HIV care over time (i.e. *retention*) (e.g., "*What types of situations can make it really hard to get in to see your HIV doctor?*"). These queries also elicited factors related to prolonged absences from HIV-clinical care of 6-months or more or reengaging in care following such a prolonged absence (e.g., "*What was it that got you back into regular care for your HIV"*, or *"What do you think would need to happen for you to begin coming to care regularly*?").

The second series of questions were theoretically guided by the sIMB model as a general framework and asked specifically about retention-relevant HIV treatment information, personal and social motivation for engaging/not engaging in HIV medical care, and behavioral skills used to negotiate attendance at HIV care medical appointments. For example, <u>information</u> prompts

were aimed to elicit participant's personal knowledge of HIV treatment and care procedures (i.e., their "freely disclosed" level of accurate/inaccurate information). An example of these items is, "*What would be really important for people to know about HIV or their HIV care that would help them to come in to care regularly*?" Motivation-based prompts sought to elicit factors that influence how important regular HIV-care is to them and similar others (i.e., personal and social motivation). An example of such an item is "*What kinds of beliefs or feelings do you have about what it means to receive HIV medical care on an ongoing basis*?"; *"In what ways are other people who are important to you supportive of your HIV care?*" Prompts to elicit behavioral skills used to access and engage in care over time inquired about strategies or skills participants may use, or believe to be helpful, in attending care appointments. An example is, "*Are there certain skills or strategies you've developed that help you to make it to your care visits*?"

**Data Analysis**

Data collected during the interviews on the quantitative demographic and recent use of HIV-care items were entered in SPSS version 17.0 (SPSS Inc., 2008) and summarized for the purposes of characterizing the study sample. Audio recorded interviews were transcribed verbatim, independently reviewed for transcription accuracy, and then uploaded into qualitative analysis software, *Atlas*.ti (Muhr & Friese, 2004), for analysis. Once uploaded, transcripts were reviewed and segmented for coding (Bernard, 2006). Through a thorough review of the transcripts by two reviewers (LS and KRA), it was mutually agreed to define a "segment" of text as any participant discourse that contained a single train of thought. Once utterances moved to a new train of thought, a new independent text segment was marked. A total of 665 segments of text was identified and coded across the 18 interviews, and individual interviews contained an average of 37.5 segments per interview (range 26-45 segments). There was no significant difference between number of segments per interview and participant recruitment venue (i.e., community clinic or medical outreach team).

All transcripts were iteratively coded by trained coders in *Atlas.ti* (Muhr & Friese, 2004), for analysis using established coding protocols (Bernard, 2006). First, *each* text segment was coded for mutually exclusive factors identifying the *type of HIV-care experience* discussed in the segment (i.e., initiation or retention in care), and if the segment discussed *factors facilitating or impeding the specific HIV-care experience* (i.e., barrier or facilitator to retention in care). Next, a series of non-mutually exclusive codes, derived from the previously discussed sIMB-model and related correlates of retention in care, anticipated to be of relevance to patients' experiences in the current study, were applied. Specifically, the type of *information*, *motivation*, and/or *behavioral skills* content present in each text segment was coded, as was the presence of and type of any sIMB theoretically-anticipated contextual factor (i.e., affect towards or acceptance of one's HIV diagnosis or experiences with depression, substance use, or housing instability in the context of HIV care). Segments that did not contain sIMB-based content were also identified to capture content that was relevant to participants in terms of facilitating or challenging their retention in care but were not included in the sIMB constructs (K. R. Amico, 2011). Inter-rater reliability was obtained by double coding ten percent of text segments per interview for the type of HIV-care discussed (e.g., reengaging or retention in care), presence or absence of facilitators/barriers, and the presence or absence of sIMB model content (e.g., information, no information) including contextual factors (e.g., substance use). Text segments were sequentially numbered from the start to the end of an interview, and were identified for double coding using a random numbers generator to obtain the segment's identification number for each interview. Based on accepted conventions for utilizing Kappa to evaluate inter-rater reliability (Fleiss, 1981; Landis & Koch, 1977), an overall Kappa of 0.81 was achieved, indicating good reliability between coders (Type of HIV care, $k = 0.93$; HIV-care Facilitators/Barriers, $k = 0.72$; sIMB content, $k = 0.78$).

To elicit and identify the types of sIMB theoretical content (i.e., information, motivation, behavioral skills, and specific IMB-relevant contextual factors) important to retention in care in

the target population, our analysis of participant discourse utilized both deductive and inductive content analysis (Bernard, 2006). Specifically, the deductive approach used content coding to characterize facilitators and barriers to retention assessing the degree to which the sIMB theoretical determinants existed within participants' discourse related to retention in HIV care. The inductive approach used emergent theme identification to obtain important facilitators and barriers of retention in care and future intervention development efforts in the target population that may not be currently well accounted for in the sIMB model, or which extend beyond the model's concepts. The combined results from these two approaches are presented in the results section to articulate the key sIMB theoretical content identified in the current study important for refining the model, future quantitative evaluation of the model, and intervention development within this clinic population.

**Content coding.** The primary purpose of the deductive approach was to (a) identify how well participants' experiences of retention in care map onto the sIMB theoretical constructs (i.e., information, motivation, behavioral skills), and contextual factors, and (b) to identify what *types* of information, motivation, and skills facilitated and hindered retention in HIV-care, as reported by the participants. This was achieved by using the qualitative analysis functions of *Atlas.ti* (Muhr & Friese, 2004) to select all text segments identified as a facilitator (165 segments) or barrier (77 segments) to retention in care. From these segments, specific information, motivation, or behavioral skills sub-codes that frequently occurred within their respective sIMB construct were identified to characterize the *types* of facilitators and barriers participants reported experiencing (e.g., perceived efficacy in employing personal reminder strategies). A specific type of information- motivation- or behavioral skills-related sub-code was defined as 'frequently occurring' if it represented ≥ 12.5% of all 165 facilitator segments, or ≥ 12.5% of all 77 barrier segments. The cutoff was set at 12.5% to ensure a reasonable number of text segments per sub-code were available to allow for a qualitative synthesis/interpretation of the data; in looking at the

distribution of segments per sub-code, a frequency below 12.5% did not yield enough text segments for such synthesis to reliably occur.

**Emergent theme identification.** The primary purpose of the inductive approach was to identify the major themes across facilitators and barriers to retention in care that emerged from participant discourse irrespective of whether or not these "fit" in the a priori sIMB-model-based theoretical determinants and contextual factors (K. R. Amico, 2011). These themes were elicited from all text segments identified as a facilitator, barrier or both across participants' discourse of HIV-care experiences ($k$ = 310). All segments were independently reviewed by two raters (LS and KRA) for themes and patterns important to retention in HIV-care, and then sorted into thematically- related groups of facilitators and barriers. The two raters then jointly discussed the identified themes, merging common themes and culling the piles into broad overarching emergent themes. This process yielded a total of eight distinct themes within facilitators and seven distinct themes within barriers to retention in HIV-care. These themes were then compared to the content of the sIMB model to identify themes that were not well represented by the *a priori* model and to allow for a qualitative exploration of the model's fit with participants' experiences with retention in HIV care.

## Results

### Sample Characteristics

Participant characteristics (see Table 1) were representative of the patient population seen by the community clinic and outreach providers. Average age at time of study participation was 49.15 ($SD$ = 6.4) years, participants were predominantly male (60%), heterosexual (80%), identified as either Latino (65%) or African-American/Black (35%), and reported acquiring HIV via consensual heterosexual intercourse (45%). Annual family income was typically between $5,000-$10,000 per year (40%) or less (40%), with 80% of participants reporting currently being

on disability or sick leave. Most participants reported a history of life experiences with some known correlates of poor retention in care (e.g., unstable housing) since diagnosis and within the past two years. Specifically, within the last two years, a number of participants reported experiencing diagnosed mental health conditions (60%), substance use (35% non-IDU, 15% IDU), incarceration (25%) or unstable housing (20%).

The sample was relatively experienced in terms of HIV care; with 75% reporting living with HIV for ten or more years (*M* = 14.3, *SD* = 5.74), most (85%) reporting they had initiated care within the first year following diagnosis (*M* = 20 months, SD = 52.96) and initiating an antiretroviral regiment an average of 2.55 (*SD* = 5.14) years after first beginning HIV care. At time of interview, most (80%) participants reported they were currently attending HIV primary care within the recommended intervals for these clinical care sites (i.e., attending care ≥ once every 2-3 months). However, in terms of stable retention in care, 30% of the sample reported experiencing a significant gap in care of 6 months or more in the past two years, with 25% reporting such a gap within the past year, demonstrating a recent experience of non-adherence to care recommendations.

Participants reported spending an average of 43 minutes traveling to clinic appointments (*SD* = 27, Range = 5-120 minutes). Various tasks implicated in accessing care were measured on a 7-point scale (0 = not at all difficult, 6 = very difficult). Participants' perceived difficulties with these tasks averaged at the lower end of the scale in terms of difficulty in traveling to clinic (*M* = 1.95, SD =1.96), paying to travel to clinic (*M* = 2.45, *SD* = 2.16), paying for care appointments (*M* = 1.1, *SD* = 2.16), or obtaining an appointment that fit their schedule (*M* = 1.05, *SD* = 2.02). Note actual cost of co-pays or payment to see a clinic provider was not assessed in the current study; however based on the clinic's insurance profile, most participants likely qualified for free or assisted health care programs such as Medicaid. No participants in the current sample reported needing to arrange for child or adult care to attend clinic appointments.

**Content Coding: sIMB Model Behavioral Determinants of Retention in HIV-care**

Across participants' discourse related to facilitators or barriers to retention in HIV care (239 text segments), sIMB-model based codes characterized all but seventeen text segments discussing facilitators and barriers to retention in HIV care (see Table 2); with information, motivation, behavioral skills content and contextual factors represented in 18.4%, 92.5%, 53.0%, and 35% of the text segments, respectively. These results suggest participants' experiences map well onto the sIMB theoretical constructs. More explicitly, the types of information, motivation, behavioral skills, and contextual factors most relevant to retention in HIV care in this sample are discussed below. *Information*-based codes were represented in 21% of the text segments on facilitators of retention in care and 13% of text segments on barriers to retention. The types of information primarily associated with facilitating retention were participants' use of accurate information or cognitive heuristics (i.e., regular monitoring is important because one's viral load or CD4 count can "*change quickly*") to guide care utilization decisions. *Motivation*-based codes were identified across most of the participants' discourse, including 97% of retention facilitator text segments and 83% of retention barrier text segments. Discourse associated with facilitating retention in care reflected personal attitudes/beliefs about the positive and negative consequences of HIV care, perceived vulnerability to the consequences of HIV disease and benefits of accessing care for disease monitoring and/or treatment and positively framed patient-provider relationships, as well as social norms and support for maintaining care over time. Conversely, discourse reflecting care in the context of competing priorities such as daily hassles or other comorbidities (e.g., depression, substance use), negatively framed patient-provider relationships, and less supportive social norms or tangible support systems were associated with impeding retention in care. *Behavioral Skills*-based codes were observed in 59% of text segments on facilitators of retention and 42% of text segments on barriers to retention. Behavioral skills for accessing ancillary services to address unmet needs, addressing practical barriers to care such as transportation,

employing personal planning/reminder strategies to remember to attend appointments, and obtaining emotional or instrumental social support for clinic visits were strongly related to facilitating retention in care. Barriers to retention in care were mostly associated with deficits in behavioral skills to address care in the context of daily hassles or comorbidities, and ineffective execution of reminder or planning strategies. Codes reflecting *Contextual factors* were observed in 27% and 52% of text segments on facilitators and barriers of retention respectively. Facilitative affective factors reflected positive emotions regarding HIV diagnosis and positive affective states related to coping with one's HIV status (e.g., acceptance, positive reframing). However, ambivalent and negative emotions regarding HIV diagnosis and negative affective states towards coping with one's HIV status (e.g., denial, avoidance) were observed as impeding engagement and retention in cares. Other contextual factors (e.g., depression, substance use) not discussed as in terms of a daily hassles/competing priorities occurred less frequently.

**Inductive Coding: Emergent Theme Identification**

An iterative review of *all* participant discourse on facilitators or barriers to HIV care utilization, *irrespective of whether or not these segments were related to sIMB content codes* identified emerging themes for facilitators and for barriers to retention in HIV care (310 text segments). This inductive emergent theme identification yielded 8 emerging themes for factors important to facilitating retention in care and 7 themes reflecting barriers to retention (see Table 3). Emergent themes identified as facilitating care reflected (a) positive adjustment and coping to living with HIV, (b) developing positive cognitive constructions of what self-directed HIV care means to the individual, (c) identifying personal reasons or benefits to monitor one's health, (d) perceived positive social interactions at care visits, (e) self-directed strategies to facilitate care attendance (i.e., scheduling or reminder strategies), (f) social-directed strategies to facilitate care such as utilizing case managers or family support, (g) clinic-based strategies (e.g., reminder calls, centralized care for comorbid medical conditions, same-day appointments), and (h) personal

desire/investment in longevity, (e.g., desire to sustain connection to important others, awareness of the toll HIV has had on the lives other PLWH).

Emergent themes identified as barriers to retention in HIV care reflected (1) poor adjustment to living with HIV or poor coping skills such as behavioral/mental disengagement in response to one's condition, (2) narrow/inflexible cognitive constructions of self-directed HIV care that enabled a rapid abandonment of all self-care behaviors if there was a lapse in any one aspect of self-care, (3) low perceived benefits of regular care attendance particularly when one is not on medications, asymptomatic, or engaging in active drug use, (4) perceived negative consequences of care attendance such as long wait times, negative interactions with providers or clinic staff, (5) prioritization or choice of other tasks over care attendance typically reflecting tasks that are more personally desirable, or competing demands such as family duties or having multiple appointments, (6) managing difficulties with remembering appointments or other effects of living with HIV such as HIV-related cognitive or physical impairments/'symptoms of HIV', (7) issues related to substance use such as internalized stigma or associated consequences of active use (i.e., without stable resources such as housing or 'hustling' to sell and/or score illicit substances).

Each emergent theme was then evaluated by two raters (LS and KRA) for fit with the sIMB model of retention in care defined core constructs (see right most column of Table 3). Overall, there was considerable convergence between the emergent themes inductively identified and the a-priori assumptions of the model. Table 3 further indicates (via the appearance of double asterisks i.e., **) elements of these themes making *unique contributions* to the types of information, motivation, or behavioral skills content relevant to retention in care (i.e., specific content within each core construct that were *not* previously well captured in the proposed sIMB model or content coding process). Very few elements identified as important to retention in care operated external to the proposed sIMB model. These external elements reflected both structural barriers (i.e., clinic wait times, transportation) and clinic-based services employed to reduce

system-level structural barriers to care. However, as noted in the sIMB model of retention in care (see Figure 1), requisite motivation and behavioral skills to attend care in the context of such structural barriers are identified by the model as relevant to facilitating retention in HIV care. Thus, the emergent themes identified in this process, as important to retention in care, generally supported the sIMB model, in addition to uncovering unique sIMB-based content relevant to the current population.

**Identifying Key Retention-Relevant sIMB content: Combined Deductive and Inductive Results**

The results identified in the current study, presented below, provide a concise overview of retention-relevant content falling within information, motivation, and behavior skills sIMB constructs across the deductive and inductive analytic approaches. The experiences of a marginalized HIV-positive inner-city sample strongly aligned with sIMB model of retention in care constructs and contextual content (i.e., affect towards and acceptance of HIV status, socio-cultural-environmental factors) proposed by Amico(2011) to be a critical part of this situated application of the IMB-model.

**Types of retention in care information.** Retention-relevant accurate/inaccurate information reflected knowledge of HIV disease as it impacts on physical and emotional health outcomes, as well as the process, benefits and costs associated with HIV treatments. An example quote is "*If I'm not feeling well, then I would come faster to see the doctor 'cause… we're open to any disease at this point.*" Building upon these concepts was participants' understanding the role of regular HIV care in relation to accessing/changing antiretroviral medications, such as the quote, "*some medications don't work for you… that's why you got to tell* [the doctor] *what's going on with your medication… that's why you have to keep seeing the doctor*." HIV care utilization was also facilitated by knowledge of the relationship between HIV and other diagnosed health

conditions, e.g., "*I see my HIV doctor every month, because I got diabetes that's not well controlled, and with the virus together, it's not real good.*" Contextual knowledge of ways active substance use can "*cause the virus to come out more*" or "*mask symptoms*" of HIV in need of medical attention also emerged as important to retention in this population and was also seen as facilitating care utilization.

Despite objective knowledge of existing ancillary services as well as actual use of these services (which reflects retention-relevant behavioral skills), participant discourse rarely involved statements where participants explicitly expressed that knowledge of such available services facilitated access to or utilization of HIV care for themselves or other PLWH. One of the few instances such knowledge was explicitly identified was by a female participant with self-disclosed HIV-related cognitive impairments, who stated:

> "*Because I be forgetting a lot of things… I got outside help. I joined a program for people that have HIV with other problems. The counselors there, I go see them, or them come see me and they remind me of my appointments and things that I have to do… that's what helps me get in here*."

However, it was more typical that participants would say they do not use any services to help them attend their HIV care appointments; e.g., "*No no, it's just me, if I can't do it for me, I'm not going to tell someone to help me do what I gotta do for me*".

<u>Cognitive heuristics</u> guiding HIV-care decisions reflected health beliefs specific to HIV, such as regular monitoring is important because one's viral load or CD4 count can "*change quickly*". Participants' further identified the need to relearn certain health beliefs as a person *now* living with HIV, e.g., learning that one is no longer a good 'barometer' of one's internal health. However, most, heuristics used to indicate need for medical monitoring integrated broader health beliefs reflecting general indicators of subjective health, such as presence or absence of acute physical symptoms, weight loss/gain, and quality of nutrition. One such heuristic was described as, "*I base my whole treatment on if I feel like there's something* [physically] *wrong with me… if*

*I'm not feeling nothing I'm not gonna go see the doctor, but if something's wrong, like recently with my joints… I'm gonna go*."

**Types of retention in care personal motivation.** Personal attitudes and beliefs regarding being HIV-positive vs. care in relation to living with HIV emerged as distinct factors important to retention in care. Attitudes related to living with HIV reflected positive and negative affect towards being HIV-positive as reasons for attending or not attending care. For example, "*I want to live today, so that's … the best incentive*" or "*Nobody likes going to the doctors, but on top of that I have to go because* [I'm positive]*… I guess that's where the depression kicks in."* Such attitudes were reflective of an adjustment and coping process related to acceptance of one's HIV-diagnosis, and HIV-related stigma concerns. Care in the context of living with HIV reflected motivational concerns related to experiences of HIV-related cognitive/memory and physical impairments. One participant stated going to the doctor even if she '*looked fine*' was important because "*Your body feels fine, 100%, now…but tomorrow you feel like crap…emotionally or mentally… You know, like tired, aches and pains here and there, and it varies every day*."

Themes surrounding perceived vulnerability to HIV disease and potential for personal benefits from accessing HIV care reflected both a reactive and proactive function. For example, coming to care out of fear something bad is happening to one's health, such as, "*If I see myself getting a little skinny or losing some weight, I'm flying to the doctor, to find out if I'm losing weight because of the HIV!*", as opposed to regularly attending care to ensure one achieves the desired health outcomes. Others found value in getting feedback from attending HIV care, such as:

> *I always get a good report when I come in… even when I get a bad report, I'll come back again, 'No you have to give me a good report Mamí* [referring to the doctor], w*hat's going on here?' Just knowing…* [helps me] *do what I'm supposed to.*

Attitudes and beliefs about accessing HIV-care and its consequences in the context of competing priorities such as daily hassles and treatment for comorbidities such as substance use

or depression were commonly reported as barriers to retention in care. For example, "*I don't miss appointments, I get here late and can't be seen until the next day or next week… because you're whole life revolves around going to get this methadone.*" In such cases, participants expressed frustration with the competing priorities and perceived added burden of treatment for other conditions. Nevertheless, such frustration did not typically diminish the belief that their HIV care appointments were equally important.

Contextually, the influence of stigma associated with comorbidities such as substance use and depression varied, but when present significantly impacted participants' attitudes towards engaging in care. In particular, internalized stigma emerged as a critical barrier to care in this population:

> *It wouldn't have been difficult* [to see the doctor]*… I think I just purposely chose not to see them…I was* [drinking heavily]. *I would come in to see the doctor, and I would like walk around and leave* [before seeing them]! *I was doing wrong… it wasn't something that they did; just the choice I made*.

The role of trust in the patient-provider relationship and in the system of care was highlighted by beliefs about the importance of being "open" with providers, particularly when one is not following care/treatment recommendations or is exhibiting poor self-care. Trust was particularly relevant in discussions where providers were viewed as a source of support for coping with barriers related to depression, substance use, or daily hassles:

> [My provider and I] *had a good talk last month… I told her that I had been depressed and that I had started getting high. I was really glad I could be honest with her… because she advised me I can go to therapy…so I can have someone to talk with when I get like that*.

**Types of retention in care social motivation.** Social norms relevant to retention in care reflected specific cultural beliefs about HIV and accessing medical care, such as, "*In my culture, in my family…you wait until the very last minute to go to the hospital… I guess that's another reason you can easily put it off* [routine HIV care]*."* Norms were also drawn from HIV-positive others, commonly reflecting a high proportion of HIV-positive others in one's or one's partner's

immediate family. Consequences of poor retention likewise reflected a substantial amount of loss of HIV-positive others, especially before the availability of antiretroviral medications:

> *My brother died from HIV and quite a few relatives passed from it. Wasn't no cure then… well ain't no cure, wasn't no medicine at all at that time. But right now… there is some medicine to help… and being that I had a lot of family members pass from it… that's what makes me come here.*

Multiple sources of perceived social support for attending HIV-care appointments were identified; including emotional and instrumental support from important others, HIV-care providers, and the presence of external support systems (e.g., case management, mental health treatment). A contextual area where the presence or absence of perceived support appeared critical was at the intersection of stigma related to drug use or mental illness, and different sources of social support such as families or HIV-care providers. These intersections demonstrated unique consequences with respect to retention-related social motivation, as seen in the following quotation:

> *I've been at it* [depression] *for more than 35 years and there* [was] *times I…choose to pick up* [drugs]. *Whereas now I know I can come tell* [my doctor] *before I pick up… so I don't have to deal with it all myself… because that's something I wouldn't tell my family – I'm depressed I feel like getting high or…I got high.*

**Types of retention in care behavioral skills**. Strategies or perceived abilities to attend HIV care appointments by overcoming practical barriers to care typically employed *functional skills* to prioritize care in the context of daily hassles, such same-day therapy appointments, and the use of effective planning and reminder strategies. For example:

> *I got little post-it things put all over… that helps. If I remember to write it right there and then, I'll put it on my mirror. I don't have no mirror cause I have paper all over it, so I can try to remember.*

*Navigation skills* for identifying and utilizing available clinic support, and accessing ancillary services or treatments to address unmet needs emerged as facilitating retention in HIV care. In particular, use of available clinic services (e.g., reminder calls, same-day or walk-in appointments, medical outreach services) to address practical barriers, left many participants with

positive perceptions of the clinic/medical system as being 'responsive' to their needs and personal situations; feeding back into participants' motivation to access and utilization of HIV care services. One participant, with debilitating anxiety, described this perceived responsiveness as facilitating her access to care as:

> "*I could miss three visits in nine months because of my anxiety... walk into the clinic whenever I wanted to, because they know of my anxiety, I'm never denied…they'll get* [any available doctor] *when they hear my name, 'Oh, shit, she's here. Let's get her.' I've been blessed with them doctors."*

*Activation skills* to negotiate care in the context of living with HIV include the ability or perceived ability to acquire instrumental and social support for care appointments, mange perceived or anticipated HIV and related stigmas (e.g., mental illness, drug use) from providers or important others, and to cope with one's HIV-diagnosis/prognosis and HIV-related cognitive or physical impairments.

> *Sometimes I go to* [another hospital, with an HIV-only clinic]… *the way the workers and people* [walking by] *look at us, it makes you feel like I don't want to go in there; oh I'm in the wrong place! But I don't care; I have to look out for me.*

Perceived and objective ability to prioritize HIV-care in the context of comorbidities (e.g., mental health, substance use), such as recognizing the role of substance use or depression in masking personal motivation, as well as physical signs/symptoms indicating a need for medical care emerged as important contextual *activation skills*. One participant, stills struggling to come to terms with his HIV status reflected on this saying, "*Feeling that I have to* [see the doctor]... *I get more depressed, keep myself occupied to not think about* [having HIV], *make other things a priority instead of going to the doctors… when I should be going to the doctors*."

In sum, the combined results from both the deductive and inductive analysis both support the utility of a situated IMB-based approach to retention in HIV care, and articulate the types of information, motivation, and behavioral skills factors most critical in the current population for future quantitative model evaluation and intervention development.

## Discussion

An understanding of the dynamics of self-directed retention in HIV care is critical to promote the development, implementation, and evaluation of effective behavioral interventions that enhance self-sustained retention in HIV care. The current research is a step in that direction, presenting the first qualitative test of a situated Information, Motivation, Behavioral Skills model of Care Initiation and Maintenance for chronic conditions (K. R. Amico, 2011). This work supports the utility and validity of this theoretical model in explicating the behavioral factors underlying retention in HIV care in an inner-city population of PLWH. Specifically, core information, motivation, and behavioral skills factors in the model were well represented across participants' experiences. The contextual factors articulated in the sIMB model as important in "situating" these core IMB factors to patients' experiences living with and seeking care for chronic conditions, such as HIV, emerged consistently from the current results. The extent to which these IMB factors appeared across both deductive and inductive analytic approaches indicate this situated IMB-based approach appropriately characterized the proposed theoretical determinants underlying retention in HIV care in the current sample. In comparison to other theoretical approaches articulated to HIV care access and utilization (e.g., Andersen's Health Behavioral Model, the Chronic Care Disease model, the Health Belief Model, Socio-ecological Framework; Andersen, 1995; McLeroy et al., 1988; Rosenstock, 1966; Wagner, 1998) these findings extend beyond demographic vulnerabilities to identify critical, potentially modifiable variables, which easily translate into actionable intervention approaches.

The majority of the current study's findings are consistent with previously identified correlates of engagement and retention in HIV care. Similar to others (Brewer et al., 2007; Burns et al., 2008; Marx et al., 2001), our data identified accurate knowledge of HIV disease, of the benefits associated with HIV care and the consequences of non-adherence to care as information-based elements relevant to retention in HIV care. Personal attitudes and beliefs regarding HIV

care utilization identified in the data, as well as previous work, included perceptions of perceived vulnerability to HIV disease, beliefs in the benefits of HIV care and available treatments (Burns et al., 2008; Catz et al., 1999; Gordon et al., 2006; Marx et al., 2001), perceived trust in HIV care providers and perceived availability of support services (Bodenlos et al., 2007; C. O. Cunningham, Sohler et al., 2007; Mallinson et al., 2007; Rajabiun et al., 2007; N. L. Sohler et al., 2009; Whetten et al., 2004). Behavioral skills related to acceptance of one's HIV diagnosis (e.g., integration of care and living with HIV into a part of one's daily life; Mallison et al., 2005), skills to overcome practical barriers to care such as transportation (Rajabiun et al., 2007), and access both instrumental and emotional support to address unmet need (C. Cunningham et al., 2007; L. Gardner et al., 2007; Lo et al., 2002; C. Tobias et al., 2007) were also commonly found to be important in the current study.

Other findings afford additional insights and extensions in previously reported relationships in the retention in care literature. For example, information on HIV treatment benefits and procedures needs to integrate knowledge related to care for comorbid health conditions and attend to information pertinent to ways in which active depression or substance use may mask physical symptoms of HIV disease progression and associated need for medical evaluation. Health beliefs identified as providing faulty heuristics guiding HIV care decisions extended beyond those previously associated with impeding engagement and retention in HIV care (Beer et al., 2009; Rajabiun et al., 2008; Rumptz et al., 2007; C. Tobias et al., 2007). Such heuristics appear to rely on patients' subjective concept of their overall health (i.e., presence or absence of physical symptoms, weight gain/loss or quality of diet) to indicate perceived need for care. Affective-based contextual factors related to acceptance of diagnosis (Bodenlos et al., 2007; Rajabiun et al., 2007) and HIV stigma (Kempf et al., 2010; Moneyham et al., 2010) have been observed by others, as well as the current study. However, our results suggest additional affective barriers related to living with HIV, which may impede attitudes and abilities to access care, extend to

cognitive and physical impairments resulting from HIV treatment and impact of HIV on one's body.

Poorer mental health status and substance use have been associated with decreased engagement and retention in HIV care (Bakken & Holzemer, 2000; Brewer et al., 2007; W. Cunningham et al., 2006; Gordon et al., 2006; C. Tobias et al., 2007), and increased use of emergency room visits and hospitalizations (C. Cunningham et al., 2007). While differences in these relationships have been examined in relation to treatment status (e.g., receipt of mental health treatment, not having a history of substance use treatment; (Bell et al., 2010; C. Cunningham et al., 2007) or differences in type and frequency of substance use (e.g., binge drinking, crack cocaine use, IDU; Bakken & Holzemer, 2000; Barash, Hanson, Buskin, & Teshale, 2007; Brewer et al., 2007; C. O. Cunningham, Sohler, Berg, Shapiro, & Heller, 2006; C. Cunningham et al., 2007; W. Cunningham et al., 2006; Rumptz et al., 2007; Torian, Wiewel, Liu, Sackoff, & Frieden, 2008); the meditational processes involved in these relationships are not fully understood. Our data suggest such processes may work through other correlates of engagement and retention in HIV care, namely levels of perceived social support (Bodenlos et al., 2007; Catz et al., 1999), provider engagement (Bakken & Holzemer, 2000; Bradford, Coleman, & Cunningham, 2007; Mallinson et al., 2007), and abilities to cope with stigma (Rumptz et al., 2007). In particular, our data suggests internalized stigma or anticipated negative reactions from providers related to one's substance use or mental health status may be one potential pathway these contextual factors are inhibiting HIV care. Furthermore, the data suggest identifying appropriate sources of social support (e.g., friends, family, providers), to address adherence to care in the presence of these contextual factors, may be a function of the perceived consequences associated with disclosure of HIV, mental health, and substance use status for that individual.

Identification of emergent themes within facilitators and barriers to care contributed further insights into patients' conceptualization of attending clinical care that are not presently well

represented in the literature. Participants' often reported viewing HIV care as an "all or nothing process", one is either doing everything they can to treat their HIV or there is no point in doing any of it. This perception, legitimizing their withdrawal from HIV care, was most typically reflected on in presence of patient's sub-optimal self-care behaviors (e.g., medication non-adherence, acute mental illness, or active substance use); implicating the use of faulty heuristics (e.g., sub-optimal self-care behaviors) to guide HIV treatment decisions (e.g., fully engaged in care vs. withdrawn from care). The data suggest anticipated negative reactions from providers, shame or initialized stigma related to these sub-optimal self-care behaviors may be an additional barrier enabling one's withdrawal from HIV care. Heuristics that challenge this "all or nothing" perception would need to legitimize HIV care in the presence of sub-optimal self-care behaviors. For example, seeing HIV care as an incremental or "step by step" process (e.g., continued viral load monitoring in the presence of active substance use) heuristically could guide care utilization decisions in the presence of other sub-optimal self-care behaviors. By underscoring that care attendance is possible and equally important when not adhering to medications, or when experiencing acute mental health symptoms or active substance use, access and linkage to support services to address low engagement in these self-care behaviors (e.g., medication adherence counseling or substance use treatment) may be better facilitated (J. D. Fisher, Smith, & Lenz, 2010).

**Study limitations and future directions**

The current study builds upon an emerging body of work aimed at identifying key factors influencing retention in HIV-care that are amenable to targeted intervention and behavior change (Beer et al., 2009; Horstmann et al., 2010; Marks et al., 2010; Moneyham et al., 2010; M. J. Mugavero et al., 2011; Rajabiun et al., 2007), by providing a theoretical framework that is clearly articulated and testable, and which directly informs and directs future intervention efforts. Although the development of the sIMB model of retention in HIV care was informed by the

existing qualitative and qualitative work on care utilization across a diverse range of PLWH, there are some limitations to the generalizability and application of the results from the current model evaluation.

Methodological limitations include reliance on participants' retrospective recall of their experiences with HIV care across a limited number of in-depth qualitative interviews. Additionally, those responsible for the qualitative analyses (LRS, KRA) were not blind to the sIMB or IMB models, thus limiting a truly objective evaluation of the results. Caution is also warranted when drawing conclusions from the proposed sIMB model of Retention in HIV Care, as the current study represents only the first phase in the development and systematic evaluation of the sIMB model, and its application to this new behavioral domain. While the results obtained support moving forward with this model as a descriptive explanatory model of retention in HIV care, the second and third phases of this work, representing quantitative structural equation modeling tests s with larger samples of PLWH, and rigorous evaluations of randomized, controlled model-based intervention approaches using randomized control designs, respectively, are needed before any conclusions regarding the model's structure and function can be inferred. Future comprehensive model tests employing structural equation model techniques will be valuable in assessing the hypothesized structural relationships of the sIMB model of Retention in HIV Care, and the model's overall utility in predicting retention in care.

The function of the proposed model is also limited in its ability to directly influence concrete structural (e.g., long clinic wait times, limited availability of local HIV-care and support services) and community-level (e.g., pervasive HIV stigma, cultural norms endorsing mistrust of the health care system) barriers, and it may work best in tandem with multi-level intervention approaches (Cheever, 2007; Horstmann et al., 2010; Marks et al., 2010; M. J. Mugavero et al., 2011). Of note to the current study, participants' descriptions of structural barriers (i.e., long clinic wait times, transportation difficulties, low perceived access to available resources) were not identified as

central to participants' concerns, when compared to previous work (Bradford et al., 2007; Coleman et al., 2007; Kempf et al., 2010; Mallinson et al., 2005; Marx et al., 2001; Moneyham et al., 2010; Rajabiun et al., 2008; Rumptz et al., 2007), but did emerge as a barrier to retention in HIV care. Conversely, discussions of clinic-based strategies to help address structural barriers (i.e., efforts to reduce wait times, offering same day appointments, ensuring continuity in one's primary care provider, providing partial transportation assistance), that have been previously identified in this population (C. O. Cunningham et al., 2007), were observed as facilitating retention in care via perceptions of the clinic/health care system as being responsive to one's individual needs.

Sample-based limitations include factors unique to this inner-city population receiving either traditional clinic- or non-traditional outreach-based HIV care that may not translate to other populations of PLWH. Most notably, participants in the current study were in contact with HIV care services at time of interview, and accessing care in a context where numerous ancillary services are typically available. As such, PLWH who are lost to follow up or who have never initiated care may not be accurately represented by these findings (Beer et al., 2009; Rumptz et al., 2007). For example, Beer and colleagues (2009) identified fear of laboratory results as a health belief-related heuristic which inhibited PLWH from seeking HIV-care altogether. Such heuristics were not observed in the current sample.

The types of HIV-related resources and structural barriers impacting retention in care for PLWH residing in a major metropolitan area are likely different than those faced by PLWH in rural or resource constrained areas (Kempf et al., 2010; Moneyham et al., 2010), or recently incarcerated PLWH reengaging in community care (Nunn et al., 2010; Zaller, Fu, Nunn, & Beckwith, 2011). For example, assessment of participants' perceived difficulty with transportation and child care related factors appeared to be less of a barrier to care in the current sample than has been observed in similar qualitative work (Kempf et al., 2010; Mallinson et al.,

2005; Moneyham et al., 2010; Rajabiun et al., 2007). This may reflect shorter distances traveled to HIV care, available public transportation, or the age and gender composition of the current study, as only one participant reported any children under the age of 18 residing in their home at time of interview. In direct contrast, qualitative work among HIV-positive women in the Deep South (Kempf et al., 2010; Moneyham et al., 2010) identified structural barriers such as long distances to HIV-care clinics, and limited access to reliable and/or affordable transportation to be particularly limiting in regularly accessing HIV care. Being responsible for childcare and concerns over inadvertent disclosure to children through continued care access was also noted in these rural samples (Kempf et al., 2010; Moneyham et al., 2010).

However, in line with past work in applying the IMB model across diverse populations (Fisher & Fisher, 1992), it is anticipated that work with the sIMB model of Retention in HIV Care across populations of PLWH will continue to support the centrality of its main information, motivation, behavioral skills constructs (K. R. Amico, 2011; J. D. Fisher et al., 2004; J. D. Fisher & Fisher, 1992). However, the specific IMB content most relevant for quantitative model tests, and intervention development should be tailored to address the types of IMB deficits most pertinent to a given population. For example, qualitative work by Beer and colleagues (2009) suggests that interventions to enhance engagement and retention in care among PLWH not currently in care might target inaccurate information regarding the purpose and relevance of HIV laboratory tests, and personal and social motivation to negotiate the fear surrounding test results. As such, their findings suggest that behavioral skills for coping with such fears and acquiring social support for accessing care and obtaining test results may be of particular relevance to treatment naïve populations (K. R. Amico, 2011; Beer et al., 2009; Rajabiun et al., 2007).

Although the intervention efforts suggested above are provided to illustrate ways in which the sIMB model might account for differences in populations of PLWH, IMB-based interventions across various populations and health behaviors (J. D. Fisher et al., 2006; J. D. Fisher et al., 2011;

J. D. Fisher, Fisher, Misovich, Kimble, & Malloy, 1996) that identify and correct information, motivation, and behavioral skills deficits have been successful. Similarly, findings from the current study may prove useful in translating theoretically grounded intervention approaches to enhance retention in HIV care should the structural relations in the proposed sIMB model of Retention in HIV care be supported in future evaluations.

Examples based on the current study's findings might suggest that future intervention efforts aim to supplement HIV care and treatment knowledge with information on how HIV care utilization relates to comorbid conditions (e.g., chronic diabetes or increased viral replication resulting from active substance use). The data also suggest reframing 'reactive' responses to perceived vulnerability to HIV disease (i.e., seeking care due to rapid changes in weight) into 'proactive' responses (i.e., regularly monitor one's weight and viral load to identify any problems before experiencing such drastic changes) may be possible by harnessing one's intrinsic motivation to know what is happening with their health and HIV progression. Findings suggest enhanced communication skills to discuss with providers difficulties related to adhering to treatment recommendations (e.g., medication non-adherence, increased substance use) may disrupt patient's disengagement from care in the presence of poor self-care behaviors. In this regard, the data also suggest skills to cope with anticipated negative reactions from providers or other support systems (e.g. family, friends, HIV-positive others) may enhance perceived and actual abilities to disclose potentially stigmatizing experiences (e.g., engaging in substance use to cope with one's depression) which may be impeding one's retention in care.

As in previous research we found approximately one- third of the sample had had a significant gap in HV care of 6 months or more in the past two years, with one fourth of the sample reporting such a gap in the past year. The ability to identify participants at risk for falling out of routine HIV care before they do so, or help reengage patients returning from a prolonged absence would be critical to enhancing the health and care of PLWH at risk of sub-optimal health outcomes. The current study employed a qualitative test of the sIMB model of Retention in HIV

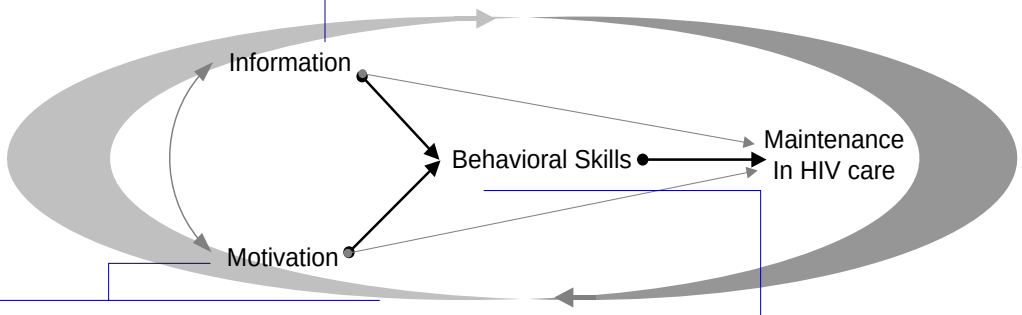
Care to evaluate the model's ability to specify important theoretical (i.e., information, motivation, behavioral skills) and contextual (i.e., affect towards and acceptance of one's diagnosis, mental health, substance use) factors involved in this behavioral process. This elicitation process, phase 1, further yielded important model content, explicating the types of information, motivation, and behavioral skills most relevant to retention in care for the study population. At present, these findings are informing phase two, the development of a sIMB-based measure to quantitatively test the model's proposed structural relations and ability to predict retention in HIV care among the inner-city clinic population. Future work (phase 3) will aim to rigorously evaluate the utility and function of the sIMB model to inform intervention development and translate the proposed behavior change process into self-sustained retention in HIV care using a randomized control design.. While future work is still needed to fully evaluate the utility and function of the sIMB model of retention in HIV care, the findings of the current study offer promise to inform current 'test and treat' efforts. Specifically this work is independently valuable in moving the known correlates of retention in HIV care into a viable comprehensive model likely to inform and easily translate future intervention efforts relevant to individual and public health.

## Figure 1. Situated Information, Motivation, Behavioral Skills Model of Retention in HIV Care

Accurate INFORMATION concerning

- **HIV TREATMENT and TREATMENT PROCESS** (Knowledge of purpose of attending care ~ every 3-months, why CD4, VL, cholesterol and liver functioning are monitored, what these values mean in terms of HIV and treatment)
- **HIV** (Knowledge of the typical course of HIV over time)
- **ADJUSTMENT PROCESS** (Knowledge of typical process of long-term adjustment to HIV and maintenance of self-care)
- **SYSTEM OF CARE** (Knowledge of patient rights to privacy, dignity in treatment, and confidentiality)

Low levels of **misinformation** about HIV-care (ineffectiveness of HIV treatments; inaccurate 'facts' about when care is needed and not needed)




**MOTIVATION:**
Attitudes/Beliefs about positive and negative consequences (intra- and interpersonally) of attendance in care. Including...

- **INTRAPERSONAL** (**PERSONAL MOTIVATION**): ***High positive cognitive and affective consequences of*** prioritizing self-care; getting results of monitoring (VL and CD4); using HIV-care; focusing on longevity and enhanced quality of life. ***Low negative cognitive and affective consequences of***; choosing care attendance over other competing priorities; getting to care when depressed, hung-over, anxious, or feeling well; using resources to get to care; managing negative affect associated with getting to and being in the HIV-care clinic.

- **INTERPERSONAL** (**SOCIAL MOTIVATION**): ***High positive cognitive and affective interpersonal consequences of***; regular attendance in care; involvement of important others in supporting HIV-care; social press to prioritize self-care; social investment in longevity and quality of life. ***Low negative cognitive and affective social consequences of;*** making self-care a priority; use of social or group resources to attend care; interacting with care-staff; getting to and being seen in HIV-care; impact of stigma. ***Low positive cognitive and affective social consequences of***; skipping care visits; choosing other priorities over self-care; avoidance of care setting or expected disclosure of substance use or non-adherence to care providers.

**BEHAVIORAL SKILLS:**
Skills and confidence in the ease with which one can successfully negotiate sustained attendance in HIV-care at recommended intervals. Including...

- **SYSTEMS NAVIGATION SKILLS-** to secure/access available resources; identify accessible HIV care providers/facilities; arrange resources to get into care; successfully navigate systems of care, benefits/coverage and case management

- **FUNCTIONAL (ORGANIZATION/PLANNING) SKILLS-** to arrange/attend care visit(s) including skills to: make care appointments at times that fit one's schedule; remember appointment dates/times; arrange for attendance to visit(s) in the context of daily life and daily life demands (arrange work schedule and maintain privacy, schedule care around childcare, care for other conditions, or appointments for other benefits/ resources); arrange for transportation to clinic

- **ACTIVATION SKILLS-** skills that minimize negative and maximize experienced/perceived benefits of care and maintain investment in care use, including skills to: increase/maintain HIV health literacy; invest in/progress towards emotional adjustment of living with HIV; achieve/maintain resiliency in prioritization of self-care; garner affective and instrumental social support; manage affect (anxiety, fear) associated with discovery of new problems, disease progression, or treatment failure during regular clinic visits; adjust to/cope with new HIV symptoms or treatment failures; prioritize self-care in the context of competing demands/priorities/barriers (such as mental health issues, substance use, housing problems)

**Table 1. Participant Characteristics.**

| Participant Characteristic | Frequency (%) | Mean (SD) | Range |
|---|---|---|---|
| **Age** | -- | 49.15 (6.40) | 39-61 |
| **Gender** | | | |
| *Male* | 12 (60%) | -- | -- |
| *Female* | 8 (40%) | -- | -- |
| **Race/Ethnicity** | | | |
| *African American/Black* | 7 (35%) | -- | -- |
| *Latino* | 13 (65%) | -- | -- |
| **Sexual Orientation** | | | |
| *Gay/Lesbian* | 4 (20%) | -- | -- |
| *Heterosexual* | 16 (80%) | -- | -- |
| **Highest Education Level** | | | |
| *Some high school or less* | 10 (50%) | -- | -- |
| *High school diploma/GED* | 5 (25%) | -- | -- |
| *Some College/Technical degree* | 1 ( 5%) | -- | -- |
| *College Degree (BA, BS)* | 4 (20%) | -- | -- |
| **Employment Status** | | | |
| *Unemployed* | 2 (10%) | -- | -- |
| *Employed part-time* | 2 (10%) | -- | -- |
| *Disability/Sick leave* | 16 (80%) | -- | -- |
| **Housing Status** | | | |
| *A place I rent or own/SRO* | 14 (70%) | -- | -- |
| *Assisted living/Housing Program* | 5 (25%) | -- | -- |
| *Homeless/Shelter* | 1 ( 5%) | -- | -- |
| **Annual Family Income** | | | |
| *≤ $5,000* | 8 (40%) | -- | -- |
| *$5,001-$10,000* | 8 (40%) | -- | -- |
| *$10,001-$20,000* | 4 (20%) | -- | -- |
| **Mode of HIV Transmission** | | | |
| *Consensual heterosexual sex* | 9 (45%) | -- | -- |
| *Nonconsensual heterosexual sex* | 3 (15%) | -- | -- |
| *Male to male sexual transmission* | 2 (10%) | -- | -- |
| *Sharing needles or works* | 5 (25%) | -- | -- |
| *Other* | 1 ( 5%) | -- | -- |

| **Correlates of Poor Retention** | Frequency (%) Since Diagnosis | Frequency (%) Past 2 Years |
|---|---|---|
| *History of unstable housing* | 9 (45%) | 4 (20%) |
| *History of mental health diagnosis* | 14 (75%) | 11 (60%) |
| *History of non-injection drug use* | 13 (65%) | 7 (35%) |
| *History of injection drug use* | 9 (45%) | 1 (15%) |
| *History of incarceration* | 9 (45%) | 5 (25%) |

**Table 2. Observed Information, Motivation, Behavioral Skills Content in Retention-related Discourse.**

| IMB Construct | Code Definitions | Frequency(%) of Retention Text Segments | | |
|---|---|---|---|---|
| | | Facilitator ($k$ = 162) | Barrier ($k$ = 77) | Total ($k$ =239) |
| **Information** | | **34 (21%)** | **10 (13%)** | **44 (18.4%)** |
| *Accurate Information* | Accurate knowledge of HIV disease, availability of care, HIV treatment recommendations/procedures/benefits/consequences. | 26 | 2 | 28 |
| *Misinformation* | Incorrect knowledge of HIV disease, availability of care, HIV treatment recommendations/procedures/benefits/consequences. | 1 | 3 | 4 |
| *Cognitive Heuristics* | Implicit theories common to the local/regional culture regarding reasons to access care or associated costs/consequences of care. | 7 | 5 | 12 |
| **Motivation** | | **157 (97%)** | **64 (83%)** | **221 (92.5%)** |
| *Personal Attitudes/Beliefs* | Attitudes/beliefs towards having HIV or engaging in HIV care system related to one's previous experiences or cultural beliefs. | 27 | 7 | 34 |
| *Perceived Vulnerability* | Attitudes/beliefs about the perceived personal benefit or positive/negative consequences of accessing available HIV care/treatment/medications. | 53 | 4 | 57 |
| *Competing Priorities* | Attitudes/beliefs about engaging in HIV care in the context of daily hassles (work/child care) or comorbidities (depression). | 1 | 23 | 24 |
| *Patient Provider Relationships* | Perceptions of trust in and positive/negative social interactions with available providers/clinic staff/systems of care. | 26 | 12 | 38 |
| *Social Norms and Support* | Perceptions of important other's attitudes/beliefs about HIV or medical care; social support or social costs for accessing care. | 50 | 18 | 68 |
| **Behavioral Skills** | | **95 (59%)** | **32 (42%)** | **127 (53.0%)** |
| *Accessing Ancillary Services* | Strategies or perceived ability/confidence to address unmet need (insurance/case management/transportation/locate care provider). | 13 | 5 | 18 |
| *Addressing Practical Barriers* | Strategies or perceived ability/confidence to attend HIV care appointments within the recommended intervals. | 17 | 5 | 22 |
| *Daily Hassles/Comorbidities* | Strategies or perceived ability/confidence to negotiate care in the context of daily hassles (work/child care) or comorbidities. | 2 | 13 | 15 |
| *Planning/Reminder Strategies* | Strategies or perceived ability/confidence to manage HIV care- related time commitments (scheduling/planning/long wait times). | 24 | 9 | 33 |
| *Obtaining Social Support* | Strategies or perceived ability/confidence to obtain support from important others (family/friends/service agency staff) for care. | 39 | 1 | 40 |
| **sIMB Contextual Factors** | | **44 (27%)** | **40 (52%)** | **84 (35.0%)** |
| *Affective Factors* | Positive or negative feelings about living with HIV including acceptance or denial of diagnosis, desire/no desire to live as HIV positive, HIV-stigma | 40 | 27 | 67 |
| *Socio-cultural Factors* | Co-occurring experiences with acute substance use and mental health diagnosis (e.g., depression, anxiety), resource/housing instability. | 4 | 13 | 17 |

**Table 3. Observed Retention-relevant Themes within Participant Discourse of Facilitators and Barriers to HIV Care Utilization.**

| Facilitator-based Themes | Relationship of Emergent Theme to Participant Discourse | sIMB Model Convergence |
|---|---|---|
| 1. Positive adjustment and coping to living with HIV | • Relearn old health beliefs/behaviors in the context of living with HIV**<br>• Adjusting to life with HIV, moving towards acceptance of diagnosis<br>• Emotional regulation of acute affect related to diagnosis and obtaining care | Information<br>Personal Motivation<br>Behavioral Skills |
| 2. Personal Cognitive Constructions of Self-Care | • Developing a working model of self-care (i.e., need to take responsibility for one's health, can't depend on others, must prioritize self-care, deserve good care) | Information<br>Personal Motivation |
| 3. Personal Reasons to Monitor Health Status | • Perceived need for regular ongoing care utilization for access to HIV medications and treatment for comorbid health conditions (i.e., diabetes, hypertension)**<br>• Dual role of perceived vulnerability; proactive wanting 'good' health outcomes/positive feedback from providers, reactive wanting to know why one doesn't feel well**<br>• Desire to stay informed and take advantage of new treatment opportunities | Information<br>Personal Motivation |
| 4. Social Interactions at Care with Providers, Staff, System of Care | • Perceptions of the care system as responsive to one's needs**<br>• Relationships with providers is seen as a source of support (discuss problems with, feel listened to and connected to providers) | Personal Motivation |
| 5. Self-directed Strategies to Facilitate Care Attendance | • Use of scheduling and reminder strategies (calendar, planner, visible notes)<br>• Identifying alternative HIV care sites when travel to clinic is impeded by physical impairments (i.e., difficulties walking) or extensive travel time is too burdensome | Behavioral Skills |
| 6. Social-directed Strategies to Facilitate Care Attendance | • Availability or reliance on others to facilitate care utilization<br>  o Accessing case managers to help with scheduling, reminders, obtain care/services<br>  o Perceived family support (inquiring about health/clinic attendance, accompany one to clinic appointments when asked) | Behavioral Skills |
| 7. Clinic-based Strategies to Facilitate Care Attendance | • Clinic-based reductions in structural barriers to care†<br>  o Consistency of provider, same-day appt., shorter wait times, centralized care, clearly defined channels to address needs<br>  o Provision of transportation vouchers (Metrocards) and nutritional supplements | External to sIMB Model† |
| 8. Expressed Desire/Investment in Longevity | • Expressed desire to live (perceptions that life is fragile/limited in time, desire to live, wanting more time with important others, feeling important to and needed by others<br>• Enhanced commitment to care through observation of the health costs/benefits associated with treatment adoption/non- adopted from other PLWH (living/deceased)** | Personal Motivation<br>Social Motivation |

| Barrier-based Themes | Relationship of Emergent Theme to Participant Discourse | sIMB Model Convergence |
|---|---|---|
| 1. Poor adjustment and coping to living with HIV | • Negative affective response and coping strategies in response to HIV diagnosis<br>o Behavioral/mental disengagement in response to HIV diagnosis (sub use, depression, indifference, avoidance of care)<br>o Experiencing a sense of isolation, HIV stigma, or poor regulation of negative affect (quick to react/frustrate/anger) when reminded of HIV diagnosis** | Personal Motivation<br>Behavioral Skills |
| 2. Negative or Limited Cognitive Construction of Self-care | • Global view of self-care (care attendance, medication adherence, addressing substance dependence/use) represented as an 'all or nothing' behavior; if one component lapses there is no reason to engage in or reengage in any of the components**<br>• Perceive other PLWH as taking advantage of /misusing HIV care/ancillary services** | Personal Motivation<br>Social Motivation |
| 3. Low perceived benefit of regular care | • No perceived benefit of attending HIV care if<br>o One is not prescribed or adhering to HIV medications or experiencing signs or symptoms of HIV<br>o Not engaging in other global self-care behaviors (e.g., self-care not possible when using or not loving yourself first)**, aren't able to care about self) | Personal Motivation<br>Behavioral Skills |
| 4. Negative consequences of going to care | • Perceived negative consequences of attending HIV care<br>o Structural (long wait time, transport problems, not using resources)†<br>o Interpersonal interactions with clinic staff or providers (bad attitudes, not stressing the importance of care, belittle or disregard patient's concerns, not providing type of care or assistance patient perceives as needed)<br>o Intrapersonal factors (experiencing pain, 'don't feel like it', want to avoid inclement weather, feel too much pressure to go) | Personal Motivation<br>External to sIMB Model† |
| 5. Prioritization/choice of other things | • Choosing to or having to prioritize other things instead of attending HIV care<br>o Family commitments (children/partners sick, hospitalized, incarcerated)<br>o Conflicting time demands (work, other appointments, methadone treatment)<br>o Prioritizing other personal desires (sleeping/relaxing/TV) or substance use (scoring drugs, treatment or recovery) | Personal Motivation<br>Behavioral Skills |
| 6. Memory, Cognitive/Physical HIV Impairments | • Misjudgment of time elapsed since last appointment, habituation to reminders/prompts<br>• "Effects of living with HIV" or treatment side effects such as organic cognitive/memory problems and physical impairments ("HIV just tires you out/ages you differently") ** | Personal Motivation<br>Behavioral Skills |
| 7. Substance Use | • Active use and associated consequences (running the streets, homeless)<br>• Internalized stigma (self-shame, anticipate MD to be angry about use/relapse, viewing care attendance as incompatible with use) **<br>• Drug use or treatment (i.e., methadone) can mask need for care (i.e., pain, symptoms) ** | Information<br>Personal Motivation |

** Unique sIMB content relevant to retention in care in the current study population
† Identified content important to retention in HIV care that is external to the sIMB model

## References

Aberg, J. A., Kaplan, J. E., Libman, H., Emmanuel, P., Anderson, J. R., Stone, V. E., . . . Gallant, J. E. (2009). Primary care guidelines for the management of persons infected with human immunodeficiency virus: 2009 update by the HIV medicine association of the infectious diseases society of america. *Clinical Infectious Diseases, 49*(5), 651-681.

Amico, K. R., Smith, L. R., Urso, J., Odesina, V., Diaz, V., Kwon, S., & Dieckhaus, K. (2010a). The situated information motivation behavioral skills model of HIV care initiation and maintenance (sIMB-CIM): Preliminary support for characterizing gaps in HIV care. *Oral Presentation at the 5Th International Conference on HIV Treatment Adherence,* Miami Beach, FL.

Amico, K. R., Smith, L. R., Urso, J., Odesina, V., Diaz, V., Kwon, S., & Dieckhaus, K. (2010b). Retention in HIV-care: Correlates of gaps in HIV-care. *Poster Presentation at the 5Th International Conference on HIV Treatment Adherence,* Miami Beach, FL.

Amico, K. R., Toro-Alfonso, J., & Fisher, J. D. (2005). An empirical test of the Information, Motivation and Behavioral Skills model of antiretroviral therapy adherence. *AIDS Care, 17*(6), 661-673.

Amico, K. R. (2011). A situated-Information Motivation Behavioral Skills model of Care Initiation and Maintenance (sIMB-CIM): An IMB model based approach to understanding and intervening in engagement in care for chronic medical conditions. *Journal of Health Psychology,* doi:10.1177/1359105311398727

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1-10.

Anthony, M., Gardner, L., Marks, G., Mahoney, P., Metsch, L., Valverde, E., . . . Loughlin, A. (2007). Factors associated with use of HIV primary care among persons recently diagnosed with HIV: Examination of variables from the behavioural model of health-care utilization. *AIDS Care, 19*(2), 195-202. doi:10.1080/09540120600966182

Bakken, S., & Holzemer, W. L. (2000). Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care & STDs, 14*(4), 189-197.

Barash, E., Hanson, D., Buskin, S., & Teshale, . (2007). HIV-infected injection drug users: Health care utilization and morbidity. *Journal of Health Care for the Poor and Underserved, 18*(3), 675-686. doi:10.1353/hpu.2007.0053

Beer, L., Fagan, J. L., Valverde, E., & Bertolli, J. (2009). Health-related beliefs and decisions about accessing HIV medical care among HIV-infected persons who are not receiving care. *AIDS Patient Care and STDs, 23*(9), 785-792.

Bell, C., Metsch, L. R., Vogenthaler, N., Cardenas, G., Rodriguez, A., Locascio, V., . . . del Rio, C. (2010). Never in care: Characteristics of HIV-infected crack cocaine users in 2 US cities who have never been to outpatient HIV care. *Journal of Acquired Immune Deficiency Syndromes, 54*(4), 376-380.

Berg, M. B., Safren, S. A., Mimiaga, M. J., Grasso, C., Boswell, S., & Mayer, K. H. (2005). Nonadherence to medical appointments is associated with increased plasma HIV RNA and decreased CD4 cell counts in a community-based HIV primary care clinic. *AIDS Care, 17*(7), 902-907. doi:10.1080/09540120500101658

Bernard, H. R. (2006). *Research methods in anthropology: Qualitative and quantitative approaches* (4th ed.). Oxford, UK: Altamira press.

Bodenlos, J., Grothe, K., Whitehead, D., Konkle-Parker, D., Jones, G., & Brantley, P. (2007). Attitudes toward health care providers and appointment attendance in HIV/AIDS patients. *Journal of the Association of Nurses in AIDS Care, 18*(3), 65-73. doi:10.1016/j.jana.2007.03.002

Bradford, J., Coleman, , & Cunningham, . (2007). HIV system navigation: An emerging model to improve HIV care access. *AIDS Patient Care and STDs, 21*, S49-S58.

Brewer, T. H., Zhao, W., Pereyra, M., del Rio, C., Loughlin, A., Anderson-Mahoney, P., . . . Metsch, L. R. (2007). Initiating HIV care: Attitudes and perceptions of HIV positive crack cocaine users. *AIDS and Behavior, 11*(6), 897-904. doi:10.1007/s10461-007-9210-2

Burgoyne, R., & Saunders, D. (2000). Perceived support in newly registered HIV/AIDS clinic outpatients. *AIDS Care, 12*(5), 643-650. doi:10.1080/095401200750003815

Burns, F. M., Johnson, A. M., Nazroo, J., Ainsworth, J., Anderson, J., Fakoya, A., . . . Fenton, K. A. (2008). Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK. *AIDS, 22*(1), 115-122. doi:10.1097/QAD.0b013e3282f1d4b6

Catz, S., McClure, J., Jones, G., & Brantley, P. (1999). Predictors of outpatient medical appointment attendance among persons with HIV. *AIDS Care, 11*(3), 361-373. doi:10.1080/09540129947983

Cheever, L. W. (2007). Engaging HIV-infected patients in care: Their lives depend on it. *Clinical Infectious Diseases, 44*(11), 1500-1502. doi:10.1086/517534

Christopoulos, K. A., Das, M., & Colfax, G. N. (2011). Linkage and retention in HIV care among men who have sex with men in the united states. *Clinical Infectious Diseases, 52*(suppl 2), S214-S222.

Coleman, , Boehmer, , Kanaya, , Grasso, , Tan, , & Bradford, . (2007). Retention challenges for a community-based HIV primary care clinic and implications for intervention. *AIDS Patient Care and STDs, 21*(9), 691-701. doi:10.1089/apc.2006.0205

Craw, J. A., Gardner, L. I., Marks, G., Rapp, R. C., Bosshart, J., Duffus, W. A., . . . Safford, L. A. (2008). Brief strengths-based case management promotes entry into HIV medical care: Results of the Antiretroviral Treatment Access Study-II. *Journal of Acquired Immune Deficiency Syndromes, 47*(5), 597.

Cunningham, C. O., Sanchez, J. P., Heller, D. I., & Sohler, N. L. (2007). Assessment of a medical outreach program to improve access to HIV care among marginalized individuals. *American Journal of Public Health, 97*(10), 1758-1761.

Cunningham, C. O., Sohler, N. L., Korin, L., Gao, W., & Anastos, K. (2007). HIV status, trust in health care providers, and distrust in the health care system among Bronx women. *AIDS Care, 19*(2), 226-234. doi:10.1080/09540120600774263

Cunningham, C. O., Sohler, N. L., Berg, K. M., Shapiro, S., & Heller, D. (2006). Type of substance use and access to HIV-related health care. *AIDS Patient Care and STDs, 20*(6), 399-407. doi:10.1089/apc.2006.20.399

Cunningham, C., Shapiro, S., Berg, K., Sacajiu, G., Paccione, G., & Goulet, J. (2005). An evaluation of a medical outreach program targeting unstably housed HIV-infected individuals. *Journal of Health Care for the Poor and Underserved, 16*(1), 127-138. doi:10.1353/hpu.2005.0007

Cunningham, C., Sohler, N., Wong, M., Relf, , Cunningham, W., Drainoni, , . . . Cabral, H. (2007). Utilization of health care services in hard-to-reach marginalized HIV-infected individuals. *AIDS Patient Care and STDs, 21*(3), 177-186. doi:10.1089/apc.2006.103

Cunningham, W., Sohler, N., Tobias, , Drainoni, , Bradford, , Davis, , . . . Wong, M. (2006). Health services utilization for people with HIV infection: Comparison of a population targeted for outreach with the U.S. population in care. *Medical Care, 44*(11), 1038-1047. doi:10.1097/01.mlr.0000242942.17968.69

Das, M., Chu, P. L., Santos, G. M., Scheer, S., Vittinghoff, E., McFarland, W., & Colfax, G. N. (2010). Decreases in community viral load are accompanied by reductions in new HIV infections in san francisco. *PLoS One, 5*(6), e11068.

Department of Health and Human Services. (2011). *Panel on antiretroviral guidelines for adults and adolescents. guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents.* Retrieved March 02, 2011, from http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf

Fisher, J. D., Amico, K. R., Fisher, W. A., Cornman, D. H., Shuper, P. A., Trayling, C., . . . Friedland, G. H. (2011). Computer-based intervention in HIV clinical care setting improves antiretroviral adherence: The LifeWindows project. *AIDS and Behavior,* doi:10.1007/s10461-011-9926-x

Fisher, J. D., Cornman, D. H., Osborn, C. Y., Amico, K. R., Fisher, W. A., & Friedland, G. A. (2004). Clinician-initiated HIV risk reduction intervention for HIV-positive persons: Formative research, acceptability, and fidelity of the options project. *Journal of Acquired Immune Deficiency Syndromes, 37*, S78-S87.

Fisher, J. D., Fisher, W. A., Amico, K. R., & Harman, J. J. (2006). An Information-Motivation-Behavioral Skills model of adherence to antiretroviral therapy. *Health Psychology, 25*(4), 462-473.

Fisher, J. D., Fisher, W. A., Cornman, D. H., Amico, R. K., Bryan, A., & Friedland, G. H. (2006). Clinician-delivered intervention during routine clinical care reduces unprotected sexual behavior among HIV-infected patients. *Journal of Acquired Immune Deficiency Syndromes, 41*(1), 44.

Fisher, J. D., Fisher, W. A., & Shuper, P. A. (2009). The Information–Motivation–Behavioral skills model of HIV preventive behavior. *Emerging Theories in Health Promotion Practice and Research*, 21–63.

Fisher, J. D., & Smith, L. (2009). Secondary prevention of HIV infection: The current state of prevention for positives. *Current Opinion in HIV and AIDS, 4*(4), 279-287.

Fisher, J. D., Smith, L. R., & Lenz, E. M. (2010). Secondary prevention of HIV in the united states: Past, current, and future perspectives. *Journal of Acquired Immune Deficiency Syndromes, 55*, S106-S115.

Fisher, W. A., Fisher, J. D., & Harman, J. (2003). The Information-Motivation-Behavioral Skills model: A general social psychological approach to understanding and promoting health behavior. In J. Suls, & K. Wallston (Eds.), *Social psychological foundations of health* (pp. 82–106). London: Blackwell Publishing. doi:10.1002/9780470753552.ch4

Fisher, J. D., & Fisher, W. A. (1992). Changing AIDS-risk behavior. *Psychological Bulletin, 111*(3), 455-474. doi:10.1037/0033-2909.111.3.455

Fisher, J. D., Fisher, W. A., Misovich, S. J., Kimble, D. L., & Malloy, T. E. (1996). Changing AIDS risk behavior: Effects of an intervention emphasizing AIDS risk

reduction information, motivation, and behavioral skills in a college student population. *Health Psychology, 15*(2), 114-123. doi:10.1037/0278-6133.15.2.114

Fleiss, J. L. (1981). *Statistical methods for rates and proportions* (2nd ed. ed.). New York: John Wiley.

Gardner, L. I., Metsch, L. R., Anderson-Mahoney, P., Loughlin, A. M., Rio, C., Strathdee, S., . . . Holmberg, S. D. (2005). Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS, 19*(4), 423-431.

Gardner, L., Marks, , Metsch, L., Loughlin, A., O'Daniels, , Del Rio, , . . . Wilkinson, J. (2007). Psychological and behavioral correlates of entering care for HIV infection: The antiretroviral treatment access study (ARTAS). *AIDS Patient Care and STDs, 21*(6), 418-425. doi:10.1089/apc.2006.0115

Gelberg, L., Andersen, R., & Leake, B. (2000). The behavioral model for vulnerable populations: Application to medical care use and outcomes for homeless people. *Health Serv Res, 34*, 1273-302.

Gifford, A. L., & Groessl, E. J. (2002). Chronic disease self-management and adherence to HIV medications. *Journal of Acquired Immune Deficiency Syndromes, 31*, S163-S166.

Giordano, T., Gifford, A., White, J.,A. Clinton, Suarez-Almazor, M., Rabeneck, L., Hartman, C., . . . Morgan, R. (2007). Retention in care: A challenge to survival with HIV infection. *Clinical Infectious Diseases, 44*(11), 1493-1499.

Gordon, A. J., McGinnis, K. A., Conigliaro, J., RodriguezBarradas, M. C., Rabeneck, L., Justice, A. C., & for the VACS Project Team. (2006). Associations between alcohol use and homelessness with healthcare utilization among human immunodeficiency virus-infected veterans. *Medical Care.Alcohol in HIV Infection: Insights from the Veterans Aging Cohort Study and the Veterans Affairs National Health Information System, 44*(8) (Suppl 2), S37-S43. doi:10.1097/01.mlr.0000223705.00175.3d

Granich, R. M., Gilks, C. F., Dye, C., De Cock, K. M., & Williams, B. G. (2009). Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: A mathematical model. *The Lancet, 373*(9657), 48-57. doi:DOI: 10.1016/S0140-6736(08)61697-9

Health Resources and Services Administration. (2006). *Providing HIV/AIDS care in a changing environment. self-management and the chronic care model.* United States:

Horstmann, E., Brown, J., Islam, F., Buck, J., & Agins, B. D. (2010). Retaining HIV-infected patients in care: Where are we? where do we go from here? *Clinical*

*Infectious Diseases: An Official Publication of the Infectious Diseases Society of America, 50*(5), 752-761.

Johnson, B. T., Redding, C. A., DiClemente, R. J., Mustanski, B. S., Dodge, B., Sheeran, P., . . . Fishbein, M. (2010). A network-individual-resource model for HIV prevention. *AIDS and Behavior, 14*, S204-S221. doi:DOI 10.1007/s10461-010-9803-z

Kalichman, S. C., Cherry, J., & Cain, D. (2005). Nurse-delivered antiretroviral treatment adherence intervention for people with low literacy skills and living with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care, 16*(5), 3-15.

Kempf, M. C., McLeod, J., Boehme, A. K., Walcott, M. W., Wright, L., Seal, P., . . . Moneyham, L. (2010). A qualitative study of the barriers and facilitators to retention-in-care among HIV-positive women in the rural southeastern united states: Implications for targeted interventions. *AIDS Patient Care and STDs, 24*(8), 515-520.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33*(1), 159-174.

Lo, W., MacGovern, T., & Bradford, . (2002). Association of ancillary services with primary care utilization and retention for patients with HIV/AIDS. *AIDS Care, 14*(4), S45-S57. doi:10.1080/0954012022014992049984

Mallinson, R., Rajabiun, , & Coleman, . (2007). The provider role in client engagement in HIV care. *AIDS Patient Care and STDs, 21*, S77-S84. doi:10.1089/apc.2007.9984

Mallinson, R., Relf, M., Dekker, , Dolan, , Darcy, , & Ford, . (2005). Maintaining normalcy: A grounded theory of engaging in HIV-oriented primary medical care. *Advances in Nursing Science, 28*(3), 265-277.

Marks, G., Gardner, L. I., Craw, J., & Crepaz, N. (2010). Entry and retention in medical care among HIV-diagnosed persons: A meta-analysis. *AIDS, 24*(17), 2665-2678.

Marx, R., Hirozawa, A., Soskolne, V., Liu, Y., & Katz, M. (2001). Barriers to getting needed services for ryan white CARE clients. *AIDS Care, 13*(2), 233-242. doi:10.1080/09540120020027404

Mayer, K. H. (2011). Introduction: Linkage, engagement, and retention in HIV care: Essential for optimal individual-and community-level outcomes in the era of highly active antiretroviral therapy. *Clinical Infectious Diseases, 52*(suppl 2), S205-S207.

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education & Behavior, 15*(4), 351-377.

Mkanta, W. N., & Uphold, C. R. (2006). Theoretical and methodological issues in conducting research related to health care utilization among individuals with HIV infection. *AIDS Patient Care & STDs, 20*(4), 293-303.

Moneyham, L., McLeod, J., Boehme, A., Wright, L., Mugavero, M., Seal, P., . . . Kempf, M. (2010). Perceived barriers to HIV care among HIV-infected women in the deep south *Journal of the Association of Nurses in AIDS Care, 21*(6), 467-477. doi:DOI: 10.1016/j.jana.2010.03.003

Montaner, J. S., Lima, V. D., Barrios, R., Yip, B., Wood, E., Kerr, T., . . . Kendall, P. (2010). Association of highly active antiretroviral therapy coverage, population viral load, and yearly new HIV diagnoses in British Columbia, Canada: A population-based study. *The Lancet, 376*(9740), 532-539. doi:DOI: 10.1016/S0140-6736(10)60936-1

Moore, R. D. (2011). Epidemiology of HIV infection in the united states: Implications for linkage to care. *Clinical Infectious Diseases, 52*(suppl 2), S208-S213.

Mugavero, M. J., Lin, H. Y., Allison, J. J., Giordano, T. P., Willig, J. H., Raper, J. L., . . . Davies, S. (2009). Racial disparities in HIV virologic failure: Do missed visits matter? *Journal of Acquired Immune Deficiency Syndromes (1999), 50*(1), 100-108.

Mugavero, M. J., Lin, H. Y., Willig, J. H., Westfall, A. O., Ulett, K. B., Routman, J. S., . . . Allison, J. J. (2009). Missed visits and mortality among patients establishing initial outpatient HIV treatment. *Clinical Infectious Diseases, 48*(2), 248-256.

Mugavero, M. J., Norton, W. E., & Saag, M. S. (2011). Health care system and policy factors influencing engagement in HIV medical care: Piecing together the fragments of a fractured health care delivery system. *Clinical Infectious Diseases, 52*(suppl 2), S238-S246.

Mugavero, M. J. (2008). Improving engagement in HIV care: What can we do? *Topics in HIV Medicine : A Publication of the International AIDS Society, USA, 16*(5), 156-161.

Muhr, T., & Friese, S. (2004). *User's manual for ATLAS. ti 5.0*. Berlin: Scientific Software Development:

Nunn, A., Cornwall, A., Fu, J., Bazerman, L., Loewenthal, H., & Beckwith, C. (2010). Linking HIV-positive jail inmates to treatment, care, and social services after release: Results from a qualitative assessment of the COMPASS program. *Journal of Urban Health, 87(6)*, 1-15.

Park, W. B., Choe, P. G., Kim, S. H., Jo, J. H., Bang, J. H., Kim, H. B., . . . Choe, K. W. (2007). One-year adherence to clinic visits after highly active antiretroviral therapy:

A predictor of clinical progress in HIV patients. *Journal of Internal Medicine, 261*(3), 268-275. doi:10.1111/j.1365-2796.2006.01762.x

Parsons, J. T., Golub, S. A., Rosof, E., & Holder, C. (2007). Motivational interviewing and cognitive-behavioral intervention to improve HIV medication adherence among hazardous drinkers: A randomized controlled trial. *Journal of Acquired Immune Deficiency Syndromes (1999), 46*(4), 443-450.

Rajabiun, S., Mallinson, R., McCoy, K., Coleman, S., Drainoni, M., Rebholz, C., & Holbert, T. (2007). 'Getting me back on track': The role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. *AIDS Patient Care and STDs, 21*, S20-S29. doi:10.1089/apc.2006.005

Rajabiun, S., Rumptz, M. H., Felizzola, J., Frye, A., Relf, M., Yu, G., & Cunningham, W. E. (2008). The impact of acculturation on latinos' perceived barriers to HIV primary care. *Ethnicity & Disease, 18*(4), 403-408.

Rosenstock, I. M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly, 44*(3), 94-127.

Rumptz, M., Tobias, , Rajabiun, , Bradford, , Cabral, , Young, , & Cunningham, W. (2007). Factors associated with engaging socially marginalized HIV-positive persons in primary care. *AIDS Patient Care and STDs, 21*, S30-S39. doi:10.1089/apc.2006.0028

Sohler, N. L., Li, X., & Cunningham, C. O. (2009). Gender disparities in HIV health care utilization among the severely disadvantaged: Can we determine the reasons? *AIDS Patient Care and STDs, 23*(9), 775-783.

Sohler, N. L., Coleman, S. M., Cabral, H., Naar-King, S., Tobias, C., & Cunningham, C. O. (2009). Does self-report data on HIV primary care utilization agree with medical record data for socially marginalized populations in the united states? *AIDS Patient Care and STDs, 23*(10), 837-843.

SPSS Inc. (2008). *SPSS version 17.0*. Chicago, IL, USA:

Tobias, C., Cunningham, W. E., Cunningham, C. O., & Pounds, M. B. (2007). Making the connection: The importance of engagement and retention in HIV medical care. *AIDS Patient Care and STDs, 21*(S1), 3-8.

Tobias, C., Cunningham, , Cabral, H., Cunningham, C., Eldred, , Naar-King, , . . . Drainoni, . (2007). Living with HIV but without medical care: Barriers to engagement. *AIDS Patient Care and STDs, 21*(6), 426-434. doi:10.1089/apc.2006.0138

Torian, L. V., Wiewel, E. W., Liu, K., Sackoff, J. E., & Frieden, T. R. (2008). Risk factors for delayed initiation of medical care after diagnosis of human immunodeficiency virus. *Archives of Internal Medicine, 168*(11), 1181-1187. doi:10.1001/archinte.168.11.1181

Ulett, K. B., Willig, J. H., Lin, H., Routman, J. S., Abroms, S., Allison, J., . . . Mugavero, M. J. (2009). The therapeutic implications of timely linkage and early retention in HIV care. *AIDS Patient Care & STDs, 23*(1), 41-49. doi:10.1089/apc.2008.0132

Uphold, C., & Mkanta, W. (2005). Use of health care services among persons living with HIV infection: State of the science and future directions. *AIDS Patient Care and STDs, 19*(8), 473-485. doi:10.1089/apc.2005.19.473

Wagner, E. H. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice: ECP, 1*(1), 2-4.

Ware, N. C., Wyatt, M. A., & Bangsberg, D. R. (2006). Examining theoretic models of adherence for validity in resource-limited settings: A heuristic approach. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 43*, S18-S22.

Whetten, , Reif, , Lowe, , & Eldred, . (2004). Gender differences in knowledge and perceptions of HIV resources among individuals living with HIV in the southeast. *Southern Medical Journal, 97*(4), 342-349.

Zaller, N. D., Fu, J. J., Nunn, A., & Beckwith, C. G. (2011). Linkage to care for HIV-infected heterosexual men in the united states. *Clinical Infectious Diseases, 52* (suppl 2), S223-S230.

# Appendix A.

(Participant Consent & HIPPA Authorization Forms)

**Montefiore Medical Center**
**Albert Einstein College of Medicine of Yeshiva University**

**Individual's Informed Consent to**
**Participate as a Subject in Clinical Research**

TITLE OF STUDY: **Engagement in HIV Care: Identifying the core factors underlying adherence to care-utilization recommendations for inner-city people living with HVI/AIDS**

PRINCIPAL INVESTIGATOR: Chinazo Cunningham PHONE NO.: 718-944-3860
OFFICIAL ADDRESS: 3514 DeKalb Ave. IRB PROTOCOL NO.: 08-12-414

By signing this form you have voluntarily agreed to participate as a participant in the research study referenced above. After reading and listening to an explanation of the following information, you should ask all the questions you want. You will be given a copy of this form whether or not you agree to participate in the study.

**INTRODUCTION:**

You are being asked to participate in a qualitative study affiliated with Montefiore Medical Center examining factors related to your ability to access and maintain HIV-related medical care across different life situations.

**STUDY SPECIFICS**

**1. PURPOSE:**

Our research team is conducting a study to learn more about the process of engagement in HIV medical care. Specifically we are interested in your experiences with your HIV-related care, what makes it easier or more challenging to meet medical appointments and tests across different life situations.

**2. PROCEDURES:**

If you decide to participate, you will be asked to participate in an interview that lasts about 45-60 minutes, which will be audiotaped. You will be asked questions about your background, your experience and attitudes about your HIV medical care in general and about times that making your regular medical appointments may have been more difficult or less important than other times. The interview will be administered by a trained interviewer, who is not associated with any of your HIV care or service providers. About 20 people will be asked to be in the study.

**AUDIO AND/OR VIDEO TAPING**: With your permission we will audiotape the interview so that it can be typed up and analyzed. To maintain your anonymity, you will be asked to choose a pseudonym or "fake name" which will be used during the interview.

**3. RISKS:**

The possible risk to you that may come from your participating in this study includes talking about sensitive matters that may cause some emotional stress.

**4. BENEFITS**:
If you agree to take part in this study, there will not be a direct benefit to you. However, the information learned from this study may benefit other people with the same medical condition in the future. While we will do everything we can to keep this information you share private, there is still a small chance other individuals outside of this study may gain access to information in this study.

**5. RISKS & BENEFITS**:
There may be no direct benefit to you for participating in the study. Although some people find comfort in talking about their experiences, it is possible that you may feel uncomfortable in discussing different life experiences related to your HIV or medical care. You are free not to answer any questions you are not comfortable with.

**6. ALTERNATIVES**:
You may choose not to participate in this study. HIV treatment at Montefiore's clinic or another HIV treatment program is available to you regardless of whether or not you choose to participate in this study.

*ADDITIONAL CONSIDERATIONS*

**PAYMENTS TO SUBJECTS**:
For your participation, you will receive $15 for the interview you complete.

**CONFIDENTIALITY**
We will do everything possible to keep the information you share with us private. Your real name will not be used on this interview. Instead, we will use a study ID number and a pseudonym (fake name).
Any papers with your name on them (like this consent form) will be kept in a locked file cabinet away from where we keep the audiotapes and transcribed interviews. Information that is entered into a computer will be protected by a password. Only those staff directly involved in the study will know the password.

You will not be identified in any written or verbal reports with the following possible exceptions. Research personnel authorized by the study supervisor will have access to these records. The Montefiore Medical Center Institutional Review Board (IRB) may also inspect your records.

Finally, if we see or are told that a child is being abused or neglected or that there is a risk of harm to yourself or others, we will disclose this information to the proper authorities.

We cannot do this study without your permission to use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

The use of your information has no time limit. You can cancel your permission to use and disclose your information at any time by calling the Montefiore Medical Center IRB at 718-798-0406 or by sending a letter to the people listed at the end of this form.

**WITHDRAWAL**:
Your participation in this study is voluntary. You may be a participant in it only if you wish, and you may withdraw from the study at any time. Your treatment by doctors and staff at the

institution(s) involved in this study, now and in the future, will not be affected in any way if you refuse to participate or if you enter the study and withdraw later. You can withdraw from the study at any time by calling the study Principal Investigator, Chinazo Cunningham, MD at (718) 944-3860 or by sending a letter to her at 111 East 210th Street, Bronx, NY 10467

**WHOM TO CONTACT FOR QUESTIONS:**

You can call the supervisor of this research study if:

- You have any questions related to this research project.
- You have any questions about your rights as a research participant.
- You believe you have any injury related to this research study.

Chinazo Cunningham, MD
Montefiore Medical Center
111 East 210th Street, Bronx, NY 10467
Phone: 718 944-3860
Fax: 718.944.3841
E-mail: ccunning@montefiore.org

If you have questions about your rights as a person in the evaluation, please call the Institutional Review Board (IRB) Offices. You may call the IRB of the Montefiore Medical Center Institutional Review Board at (718) 798-0406, Monday through Friday between 9 AM and 5 PM.

Signatures

_____
Name of Participant

_____ _____
Signature of Participant Date

_____
Name of the person conducting the informed consent process

_____ _____
Signature of the person conducting the informed consent process Date

***MONTEFIORE MEDICAL CENTER*** ***YESHIVA UNIVERSITY***
***AUTHORIZATION TO USE OR DISCLOSE PROTECTED HEALTH INFORMATION FOR A RESEARCH STUDY***

You have agreed to participate in the research study titled:

**Engagement in HIV Care: Identifying the core factors underlying adherence to care-utilization recommendations for inner-city people living with HVI/AIDS**

AECOM CCI #: _____ MMC IRB#: 08-12-414

Principal Investigator Name: Chinazo O. Cunningham, MD

You authorize use or disclosure of the information described below.

| |
|---|
| **The information may be disclosed, as applicable, by:**<br>▪ The research team (investigators, nurses, data managers, etc.)<br>▪ Montefiore Medical Center<br>▪ Albert Einstein College of Medicine (Yeshiva University)<br>▪ University of Connecticut, Storrs |
| **The information may be disclosed, as applicable, to:**<br>▪ Montefiore Medical Center<br>▪ Albert Einstein College of Medicine (Yeshiva University)<br>▪ The sponsor(s) of this research and any company with which the sponsor has contracted to oversee the research<br>▪ U.S. Food and Drug Administration, the U.S. Office of Human Research Protection, other federal agencies involved with research<br>▪ University of Connecticut, Storrs |
| **The following information is to be disclosed:**<br>The specific health information about you to be used or disclosed in the research includes all personally identifiable health information concerning you collected or generated as a result of this research. The purpose of the use and/or disclosure of Protected Health Information is to be able to use the information collected about you in the results of the research. |
| **Right to Revoke:** You have the right to revoke (or cancel) this authorization at any time. If you revoke this authorization, you must do so in writing to the Principal Investigator at the address shown on the first page of the research consent form. The revocation will not apply to information that has already been disclosed based on this authorization. |
| **Expiration:** This Authorization does not have an automatic end date. |
| **Redisclosure:** Your information may be re-disclosed by the organization that receives it, and the information may no longer be protected by HIPAA rules. Please refer to the Confidentiality Section of your Research Subject and Information Consent Form for additional information |

| | | |
|---|---|---|
| regarding confidentiality outside the Research Study. | | |
| **Other Rights:** Authorizing the disclosure of this health information is voluntary. You can refuse to sign this authorization. You do not need to sign this form to assure treatment. However, since this authorization is needed for participation in a research study, your enrollment in the research study will be denied. You will receive a copy of this signed form. | | |
| | | |
| **Signature of Research Participant/Authorized Representative** | **Date** | **Printed Name of Individual Signing Form** |
| **Printed Name of Research Participant (If different from the individual signing the form.)** | | ***Relationship of Individual Signing Form*** |

## Appendix B.

(Eligibility Screener)

**PARTICIPANT #:_____** **DATE: ____/_____/_____**

## I. INTRODUCTION

*Thank you for your interest in our project, in this study we are interested in factors related to you receiving HIV-related services today, and different experiences you may have had related to your ability to make it to regular HIV-related medical appointments.*

*The investigators of this study work with Montefiore Medical Center and the University of Connecticut. Participating in this project would involve answering a series of brief questions about your back ground and telling us a bit more about your experiences receiving your HIV medical care. Your answers will NOT be directly shared with any of your providers and would not affect the quality of care you receive at CHCC or any Montefiore clinic either positively or negatively. Your name will not be on any of your responses; instead, we will use a pseudonym or "fake name" during the interview and will label your responses with unique ID number to protect your confidentiality.*

*The interviews are conducted in English and take approximately 45-60 minutes of your time, depending on how much you have to say, and will be audio taped so that we can refer to your exact words instead of our interpretation of your words, again your name will never be associated with the audiotape or any of your responses, and you do not have to answer any questions you don't want to. You would be compensated $15.00 for your time to complete the interview. Does this sound like something you would be interested in doing today?*

**If no:** *I understand, thank you for your time. Have a good day.*

**If yes**: *Wonderful, I just have a few quick questions to ask you to be sure this study is a good fit for you.*

## II. ELIGIBILITY QUESTIONS

1. **How old are you?**
   - [must be 18 years of age or older]
2. **When were you first diagnosed as HIV-positive?**
   - [must at least 24 months prior to today's date]
3. **After you were first diagnosed as HIV-positive, when did you first see a doctor for your HIV?**
   - [must at least 24 months prior to today's date]
4. **In the past year have you gone a period of six months or more without seeing a doctor for your HIV, unless advised by your doctor?**
   - [recruit equal number of participants who answer either Yes or No]
5. **Are you currently receiving HIV care services from Drs. Cunningham, Mund, Fox or Biel? Or were you escorted to CHCC by a CityWide employee for HIV care services?**
   - [must answer yes]

## III. ELIGIBILITY DETERMINATION

If participant is (not) eligible, please say:

**Not Eligible:** *Unfortunately, it looks like this study is not a good fit for you, I very much appreciate your interest in learning about our study. I am happy to answer any questions you might still have about the study.*

**Eligible:** *It looks like this study would be a good fit for you, if you are interested and have approximately 45-60 minutes to complete the interview today we would appreciate your participation. I am happy to answer any questions you might have about the study.*

## Appendix C.

(Demographics Measure)

These questions have to do with your background. Your answers will help us to describe the people involved in this project. We are grateful for the information you share with us.

1. What year were you born? _____.
2. What is your racial/ethnic background? *(Please check all that apply.)*
   - ❑ African American or Black
   - ❑ Hispanic American or Latino(a)
   - ❑ White (not Hispanic)
   - ❑ Asian American
   - ❑ American Indian or Alaskan Native
   - ❑ Native Hawaiian or Other Pacific Islander
   - ❑ Other
3. Are you…? *(Please check one.)*
   - ❑ Male
   - ❑ Female
   - ❑ Transgender
   - ❑ Intersexed
4. What is your sexual orientation? *(Please check one.)*
   - ❑ Gay or lesbian
   - ❑ Straight or heterosexual
   - ❑ Bisexual
   - ❑ Unsure / don't know
5. What is the highest level of education you have completed? *(please check one)*
   - ❑ Some high school or less
   - ❑ High school diploma or GED
   - ❑ Some college
   - ❑ College degree (BA, BS)
   - ❑ Some graduate school
   - ❑ Graduate degree (MA, JD, PhD, MD, etc)
6. What statement best describes your employment status? (*please check one*)
   - ❑ Currently unemployed
   - ❑ Employed full-time
   - ❑ Retired
   - ❑ Employed part time
   - ❑ On disability or sick leave

7. What is your family income per year? *(Please check one. If you don't know, please make your best guess.)*
   - ❑ Under $5,000
   - ❑ $5,000 to $10,000
   - ❑ $10,001 to $20,000
   - ❑ $20,001 to $30,000
   - ❑ $30,001 to $50,000
   - ❑ $50,001 to $75,000
   - ❑ Over $75,000

8. How many people are supported by this income, including yourself? *(Please check one.)*
   - ❑ 1 (myself)
   - ❑ 2
   - ❑ 3
   - ❑ 4
   - ❑ 5
   - ❑ 6
   - ❑ 7
   - ❑ 8
   - ❑ 9
   - ❑ 10 or more

9. For how many children or older adults are you the primary care-taker? *(Please check one.)*
   - ❑ 0
   - ❑ 1
   - ❑ 2
   - ❑ 3
   - ❑ 4
   - ❑ 5
   - ❑ 6
   - ❑ More than 6

10. Where are you living right now? *(Please check one.)*
    - ❑ Living in a house, condominium, apartment or room that you rent or own.
    - ❑ Living in a friend's or family member's house or apartment.
    - ❑ Living in a halfway house, assisted living residence, or rehabilitation program.
    - ❑ Living in a homeless shelter.
    - ❑ Living in an abandoned building.
    - ❑ Living on the street.

**HIV Diagnosis and Treatment History**

11. In what year were you diagnosed with HIV?* *(Please check one.)*

| | | | | | |
|---|---|---|---|---|---|
| 1981 | ☐ | 1991 | ☐ | 2001 | ☐ |
| 1982 | ☐ | 1992 | ☐ | 2002 | ☐ |
| 1983 | ☐ | 1993 | ☐ | 2003 | ☐ |
| 1984 | ☐ | 1994 | ☐ | 2004 | ☐ |
| 1985 | ☐ | 1995 | ☐ | 2005 | ☐ |
| 1986 | ☐ | 1996 | ☐ | 2006 | ☐ |
| 1987 | ☐ | 1997 | ☐ | 2007 | ☐ |
| 1988 | ☐ | 1998 | ☐ | 2008 | ☐ |
| 1989 | ☐ | 1999 | ☐ | | |
| 1990 | ☐ | 2000 | ☐ | | |

12. In what year did you start going to a medical clinic to get HIV-care? *(Please check one.)*

| | | | | | |
|---|---|---|---|---|---|
| 1981 | ☐ | 1991 | ☐ | 2001 | ☐ |
| 1982 | ☐ | 1992 | ☐ | 2002 | ☐ |
| 1983 | ☐ | 1993 | ☐ | 2003 | ☐ |
| 1984 | ☐ | 1994 | ☐ | 2004 | ☐ |
| 1985 | ☐ | 1995 | ☐ | 2005 | ☐ |
| 1986 | ☐ | 1996 | ☐ | 2006 | ☐ |
| 1987 | ☐ | 1997 | ☐ | 2007 | ☐ |
| 1988 | ☐ | 1998 | ☐ | 2008 | ☐ |
| 1989 | ☐ | 1999 | ☐ | N/A, I am not in clinical care for HIV | ☐ |
| 1990 | ☐ | 2000 | ☐ | | |

13. In what year did you start taking HIV medications? *(Please check one.)*

| | | | | | |
|---|---|---|---|---|---|
| 1981 | ☐ | 1991 | ☐ | 2001 | ☐ |
| 1982 | ☐ | 1992 | ☐ | 2002 | ☐ |
| 1983 | ☐ | 1993 | ☐ | 2003 | ☐ |
| 1984 | ☐ | 1994 | ☐ | 2004 | ☐ |
| 1985 | ☐ | 1995 | ☐ | 2005 | ☐ |
| 1986 | ☐ | 1996 | ☐ | 2006 | ☐ |
| 1987 | ☐ | 1997 | ☐ | 2007 | ☐ |
| 1988 | ☐ | 1998 | ☐ | 2008 | ☐ |
| 1989 | ☐ | 1999 | ☐ | N/A, I have not been prescribed ARVs | ☐ |
| 1990 | ☐ | 2000 | ☐ | | |

14. How do you think you got HIV? *(Please check all that apply. If you are unsure, please make your best guess.)*
    - ❑ Having sex with a man who had HIV
    - ❑ Having sex with a woman who had HIV
    - ❑ Sharing needles or works
    - ❑ Blood transfusion
    - ❑ Got it at birth

15. In the last year, how often do you come to clinic to get HIV-care (if at all) *(Please check one.)?*
    - ❑ I haven't come in for my HIV-care in the last year
    - ❑ Less than once every 6 months
    - ❑ About once every 6 months
    - ❑ About once every 4-5 months
    - ❑ About once every 2-3 months
    - ❑ At least once a month

16. Have you ever experienced a gap in HIV care of 6 months or more *(Please check one.)*?
    - ❑ Yes, within the past year
    - ❑ Yes, within the past 2 years
    - ❑ Yes, within the past 5 years
    - ❑ Yes, but it was more than 5 years ago
    - ❑ No, I have never had a gap in care of 6 months or more

17. Have you ever had a past or current history of unstable housing since your HIV diagnosis *(Please check one.)*?
    - ❑ Yes, within the past year
    - ❑ Yes, within the past 2 years
    - ❑ Yes, within the past 5 years
    - ❑ Yes, but it was more than 5 years ago
    - ❑ Yes, but it was before my HIV diagnosis
    - ❑ No, I have never had a gap in care of 6 months or more

18. Have you ever had a past or current diagnosis or treatment for mental health (e.g., anxiety, depression, etc.) since your HIV diagnosis *(Please check one.)*?
    - ❑ Yes, within the past year
    - ❑ Yes, within the past 2 years
    - ❑ Yes, within the past 5 years
    - ❑ Yes, but it was more than 5 years ago
    - ❑ Yes, but it was before my HIV diagnosis
    - ❑ No, I have never had a gap in care of 6 months or more

19. Have you ever had a past or current history of substance abuse since your HIV diagnosis with drugs you *did not* inject *(Please check one.)*?
    - ❑ Yes, within the past year
    - ❑ Yes, within the past 2 years
    - ❑ Yes, within the past 5 years
    - ❑ Yes, but it was more than 5 years ago
    - ❑ Yes, but it was before my HIV diagnosis
    - ❑ No, I have never had a gap in care of 6 months or more

20. Have you ever had a past or current history of substance abuse since your HIV diagnosis with drugs you *did* inject *(Please check one.)*?
    - ❑ Yes, within the past year
    - ❑ Yes, within the past 2 years
    - ❑ Yes, within the past 5 years
    - ❑ Yes, but it was more than 5 years ago
    - ❑ Yes, but it was before my HIV diagnosis
    - ❑ No, I have never had a gap in care of 6 months or more

21. Have you ever had a past or current history of incarceration since your HIV diagnosis *(Please check one.)*?
    - ❑ Yes, within the past year
    - ❑ Yes, within the past 2 years
    - ❑ Yes, within the past 5 years
    - ❑ Yes, but it was more than 5 years ago
    - ❑ Yes, but it was before my HIV diagnosis
    - ❑ No, I have never had a gap in care of 6 months or more

22. How far do you travel to clinic? _____

*Please circle the most appropriate response for the following question:*

23. How difficult is it for you to travel to clinic?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| **Very Difficult** | | | | | | **Not at All Difficult** |

24. How difficult is it for you to pay to travel to clinic?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| **Very Difficult** | | | | | | **Not at All Difficult** |

25. How difficult is it for you to pay to come to clinic?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| **Very Difficult** | | | | | | **Not at All Difficult** |

26. How difficult is it for you to get an appointment that fits your schedule?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| **Very Difficult** | | | | | | **Not at All Difficult** |

27. Do you have to arrange for child or adult care when you come to clinic?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| **Very Difficult** | | | | | | **Not at All Difficult** |

- ❑ I do not have to arrange for child or adult care to come to clinic

# Appendix D.

(Patient Semi-structured In-depth Interview Tool)

## I. INTRODUCTION & CARE UTILIZTION HISTORY

*Thank you for agreeing to be part of this study. Our main interest is to understand your experience with your HIV medical care, specifically attending doctor appointments and labs. In this study we want to understand people's experiences with obtaining their HIV medical care. We are equally interested in understanding what works to help you get your medical care, and what can make it more challenging. We hope that from your experiences we may be able to help others who might be in a similar situation.*

*Remember during the interview we will use a pseudonym or "fake name" to help ensure everything you say will remain confidential and if there are questions you don't want to answer, we can skip them. I may also enter some of your answers into the computer or take notes as we are talking, this is just to help me remember main themes in your answers, and to be sure your experiences are fully understood and represented, we will also be audio taping the interview.*

*Do you have any questions before we begin?*

*To start with, I'd like to ask you a few background questions about your HIV and health care history.*

1) **After you were first diagnosed as HIV-positive, how long was it before you were able to see a doctor about your HIV?**
2) **How long have you been receiving your HIV-care at CHCC?**
3) **When was the last time you saw a doctor for your HIV?**
4) **Have you been diagnosed with other conditions that require regular medical monitoring? (e.g., Hepatitis C, diabetes, anxiety, depression)**
    - If yes, what is the condition(s)?
    - Where do you receive care for this condition(s)?
    - How long have you had this diagnosis (es)?

*Because having HIV is only one part of who you are as a person, many people have different life experiences that may take precedence or need more attention than getting into see your doctor or get lab work done for their HIV.*

5) **For whatever reason, how many times in the last year have you missed an appointment to see a doctor about your HIV or get labs done?**

If participant has not missed any appointments over the past year, probe: **what types of situations can make it really hard to get in to see your HIV doctor?**

If participant has missed any appointments over the past year, probe: **In general, about how long does it take you to get back in to see your doctor or get labs done once you've missed an appointment?**

6) **In general, about how long does it take you to get back in to see your doctor or get labs done once you have missed an appointment?**

7) **Since the first time you saw a doctor about your HIV, what is the longest period of time you have gone without seeing a doctor for your HIV or getting your HIV labs done?**

*Now I'd like to ask you a little bit more about the times you have experienced gaps in your HIV care.*

8) **Thinking about this period of time, tell me a bit more about what else was happening your life:**
   - work
   - housing
   - substance use
   - mental health (for example, depression)
   - recently incarcerated
   - relationships with family, friends, partners
   - what would you say was the main reason you weren't in care?

9) **At that time, what was your biggest priority?**

10) **On a scale from 1 to 10, with 1 being very important and 10 being not at all important, with all that was going on during this gap in care how important it to you to get in to see you're a doctor for your HIV?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **1** | **0** |
| **Very Important** | | | | | | | | | | **Not at All Important** |

11) **During this time how would you describe your overall health?**

12) **At that time, how difficult would it have been to get in to see a doctor about your HIV given everything else that was going?**

13) **How long ago was you're most recent gap in care, and how long did it last?**

14) **Thinking about your most recent gap in care, tell me a bit more about what else was happening in your life:**
   - work
   - housing
   - substance use
   - mental health (for example, depression)
   - recently incarcerated
   - relationships with family, friends, partners
   - what would you say was the main reason you weren't in care?

15) **At that time, what was your biggest priority?**

**16) On a scale from 1 to 10, with 1 being very important and 10 being not at all important, with all that was going on during this gap in care how important it to you to get in to see you're a doctor for your HIV?**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **1 0** |
| **Very Important** | | | | | | | | | | **Not at All Important** |

**17) During this time how would you describe your overall health?**

**18) At that time, how difficult would it have been to get in to see a doctor about your HIV given everything else that was going?**

**19) What was it that got you back into regular care, or what do you think would need to happen for you to begin coming to care regularly?**

**20) In general, what are 3 things that help you to see your HIV doctor and get your HIV labs done when scheduled?**

**21) In general, what are 3 things that make seeing your HIV doctor and getting your HIV labs done when scheduled more difficult?**

## II. HIV TREATMENT KNOWLEDGE

**22) How often would you say people are recommended to come in for regular care HIV care visits, like viral load checks, in terms of months?**

- Why do you think that is?

**23) What is the point of a regularly scheduled HIV care visit, if you are not feeling sick or having trouble with your medications**

- do you think such visits matter even when you don't feel sick

**24) What would be really important for people to know about HIV or their HIV care that would help them to come into care regularly?**

**25) What do you think makes it seem like regular HIV care is not important to people?**

**26) How often are you supposed to get your labs done?**

- Why do you think that is?

**27) What does your CD4 and viral load tell you?**

## III. HIV TREATMENT MOTIVATION

*Now I'd like to ask you some questions that may relate to your beliefs or feelings about getting HIV care. I want you to consider your own personal beliefs and feelings as well as the*

*types of beliefs and feelings people who are close to you (such as your family or friends) or may share the same culture as you.*

**28) What are the challenges or sacrifices you make to make to get in to see your HIV care provider or get labs done at least once every 3-4 months?**

**29) What encourages you to come in to see your doctor or get labs done regularly, say at least once every 3-4 months?**

**30) What kinds of beliefs or feelings do you have about what it means to see a doctor or receive medical care in general on a regular basis?**

- What kinds of beliefs or feelings do you think those close to you or similar to you have?

**31) What kinds of beliefs or feelings do you have about what it means to receive HIV medical care on an ongoing basis?**

- What kinds of beliefs or feelings do you think those close to you or similar to you have?

**32) Are there other people with HIV who are important to you that stay involved in their regular HIV medical care?**

**33) Are other people who are important to you supportive of your HIV care?**

1. Do they help by giving you rides
2. Do they help by supporting or pressuring you to get to your appointments?
3. Who are these people and how do they support you?

**34) How much pressure do you put on yourself to get into HIV care regularly, like every 3-4 months or so?**

**35) How much pressure do other people put on you to get into HIV care regularly?**

- Who puts that pressure on you?
- What does that pressure look like?
- What do they say or do?

**36) Please tell me a bit about your relationship with your HIV doctor?**

- How well does your doctor explain information related to your HIV treatment?
- How easy is it to ask your doctor questions regarding your treatment

**37) Please describe anytime(s) you ever felt that you were disrespected or discriminated against or did not receive the same level of HIV care because of your:**

- Route of transmission
- Race/ethnicity
- Gender
- Substance use history
- Housing status
- Mental health status
- Sexual orientation

a. **Please describe this experience(s).**

b. **How does this experience make you feel about coming in to an appointment?**
(e.g., anxious, nervous, worried, not want to come back?)

c. **How likely do you think it is that this would happen again?**

d. **Have any of these experiences changed how you view your HIV providers?**
- if so, how?

## IV. HIV TREATMENT BEHAVIOR SKILLS & STRUCTURAL BARRIERS

*Now I'd like to ask you some questions about different skills or strategies that may help some people to see their HIV doctors or get their labs done more regularly.*

**38) What kinds of things do people need to be able to do to keep coming in for regular HIV care visits?**
- reminders
- support
- transportation

**39) What is the most common reason you are unable to make it to our medical care appointments?**

**40) Are there certain skills or strategies you've developed that help you to make it to your care visits?**

**41) Do you use any non-medical services help you meet your regular medical care appointments?**
- (e.g. financial assistance, transportation services, substance abuse support or harm reduction services, mental health services)
- Are there any particular services you think would be helpful for either yourself or others?

**42) How does clinic staff influence you meeting your medical care appointments?**
- Courteous helpful staff
- Difficult staff

**43) Given everything else going on in your life, what kinds of other priorities make getting to a HIV care appointment impossible sometimes?**
- (e.g., child care, housing status, recent history of incarceration)

*We are thinking of developing a program or resource list that could help people meet their regular HIV care appointments. I am very interested in your thoughts on what you think such a program might look like to most helpful to people? What might it need to offer, where would be a good place to locate the program, what would make people want to come to the program or recommend it to others?*

**44. Is there anything else related to your HIV medical care that I didn't ask you that you feel is important for either the doctors, staff, or other people living with HIV to know?**

*Those are all of my questions. I'd like to thank you for taking the time to talk with me. Do you have any questions for me?*

**Interviewer Assessment (to be completed immediately after the interview)**

1. Was the interview completed? If not, why not?
2. Did you feel the interviewee was reliable (i.e. trying to give honest, accurate answers, able to think and remember clearly)?
3. Were there particular questions or portions of the interview that you felt the interviewee did not respond to honestly? If so, which ones?
4. Were there particular questions that the interviewee did not want to respond to? If so which ones?
5. Were there noticeable inconsistencies in responses? If so, please describe?
6. Describe the interviewee's emotional & mental state (if s/he seemed high, got agitated, got upset, etc.)
7. Other comments: