A COMMUNITY BASED PARTICIPATORY APPROACH TO FACILITATE LINKAGE TO CARE FOR PERSONS WITH HIV

By

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To my husband Bob and sons, Cameron, Noah, and Christian
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and complete doctoral level education. My in-laws assumed many child care duties and emergency help when I had to be in several places at once.

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<td>HIV</td>
<td>Human Immunodeficiency Virus, the virus that causes AIDS. The virus is known for destroying cells critical to a person’s immune response (<a href="http://www.cdc.gov/hiv/topics/basic/index.htm">http://www.cdc.gov/hiv/topics/basic/index.htm</a>).</td>
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<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome. The late stages of HIV infection in which a person’s immune response is compromised making them at risk of infections and cancers. A CD4 cell count less than 200 is classified as AIDS (<a href="http://www.cdc.gov/hiv/topics/basic/index.htm">http://www.cdc.gov/hiv/topics/basic/index.htm</a>).</td>
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<tr>
<td>CD4 T-CELL</td>
<td>A type of cell in the body that is important in fighting infection. The HIV virus destroys these cells (<a href="http://www.cdc.gov/hiv/resources/qa/definitions.htm">http://www.cdc.gov/hiv/resources/qa/definitions.htm</a>).</td>
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<td>Ryan White</td>
<td>A teenager who contracted HIV from a blood transfusion and became nationally known when he was expelled from school because of fear of HIV. Congress passed the Ryan White CARE Act months before he died.</td>
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<td>RYAN WHITE CARE ACT</td>
<td>The Comprehensive AIDS Resources Emergency (CARE) Act was passed by Congress in 1990 to assist persons with HIV/AIDS to pay for HIV/AIDS treatment if no other sources of payment are available. It has been reauthorized 4 times (1996, 2000, 2006, 2009) and is now called the Ryan White HIV/AIDS Treatment Extension Act of 2009.</td>
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<tr>
<td>CD4 T-CELL</td>
<td>A type of cell in the body that is important in fighting infection. The HIV virus destroys these cells (<a href="http://www.cdc.gov/hiv/resources/qa/definitions.htm">http://www.cdc.gov/hiv/resources/qa/definitions.htm</a>).</td>
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<td>Ryan White CARE Consortium</td>
<td>A requirement of Part A of the Ryan White Care Act requires each eligible metropolitan area to develop a local planning council that includes representation from providers and consumers of Ryan White services to plan for the provision of services with allocated Federal funds. The name of this council in Area 3/13 is the Ryan White CARE Consortium (RWCC).</td>
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<td>AREA 3/13</td>
<td>A 15-county service area in North Central Florida (Figure 3-4).</td>
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<td>LINKAGE TO CARE</td>
<td>A term used among persons working in the HIV field that refers to the process of a person with HIV not seeking care for their HIV and changing this to when they engage in the healthcare system.</td>
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<td>CBPR</td>
<td>Community Based Participatory Research (CBPR) is an approach to research focusing on the research needs identified through partnerships between the community and the researcher.</td>
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A COMMUNITY BASED PARTICIPATORY APPROACH TO FACILITATE LINKAGE TO CARE FOR PERSONS WITH HIV

By

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Chair: Barbara Lutz
Major: Nursing Sciences

This dissertation research serves as a foundation for building an ongoing program of research devoted to facilitating linkage to care among persons with Human Immunodeficiency Virus (HIV). Approximately 25% of persons testing positive for HIV infection do not access healthcare for HIV infection within 3 months of diagnosis. Increasing the proportion of newly identified persons who are “linked to HIV care” is currently a high priority for HIV prevention. Several barriers in linkage to care have been identified, and the few interventions to improve linkage involve additional healthcare resources that may not be available outside a research setting or in small metropolitan or rural areas. Thus, there is a critical need to identify strategies to improve linkage to care for HIV that do not require additional resources. In completing this research, we used a Community Based Participatory Research (CBPR) approach to partner with community providers, consumers and advocates to identify linkage strategies that would not further strain current limited resources.

The project consisted of two components. First, we established a Community Advisory Board (CAB) for Area 3/13 (a 15-county area in North Central Florida that provides a range of HIV-related services). The CAB provided input on all phases of the
research process. Second, we conducted a qualitative grounded theory study with a sample of 19 persons with HIV who were representative of HIV-infected persons in North Central Florida. To gain understanding of the spectrum of issues involved in seeking HIV care, we recruited participants who had not initiated HIV care, who delayed seeking HIV care, and who initiated HIV care as soon as they were diagnosed. Transcripts were analyzed using grounded theory methods and we developed a theory identifying the provision of support throughout the care trajectory as the central influence on linkage to HIV care. Participants identified when and how support should be provided. Results from this research will be presented to the CAB, and members will then help to identify specific intervention strategies to improve linkage to care. Based on these findings, we will develop and test an intervention for linkage to care.
CHAPTER 1
WHY RESEARCH LINKAGE TO CARE?

Every nine and a half minutes someone in the United States is diagnosed with Human Immunodeficiency Virus (HIV), the virus that causes Acquired Immune Deficiency Syndrome (AIDS) (Centers for Disease Control, n.d.). The virus is transmitted primarily through unprotected sex, needle sharing and perinatal (mother to child) transmission. In the US, approximately 1.1 million persons are living with HIV/AIDS, and 56,300 are newly infected with HIV each year (Centers for Disease Control, 2010; Florida Department of Health, 2013). In Florida, there were 5,608 new cases of HIV diagnosed last year, and there are approximately 117,612 Florida residents living with HIV/AIDS (Florida Department of Health, n.d.). In a 15-county region of North Central Florida, there are almost 2,900 persons living with HIV/AIDS (Florida Department of Health, 2013).

In recent years, as part of prevention efforts for Human Immunodeficiency Virus (HIV), there has been increased focus on helping people become aware of their HIV status through expanded testing efforts. However, not everyone testing positive for HIV seeks medical care for the disease. National estimates indicate approximately 25%-31% of persons with HIV/AIDS fail to seek treatment after initial diagnosis (Gardner, McLees, Steiner, Rio, & Burman, 2011; Marks, Gardner, Craw, & Crepaz, 2010; Torian & Wiewel, 2011). The State of Florida estimates 63% of persons diagnosed with HIV link to HIV care within 90 days. Within the North Central Florida region, approximately 57% link to care within 90 days (Florida Department of Health, 2012). The Centers for Disease Control (CDC) have implemented several strategies to advance HIV prevention, among them to prevent new infections by educating persons diagnosed with
HIV (and their partners) about the importance of care. Thus, to address the CDC strategy, persons with HIV must initiate care. The process of being diagnosed and seeking care for the disease is known among people who work with HIV patients as engagement in HIV care or linkage to care, and empirical evidence supports timely linkage for prevention.

Linkage to care encompasses a continuum of HIV care that ranges from those who are unaware of their HIV status to persons fully engaged in care (Table 1-1) (Health Resources and Services Administration, 2006). Currently, the local standard for linkage to care is a passive referral system in which a newly diagnosed person is told of care options. This leaves the next steps of facilitation for his or her own care up to the person with HIV. For many, this transition is apparently a challenge. The significant number of people newly diagnosed with HIV who are not seeking treatment despite available resources for HIV care (i.e., Ryan White HIV/AIDS Program) has led to a surge of interest in investigating what is happening with this population. While prevention efforts and improved screening methods have fostered identification of more persons with the disease, an important issue remains: how can we encourage or facilitate persons newly diagnosed with HIV/AIDS to seek care that will help them transition into chronic disease management—specifically, management that will decrease spread of the infection?

Improved outcomes from engaging in HIV care can be seen at both individual and population levels. At the individual level, persons engaged in care experience decreased mortality and fewer opportunistic infections. Persons who do not engage in HIV care in the first year after diagnosis have a 2.3 times higher mortality risk than
those who do engage in care (Mugavero et al., 2009). In a recent study of HIV transmission risk behaviors among persons successfully linked to care, researchers found that persons seen at least 3 times for HIV care 6 months after their initial diagnosis were twice as likely to abstain from having unprotected sex with a person whose status was HIV-negative or unknown (Metsch et al., 2008). Furthermore, persons engaged in both care and Highly Active Antiretroviral Therapy (HAART) have a decreased viral load and are less likely to transmit the virus which further aids in prevention strategies (Quinn et al., 2000).

Reducing Health Disparities

Health disparities, such as those in HIV/AIDS, are at the forefront of concern for public health, and reducing these disparities was identified as one of the main goals in the National HIV/AIDS Strategy for the United States (Obama, 2010). While African Americans/Blacks comprise approximately 13% of the total U.S. population, approximately 50% of the HIV/AIDS cases diagnosed between 2005-2008 were African American/Black (Laffoon, Johnson, Cohen, Hu, & Shouse, 2011). Men who have sex with men experience the greatest burden in this population (Laffoon et al., 2011). Among women, African American/Black women account for 65.9% of diagnoses, with most being through heterosexual contact (Laffoon et al., 2011). Latinos are also disproportionately impacted by HIV, accounting for 13.4% of the total population, and 17.8% of HIV diagnoses (Laffoon et al., 2011). To address disparities among those being infected with HIV/AIDS, persons infected with this disease must be linked to care.

Overview of Linkage to Care Barriers

To understand the complexity of linkage to HIV care, Social Ecological Models can help differentiate the levels of influence in the decision to link to HIV care. At the
Intrapersonal level, issues such as lack of knowledge about HIV, care options, attitudes, beliefs, mental health issues, substance abuse, and socioeconomic status can hinder persons with HIV from linking to care (Tobias, Cunningham, Cunningham, & Pounds, 2007). Low socioeconomic status may, for example, hinder linkage, since priorities for basic needs such as food and shelter compete with health care needs (Tobias et al., 2007). Barriers to HIV care at the interpersonal level include stigma and homophobia (Tobias et al., 2007). HIV-related stigma refers to prejudice and discrimination toward people with HIV/AIDS. Homophobia is a dislike or aversion to individuals with a same-gender sexual orientation (homosexual), with which the disease has been associated (Herek, 2009). Community, organizational and policy influences on barriers to HIV linkage to care include integrated surveillance, testing, support services, clinical care services, treatment guidelines, funding, limited workforce, and reimbursement for HIV services (Mugavero, Norton, & Saag, 2011).

Influences on the decision to seek HIV care have been investigated only in large metropolitan areas. Beer and colleagues (Beer, Fagan, Valverde, & Bertolli, 2009) conducted a qualitative analysis of 37 persons from five US cities and found three key themes that influenced persons’ decisions to initiate care: disbelief about HIV status; conceptions of illness and appropriate health care; and negative experiences and distrust of health care. Alfonso, Bermbach, Geller, and Montaner (2006) used a critical incident technique that specifically addressed initiation of antiretroviral therapy and identified four categories of decisional influence: medication factors, mood, lack of support, and outcome expectancies. Both studies identified interpersonal, intrapersonal, and organizational influences on the decision to seek HIV care.
However, given the geographic regions of these studies (5 major cities and Canada), processes of decision making may differ for persons in smaller metropolitan or rural areas. For example, stigma associated with obtaining care and limited numbers of providers in rural areas provide additional challenges for persons diagnosed with HIV who are afraid of their status being discovered.

Current literature identifies several successful strategies for linkage to care including case management, system navigation, outreach models, and integrated health care systems. For example, findings from the Antiretroviral Treatment Access Study (ARTAS), a strengths-based case management intervention, revealed significant increase in linkage to care for the intervention group (Gardner et al., 2005). While these findings show promise, small metropolitan or rural health departments do not have access to the same amount of funding as larger metropolitan regions. Thus, without additional funding, they do not have resources to implement this type of case management strategy. System navigation, an intervention modality that is based on a social work model, assists patients to overcome barriers (structural, financial, and personal), improve mediators (efficacy of treatment, quality of treatment, adherence), and improve outcomes (morbidity, mortality, well-being, and functioning) (Bradford, Coleman, & Cunningham, 2007). This type of model requires assistance from trained personnel to help patients navigate through the system and treatment, but personnel are not always adequately trained for the challenging evaluation process involved (Bradford et al., 2007).

Similar to system navigation, outreach initiatives for linkage to care have also shown some promising results in larger metropolitan areas. In the California Bridge
Project, peer-based staff assisted with linkage to care for approximately one third of HIV-positive persons not currently in care (Molitor et al., 2006; Mugavero et al., 2011). However, this effort was time and resource-intensive. Finally, integrated health care systems such as Kaiser and the Veterans Administration (VA) have adopted system-level improvements to streamline the process from diagnosis to care, but these systems do not have the same types of service fragmentation seen in a majority of US health care systems (Mugavero et al., 2011).

While innovative strategies enhancing linkage to care have shown promise in large metropolitan areas, implementation in smaller targeted metropolitan/rural areas, such as Area 3/13, have met with considerable challenges in funding and feasibility (Davis, 2010; Mugavero et al., 2011). Thus, with our currently available resources, we have not been able to foster linkage to care for persons diagnosed with HIV. Furthermore, national funding shortages for HIV care prevent implementation of linkage to care strategies that require additional personnel (Mugavero et al., 2011). Despite these limits, while working as a public health nurse intern in the Alachua County Health Department, the author was able to envision ways to adapt aspects of current successful interventions (e.g., ARTAS program, see Aims page) for integration with the present system of care. Mkanta and Uphold (2006) recommended researchers explore qualitative approaches to explore HIV-related utilization to provide detailed descriptions of the barriers and facilitators persons with HIV face when seeking care. Using a CBPR approach, key community stakeholders can help identify what works best in the system to determine strategies for change to address linkage to care for people with HIV.
Community-based participatory research (CBPR) is an approach that incorporates involvement of community stakeholders in all stages of the research process and has been successfully used to address issues related to HIV (Berkley-Patton et al., 2010; Corbie-Smith et al., 2010; Rhodes et al., 2010). Through development of an HIV Community Advisory Board (CAB) and through individual interviews with persons with HIV, members of the HIV community have the potential of working together with a research team to identify issues impacting linkage to care for persons with HIV and help propose feasible, affordable, and equitable solutions.

This dissertation study will serve as a foundation for building an ongoing program of research devoted to facilitating linkage to care among persons with HIV that would be effective in non-urban settings in the southeastern US. The goals of this program of research are to promote health for persons with HIV and reduce disparities among special populations. These goals are also in line with the Presidential National HIV/AIDS Strategy (NHAS) (Obama, 2010) to increase access to care and improve health outcomes. While recommendations in the President’s NHAS are clear, funding to support them is sparse (Mugavero et al., 2011), especially given the country’s current economic crisis, The results of this research will help to identify strategies that will improve linkage to care without putting further strain on scarce resources. This research is novel because it is the first, to my knowledge, to employ a CBPR approach to examine the decision-making process of linkage to care among persons with HIV in small metropolitan and rural areas.

**HIV Linkage to Care in Florida – Current Picture**

Current practices in Florida for linkage to care services involve a passive referral made during the delivery of HIV counseling and testing services. A disease
investigation specialist (DIS) makes contact with a newly diagnosed patient for partner identification and notification within a few days of diagnosis. The DIS provides the client with information about HIV services in this visit, and contact between the DIS and HIV client is then terminated. In Florida, HIV is considered super confidential, prohibiting the release of HIV test results to unauthorized persons. Public health officials can only access results if directly participating in diagnosis or care (Florida Statutes, 2011). This has been operationalized as data entering surveillance systems (one way in), but providers and HIV/AIDS prevention staff are not allowed access. This policy prevents any integrated means of tracking clients statewide, although some health departments have attempted hand-tracking newly diagnosed clients through health department medical records.

**Preliminary Work**

In preparation for this dissertation research, I chose to conduct my Masters of Science in Public Health Nursing Internship at the Alachua County Health Department Linkage to Care Program (Summer 2010). In this program, I managed and refined a database of 1400 individuals with HIV in the local health department and made system revisions for better tracking related to linkage to care and adherence to treatment. In collaboration with local and state health department representatives, we were able to locate 249 out of 300 persons diagnosed with HIV who were lost to follow-up. I attended monthly staff meetings to discuss issues related to linkage and met with staff in each department to discuss their roles in linkage to care. I also implemented a gift card program/policy for persons newly diagnosed to receive incentives for treatment while waiting for eligibility to the Ryan White HIV/AIDS Program for HIV care. Finally, I worked with health department staff to implement a follow-up/tracking system for
persons newly diagnosed with HIV. In working with local and state agencies, I learned about the problems existing in small metropolitan and rural areas in linking persons with HIV into care, such as absence of a centralized database for tracking persons entering care, and the stigma associated with receiving HIV care in small communities. Furthermore, in conversation with an HIV-positive community member, I learned that no-cost, simple strategies such as removing HIV-related posters and literature from exam rooms would have helped her feel less stigmatized about seeking care.

Summary

Linkage to care is identified as a priority by the Presidential National HIV/AIDS Strategy (NHAS), the CDC, and the Health Resources and Services Administration (HRSA). Several strategies were identified in the literature that enhanced linkage to care, but these were implemented in largely urban populations with adequate resources. To date, there appears to be no CBPR research that has examined linkage to care issues for persons with HIV in small metropolitan (<500,000) and rural areas. Thus, this dissertation research is innovative in that it provides a foundation that incorporates community involvement, through a CBPR approach, in identifying strategies to improve linkage to care while decreasing strain on scarce resources in small metropolitan and rural areas. Findings from the Community Advisory Board (CAB) and individual interviews with persons with HIV will be used to develop a linkage to care intervention that is sensitive to both barriers faced by persons with HIV and financial limitations of small metropolitan and rural health care providers.
<table>
<thead>
<tr>
<th>Not in Care</th>
<th>In Care</th>
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<tr>
<td>Unaware of HIV status but not in care.</td>
<td>Aware of HIV status but not in care.</td>
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<tr>
<td></td>
<td>Receiving Medical Care but not HIV specific care.</td>
</tr>
<tr>
<td></td>
<td>Entered HIV care but lost to follow-up.</td>
</tr>
<tr>
<td></td>
<td>Receiving HIV care intermittently.</td>
</tr>
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<td></td>
<td>Fully engaged in HIV care.</td>
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Historically, research regarding new HIV care linkage in the quantitative and qualitative literature has been sparse. Research related to linkage has fallen into two main categories – describing barriers to linkage to care, and interventions to enhance linkage to care. Linkage to care represents a transition, or movement, from not having HIV, a chronic, highly stigmatized disease, to learning how to live with and manage the disease. After reviewing recent literature focusing on descriptions and interventions specific to linkage to care and decisions to seek care, I will explore literature specific to transitions in health: public health nursing case management, transitional care models, and patient-centered medical homes, to uncover concepts that may contribute to the decision to link to care. Finally, the disparities in linkage to care and the concepts identified in the literature that may help overcome disparities in HIV care will be addressed.

**Barriers to Linkage to Care**

**Clinical and Epidemiological Review of HIV and Linkage to Care**

The HRSA definition of “in care” is considered a proxy measure of care and focuses on the clinical aspects of care; i.e., CD4 counts, Viral Loads and visits with an HIV provider (Health Resources and Services Administration, 2006). For example, in Florida, “in care” is considered to be in receipt of two viral load/CD4 tests and/or two provider visits within a 6 month period (Davis, 2013). HRSA (2006) also recognizes the fluidity of the definition of care, since people can fall in and out of care for various reasons. To help clarify the concept of HIV care, HRSA created the Engagement in Care Continuum (Health Resources and Services Administration, 2006) (Table 1-1).
Mathematical models support strategies for preventing the spread of HIV that help individuals learn their HIV status through testing and decrease viral load through treatment with antiretroviral therapy (Gardner et al., 2011). Gardner, et al., (2011) estimated that among the total number of people with HIV in the United States (1,106,400), 79% (874,006) know their status. Of those that are aware of their status, only 75% (655,542) link to care and only 19% of all people with HIV (diagnosed and undiagnosed) are adherent with ART and have a suppressed viral load (Gardner et al., 2011). Interventions need to address multiple social and ecological influences to successfully increase the proportion of people with an undetectable viral load.

Several models of care addressing linkage have been discussed in the literature, including case management, navigation, and outreach. Perhaps the most well-known intervention to date addressing linkage to care is the Anti-Retroviral Treatment Access Study (ARTAS), in which investigators found that a brief, strengths-based case management intervention improved linkage to care when compared to standard of care (SOC) (Gardner et al., 2005). While improving linkage proportions from 60% in the SOC arm, to 78% in the intervention arm at 6 months, and from 49% (SOC) to 64% (intervention) at 12 months, there were still many who did not link to care (Gardner et al., 2005). Furthermore, while the researchers in ARTAS felt costs of the intervention were reasonable, from about $600-$1200 per client linked to care (Gardner et al., 2005), costs may be prohibitive in areas without large amounts of HIV funding.

With the fragmentation in HIV services, people newly diagnosed are challenged in understanding where to seek services for HIV. Navigation models are similar to care coordination models and can help assist people newly diagnosed with HIV to access
care resources, develop health communication skills, and enter HIV care (Bradford et al., 2007). HIV navigation models are similar to cancer navigation models in which patients are taught how to find the services they needed from multiple areas (Bradford et al., 2007).

A specialized type of HIV navigation has also emerged in the HIV literature – peer navigation. In peer navigation models, people with HIV have assisted with educating, recruiting, navigating and retaining other people with HIV into care (Hallum-Montes, Morgan, Rovito, Wrisby, & Anastario, 2013). Helping people navigate into the clinical setting has improved linkage for many. However, it has also been met with challenges such as lack of communication between the peers and providers and an increased risk of emotional burnout for the peers (Hallum-Montes et al., 2013).

**Qualitative Review of HIV and Linkage to Care**

Using the social ecological model as a guiding framework for assessment, examination of the process of linkage to care was done through review of the qualitative literature. Using a photovoice methodology of persons with HIV, Rhodes, Hergenrather, Wilkin, and Jolly (2008) identified facilitators of successfully living with HIV. These factors included independence, responsibility, social support, goal setting, personal growth, spirituality, and desire to contribute. They also identified challenges of being HIV positive, including substance use, and fear and ignorance about HIV within the community. Examining the processes of living with HIV in a rural environment, Leasure, Seideman, and Pascucci (2009) identified similar themes: support, managing symptoms, receiving health care, and altering life plans. While both of these studies contribute strongly to the understanding of the context of living with HIV, the persons
participating in the studies were receiving HIV care, and therefore explorations into the decisions related to the initiation of care were not addressed.

Adherence to antiretroviral medications is also of great interest in the HIV/AIDS research community. Adherence, for the purposes of this research, implies that a person has already chosen to initiate care by HRSA standards and has decided either to maintain or not maintain HIV care. In examining the adherence literature to identify issues that may be related to the decision-making process to initiate care, medication side effects and scheduling of medications were important themes (Adamian, Golin, Shain, & DeVellis, 2004; Beusterien, Davis, Flood, Howard, & Jordan, 2008; Kremer, Ironson, & Porr, 2009). Provider communication was also addressed in this literature and reflects organizational influences on outcomes (Adamian, et al., 2004; Beusterien, et al., 2008).

Using a different approach, Lewis, Erlen, and Meyers (2006) examined characteristics of people 100% adherent to HIV medications. Three themes emerged from this analysis: regimen (tailoring treatment to fit lifestyle), self (owning problems and pride), and environment (support and health care provider relationship). Since adherence literature focuses on persons who have already decided to engage in care, it may offer limited insight into the decision to initiate care after diagnosis.

Finally, examination of the literature specifically addressing initiating HIV Care after diagnosis yielded somewhat different results. Beer, Fagan, Valverde, and Bertolli (2009) conducted a qualitative analysis of 37 persons from five U.S. cities and found three key themes that influenced the decisions of people to initiate care: disbelief about HIV status, conceptions of illness and appropriate health care, and negative
experiences and distrust of health care. Utilizing a critical incident technique and specifically addressing the initiation of antiretroviral therapy, Alfonso, Bermbach, Geller, and Montaner (2006) identified four categories of decisional influence: medication factors, mood, lack of support, and outcome expectancies. Both studies identified individual and contextual influences on the decision to seek HIV care. However, it is possible that given the geographic regions of the studies (5 major cities and Canada), the processes of decision-making may differ for persons in north central Florida (specifically Area 3/13).

With the sparseness and inconsistencies of the research literature specific to the decision process to initiate HIV care, the current research is timely and will investigate the process associated with the likelihood to initiate and maintain HIV care. While there is overlap in the conceptual themes identified from case management models, transitional care models, and patient-centered medical home models, evaluation of the relationships among the themes is important in the development of theory. The establishment of theory influencing the decision-making process related to HIV care will foster research towards the development of effective interventions with this hard-to-reach population.

Strategies, including case management, navigation and outreach, have been shown to improve linkage to care. Most of these strategies have been instituted in larger urban areas where adequate funding is available. It is necessary to determine what aspects of these models may be effective in areas where HIV funding is sparse.

**A Review of Interventions for Newly Diagnosed HIV**

This dissertation research, *CBPR to Facilitate Linkage to Care for Persons with HIV*, begins to identify the decision making process of persons newly diagnosed with
HIV. However, in planning a program of research, considerations need to be made about what has been done in the past, what is currently being done, and what could be done with the findings in the current project. The following sections will compare, contrast, and critique several chronic disease management models popular in the literature (public health case management, transitional care, patient-centered medical home) and identify the potential benefits and weaknesses in addressing the health care needs for persons with HIV. Ethical, social, policy, economic and cultural issues relevant to these models will be incorporated throughout the paper, as well as how the models may be used to address health disparities in the HIV population.

**Public Health Case Management Model**

Case management models in HIV care have focused primarily on people who have already engaged in care. Of the transition models of care reviewed for this research, public health case management in the treatment and management of disease and illness has a long and diverse history in both social work and nursing (Zander, 2002). Case management is used extensively in the HIV population and is the only model in this paper that has been tested for efficacy and effectiveness for linkage to HIV care (Craw et al., 2008; L. I. Gardner et al., 2005). While the case management model’s effectiveness has been determined, the costs associated with utilizing this particular case management intervention remains prohibitive for smaller health departments (Davis, 2010). Though it is practiced among a variety of disciplines (nursing, social work, rehabilitation), and in a variety of settings (hospital, community, insurance, and private industry) (Huber, 2002), there is no specific standardized model of case management. Table 2-1 highlights the diversity of many case management models and the focus areas for each model.
Given the number and diversity of case management models found in the literature, the model(s) presented in this dissertation research have been used primarily in HIV care. The HRSA HIV/AIDS Bureau (HAB) outlines the concepts of HIV medical case management as being client centered, focused on linkages, coordination, and continuity of care and services (Health Resources and Services Administration, 2008). The Federal Interagency HIV/AIDS Case Management Work Group identified six core functions that serve as the foundation for HIV case management practice in federally funded programs (U.S. Department of Health and Human Services, 2008). Functions include: client identification, outreach and engagement, assessment, planning, coordination and linkage, monitoring and reassessment, and discharge.

Approaches to HIV case management are determined by the agency and program goals. Agencies can choose from several models including: gatekeeper, generalist, intensive, strengths-based, broker, and assertive community treatment (U.S. Department of Health and Human Services, 2008). Variance of the models among agencies and programs include: duration, intensity, focus, resource responsibility, availability, location of services, and staffing patterns (Morse, 1999). The variability of case management has the advantage of adaptability to resources, needs, and goals of the target population.

However, different models, educational requirements and methods used by each model within an agency have led to confusion about the concept of case management and whether it is a profession, method, or a group of activities (U.S. Department of Health and Human Services, 2008). This confusion is also experienced by the HIV client in terms of which case manager is in charge of the different services (U.S.
Some HIV clients may have 5-6 different case managers and there is a significant lack of communication between case managers due to fragmentation in service delivery (U.S. Department of Health and Human Services, 2008).

A number of ethical, social, policy, and economic, issues are associated with case management interventions for linkage to care. Each type of case manager has a specific code of ethics, which vary depending upon departmental and public health regulations, state and Federal laws protecting health information, and goals of the agency for case management services. For example, circumstances such as poverty, geographic location, transportation, and child care can create challenges for clients needing to enroll in multiple case management services. Furthermore, clients can become confused or annoyed by the need for repetitive assessments for each case management agency, possibly contributing to a failure to seek care (U.S. Department of Health and Human Services, 2008).

Limited funding creates competition for scarce resources, and case management agencies may discourage collaboration as they try to win contracts. Categorical funding also prohibits collaboration and coordination because agencies are not able to pool resources to streamline care. While Federal guidelines allow for flexibility, an absence of a consensus has contributed to the fragmentation and oversight in some services. Caseloads and tensions between competing case managers further contribute to fragmentation (U.S. Department of Health and Human Services, 2008).

In short, case management interventions are beneficial for people with HIV but clients do not always understand the scope of practice of their different case managers.
Limited funding, competition, and multiple guidelines further complicates the issue making it difficult for client to navigate the system and receive the unified care they need.

**Transitional Care Models**

Coleman and Berenson (2004) define transitional care as “a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or levels of care…” (p.533). The authors cite evidence that patient care is compromised during transitions. The idea of transitional care has become popular in recent years. Through randomized clinical trials, transitional care has generated evidence that help support its incorporation into healthcare practice and the Affordable Care Act of 2010 (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011; Naylor & Sochalski, 2010).

In the development of their transitional care model, Brooten and Naylor were influenced by the quality of care framework outlined by Doessel and Marshall (1985) which focused on three variables: outcomes, costs, and satisfaction (Brooten et al., 2002). With outcomes and costs defined as the endpoint in the model, the authors developed an intervention centered on the concepts of comprehensive discharge planning (patient readiness, environmental adequacy, and coordination of discharge), and home follow up (assessment, monitoring, direct care, environmental assessment, support assessment, referral to community resources, teaching and counseling). To carry out both parts of the intervention, an advanced practice registered nurse was chosen to ensure quality of care delivery and attention to costs (Brooten et al., 2002). The model has been repeatedly tested and refined with populations throughout the
lifespan; however it focuses specifically on the transition from hospital (acute care setting) to home.

Studies identified in a systematic review of transitional care identified coaching, comprehensive discharge management, follow up, and Tele-health as effective interventions to address transitional care (Naylor et al., 2011). Another transitional care model, delivered by a nurse transitions coach, added the concepts of a dynamic patient-centered health record and empowerment to concepts identified from the Naylor model (Parry, Coleman, Smith, Frank, & Kramer, 2003).

The delivery of transitional care models for persons newly diagnosed with HIV/AIDS may be difficult to implement. Twenty-one studies, recently presented in a systematic review of transitional care, were implemented in acute care settings; 18 with a nurse delivering the intervention (Naylor et al., 2011). Research appears sparse concerning the effectiveness of transitional care interventions initiated in community settings, and delivered by nurses. Furthermore, cost constraints in public health make hiring registered nurses (or advanced practice registered nurses) to facilitate transitions to care prohibitive. Some concepts underlying transitional care and case management, however, may be appropriate for the HIV population, and will be explored in developing a model in the conclusion of this paper.

Upon closely examining the definition of transitional care, concepts similar to case management emerge – coordination (discharge planning), continuity of care (home care follow up) and patient-centered care (patient-centered health records). Transitional care models may be considered a specialized form of case management with an emphasis on nursing intervention and transition between levels of care. Both
have the advantage of helping patients navigate their way through our current healthcare system. Improved health outcomes and potential overall cost savings may also be an advantage when using both transitional care models and case management models. Limitations of the models include the potential for duplication of services within the hospital (discharge planners), home health nursing or in the community (medical, psychological, and social) (Parry et al., 2003; U.S. Department of Health and Human Services, 2008).

**Patient-Centered Medical Home Model**

Medical home models have also gained popularity in the delivery of health care and management of chronic disease. The concept of the medical home was first introduced by the American Academy of Pediatrics in 1967. In 2004 and 2006, the American Academy of Family Practice and the American College of Physicians developed their own patient-centered care models (American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, & American Osteopathic Association, 2007). The Affordable Care Act of 2010 also includes a provision for Patient-Centered Medical Homes to improve quality, reduce costs, focus on preventive services, and decrease reliance on emergency care (Haney, 2010). Medical homes have the overarching goal of system integration. Concepts central to medical homes include: improved coordination, improved communication, streamlined protocols for health across the continuum, co-location of services, and utilization of health teams (Willenbring, 2005). Furthermore, the concepts of patient-centered care include: incorporating patient’s perceptions of illness and care goals, understanding of the entire patient (beyond the biological aspect) including culture and values, seeking to find a common perception of health issues, focusing on prevention.
and health promotion, and providing continuity between the patient and the healthcare system (Stewart, 2001).

Coordination, continuity, and patient-centered care are core concepts emerging in all of these models. The patient-centered medical home concept is an attempt to reorient the way health care is delivered from a systems approach. The focus is on integration, patients actively participating in health care decisions, and the primary provider taking responsibility for arranging all care services (American Academy of Family Physicians et al., 2007). Case management and transitional care models reflect an attempt to address an individual level within the current healthcare system. In these models, providers target gaps in care in to overcome some of the existing fragmentation.

There are limitations, however, in utilizing a medical home model for HIV care in the current healthcare system. First, if an established patient in a medical home is diagnosed with HIV, the fragmentation of the system does not allow the primary care provider to be aware of the diagnosis, as Florida Statutes prohibit the release of HIV test results without written authorization from the client (Florida Statutes, 2011). Obstacles to incorporating a medical home model include a shortage of HIV providers, ethical concerns if the client does not want his/her provider to be aware of their status, and complications in the way Ryan White care services are currently delivered. Ryan White case management is currently contracted through a single agency, while Medicaid medical HIV case management is contracted through a different agency.

Partnership agreements between agencies need to be negotiated for a medical home model to work, and at present, developing partnerships is challenging since
agencies are competing for provider contracts. While patient-centered medical homes may represent an ideal approach to assist persons newly diagnosed with HIV to transition into care, the concepts central to the model, based on the principles of integrative care, may foster greater HIV care engagement and retention. Moreover, the development and testing of patient-centered medical homes in the current healthcare system may offer future possibilities for HIV medical homes.

**Disparities and Linkage to Care**

Disparities exist in the provision of care for persons with HIV. Factors associated with persons receiving highly active antiretroviral therapy (HAART) for HIV include: race/ethnicity, insurance status, educational background, competing demands, and transmission category (Andersen et al., 2006). Among these factors, include linkage to HIV care may possible explains some of the disparities. African Americans/Blacks and Hispanics often delay entering care at least 3 months and enter treatment with more advanced disease (Andersen et al., 2006). Individuals in these disparate groups, and those living more than a mile from the nearest clinical trial center appear less likely to participate in research for investigational therapy (Andersen et al., 2006). HIV clients in rural areas and clients who saw generalists with few HIV patients were also less likely to receive HAART (Andersen et al., 2006).

Addressing cultural norms and incorporating cultural values and expectations into healthcare practices may help address some of these disparities including linkage to HIV care (Chin, Walters, Cook, & Huang, 2007). Exploring culture in HIV intervention research, Wyatt, Williams, Gupta, and Malebranche (2011), examined 166 HIV intervention prevention studies, and found only 34 addressed some aspect of culture. The Working Group on Changing Health Care Professionals' Behavior (Horner et al.,
2004) suggested the following methods for reducing disparities in care: Providing training in cultural awareness and sensitivity; monitoring processes of care related to disparities; certification of cultural competence training; monitoring of licensing boards for cultural competence training; and promoting workforce diversity. A community model that reduces disparities, from the Bureau of Primary Health Care and the chronic care model, includes an element of care incorporating empowerment, collaboration, cooperative decision-making, integration of clinical systems, healthcare teams, and development of partnerships to address disparities (Baquet, Carter-Pokras, & Bengen-Seltzer, 2004). These concepts are very similar to those in the patient-centered medical home.

Summary

All of the models of care presented in this section deal with similar concepts including: coordination, continuity, advocacy, outcomes, quality, and costs. The differences are the scope of the model, the time in the continuum of wellness and illness in which the patient engages in the model, and the healthcare setting of the model. The patient-centered medical home is the most comprehensive in scope and encompasses many aspects of case management. Transitional care models, a type of case management model, focus primarily on transitions in healthcare settings – specifically from acute care to community or home. Case management models are the most diverse and the most flexible. They have been applied and tested in numerous settings with multiple diseases and conditions, and they have been adapted to streamline care, conserve resources, or enhance service delivery. The concepts central to case management, as it was originally implemented, are aligned with the concepts of both medical homes and transitional care.
Linkage to HIV care remains an important concern among healthcare providers and public health officials. Implementing concepts from case management, transitional care, and the patient-centered medical home will provide integration into the current system of HIV care and may fill a critical gap in healthcare coverage for persons with this disease. Through enhanced cultural training for providers of HIV/AIDS care and services, we can also begin to address disparities that impact populations at risk.
<table>
<thead>
<tr>
<th>Model</th>
<th>Setting</th>
<th>Focus</th>
<th>Key Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Models - Management of health/illness/disease</td>
<td>Nursing Care Management</td>
<td>Hospital</td>
<td>Outcomes management to balance costs, process, and outcomes.</td>
</tr>
<tr>
<td>Community Based Case Management</td>
<td>Community</td>
<td>Clients at high risk from acute care to community</td>
<td>Care across continuum, chronic care, broker</td>
</tr>
<tr>
<td>Broker</td>
<td>Varies</td>
<td>Clients receive the right services in a timely manner</td>
<td>Traditional linkage function and direct service coordination. Often temporary, once services provided, CM relationship terminated.</td>
</tr>
<tr>
<td>Interdisciplinary Team - Full Support</td>
<td>Often inpatient</td>
<td>Team CM Approach. CM coordinates care and provides clinical support and life skills training.</td>
<td>Each member serves the need reflective of their expertise. Relationship between CM and client is ongoing during treatment.</td>
</tr>
<tr>
<td>Comprehensive - Rehabilitation</td>
<td>Long Term Care</td>
<td>Comprehensive Services</td>
<td>Social and emotional support, vocational training, residential services. Assists client in overcoming barriers (medical, social, emotional, physical) that prevent independent functioning in the community.</td>
</tr>
<tr>
<td>Personal Strengths</td>
<td>Varies</td>
<td>Self-management through recognition of personal strengths</td>
<td>Assist people to develop personal potential in accessing available resources. Does not focus on needs based on disease process, but focuses on promoting self-determination in the client. Strong emphasis on client CM relationship.</td>
</tr>
<tr>
<td>Other Healthcare Models</td>
<td></td>
<td>Medically related condition or psychosocial condition</td>
<td>Coordinate, monitor, advise, and advocate for employee</td>
</tr>
<tr>
<td>Rehabilitation-Assertive Community Treatment</td>
<td>Workplace</td>
<td>Interaction between client and workplace</td>
<td></td>
</tr>
<tr>
<td>Occupational Health</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2-1. Continued

<table>
<thead>
<tr>
<th>Model</th>
<th>Setting</th>
<th>Focus</th>
<th>Key Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical (Disease Management)</td>
<td>Insurance Industry</td>
<td>High Cost/High Volume Diseases</td>
<td>Monitor across continuum of disease</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
<td>Brokerage with no provision of direct service</td>
</tr>
<tr>
<td>Gatekeeper (Managed Care and HMO)</td>
<td>Insurance Industry</td>
<td>Emphasis on conservation of benefits</td>
<td>Restrict access and control utilization and subsequently costs. Success depends on available alternatives</td>
</tr>
<tr>
<td>Catastrophic</td>
<td>Varies</td>
<td>Life Care Planning</td>
<td>Diseases such as brain injury or AIDS. Maximize benefits that may be capped.</td>
</tr>
</tbody>
</table>

Adapted from Huber (2002) and Fleisher and Henrickson (2002)
CHAPTER 3
CONCEPTUAL FRAMEWORK AND METHODS

In the first part of this chapter, the perspective and conceptual frameworks used to design this dissertation research and identify the researcher assumptions prior to initiation of the project are reviewed. Next, the methods used to conduct the research, evaluative criteria, and protections of human subjects are evaluated.

A Note about Perspective

Perspective is our interpretation of the world around us. It helps people make sense of the world, understand phenomena and describe reality. Furthermore, when trying to understand and describe reality, we cannot isolate our views into one single perspective, and instead must use many perspectives to interpret and describe a phenomena of interest (Charon, 2010). Perspective is important in studying linkage to care because while some aspects of linkage to care can be measured, these measurements may not tell you how someone will act, respond, or construct meaning in a situation. Constructivists consider reality as socially constructed, and suggest that science can never be fully objective as individuals are constantly negotiating the interplay between objectivity and socially construction (Morse et al., 2009).

Conceptual Frameworks

The theoretical underpinnings of this research are based on social ecological theory and symbolic interactionism utilizing a Community Based Participatory Research (CBPR) approach. Social ecological models (SEM) address multiple determinants of health and provide a conceptual framework for investigating linkage to care (Committee on Educating Public Health Professionals for the 21st Century & Institute of Medicine, 2003). In this study, qualitative, constructivist grounded theory methods were chosen to
identify broader social (ecological) and personal factors related to linkage to HIV care (Braun & Clarke, 2006). The constructivist grounded theory approach further expands on Social Ecological Models and is used to explore how persons perceive phenomena within a larger social context. It is based on the theoretical perspective of symbolic interactionism in which human beings are active, interact with others, and use their perspective and experiences to define situations from social interactions (Charon, 2010; Richards & Morse, 2007; Strauss, 1987). After describing social ecological models, symbolic interactionism, and constructivist grounded theory, I will summarize how the theoretical foundations are appropriate to use with a CBPR approach to study linkage to care for persons with HIV.

**Social Ecological Models**

The social ecological models can be used to examine populations at any point in the lifespan— and can range from individual behavior, social, family and community networks, living and working conditions—to broad social economic, cultural health and environmental conditions and policies (National Cancer Institute, 2005; Shortell, Weist, Sow, Foster, & Tahir, 2004). There are numerous versions of Social Ecological Models but all have key features that include 4-5 levels of influence on an individual: interpersonal, intrapersonal, organizational/community, and public policy (Committee on Educating Public Health Professionals for the 21st Century & Institute of Medicine, 2003; Glanz, Rimer, & Viswanath, 2008). Endorsed by the Institute of Medicine, social ecological models address multiple determinants of health (Committee on Educating Public Health Professionals for the 21st Century & Institute of Medicine, 2003) and allows for use of smaller, mid-range theory to explain relationships among the broader constructs. Established theory can be employed to explore and test these relationships,
or an interpretive approach may serve to develop a new theory explaining relationships among constructs. Using an ecological model as a framework to analyze factors that influence linkages to HIV care is the first step in identifying areas of possible intervention.

In his ecological model, Urie Bronfenbrenner acknowledged a wide variety of influences on behavior, including personal environment, external influences on environment, and relationships of a person within and to the environment (Bronfenbrenner, 1977). The model in Figure 3-1 portrays Bronfenbrenner’s version of a Social Ecological model and included four nested levels: microsystem, mesosystem, exosystem, and macrosystem. Bronfenbrenner (1977) describes the principal main effects of this system as the interactions between the systems and each of the specific properties of each of the levels (Figure 3-1). The individual lies at the center of the model and the nesting of the levels allows us to see the levels of influence and interaction on the individual. Properties of the microsystem include the physical environment, social roles, and relationships as an influence on the organism (Bronfenbrenner, 1994). Examples of influence at this level would include family, schools, and work.

Bronfenbrenner (1994) describes the mesosystem as an interaction between microsystems, such as work and school, that impact on the developing organism. The exosystem also represents interactions between settings, however, these settings may or may not have a direct impact on the developing organism (Bronfenbrenner, 1994). For example, a parent’s social network may have an indirect influence on the
development of a child. The macrosystem represents the overall characteristics of a
culture and society (Bronfenbrenner, 1994).

While Bronfenbrenner focused on a social ecological model for application in
developmental psychology, others have expanded on this model for use in health
behaviors. Social Ecological Models have been utilized in a wide variety of health
promotion topics including tobacco cessation, diabetes care, injury and violence
prevention, diet, and exercise. Glanz (2008) suggests multiple versions of Social
Ecological Models presented in the literature have four core principles: 1) Influences on
health behavior exist at interpersonal, intrapersonal, organizational, community, and
policy level; 2) Influences interact across these levels; 3) Models should be behavior
specific, and, 4) Multiple level interventions are strongest when they are behavior
specific. McLeroy, Bibeau, Steckler, and Glanz (1988) adapted Bronfenbrenner’s model
specifically for use in health promotion.

An important consideration when utilizing the Social Ecological Models is that at
all levels of intervention, the target of the intervention is the individual (Kok, Gottlieb,
Commers, & Smerecnik, 2008; McLeroy et al., 1988). Another important factor in Social
Ecological Models is the interaction among the levels (Kok et al., 2008). Several
problems are associated with the use of Social Ecological Models. These models are
non-specific in guiding conceptualizations or interventions (McLeroy et al., 1988) and
utilize domains of variables instead of specific variables (Elder et al., 2007). Elder, et al.
(2007) further explained that Social Ecological Models must be adapted to specific
behaviors or health-related problems, since environmental influences differ depending
on the behavior or condition. Incorporation of other theoretical models to explain specific concepts may also be utilized in Social Ecological Models (Elder et al., 2007).

Specific to HIV, social ecological models have been utilized in many prevention programs. Sumartogo (2000) identified specific factors, individual and societal, at each level of influence related to HIV prevention programs. Individual level factors may include knowledge of HIV and risk behaviors, prevention, individual characteristics, and personal vulnerabilities. Macrosystem or societal factors affecting HIV prevention include the socioeconomic status of populations, and societal vulnerabilities such as discrimination, class, race, and gender inequalities.

Several outreach initiatives which were utilized early in the AIDS epidemic to promote prevention measures included the distribution of condoms, bleach kits, and education materials by community workers (Tobias et al., 2007), and interventions at multiple levels – individual, intrapersonal, and community. DiClemente, Salazar, and Crosby (2007) reviewed interventions to prevent HIV in adolescents utilizing an ecological approach, and stressed the importance of multilevel interventions. In a comparative study of urban and rural African American women with HIV/AIDS, which incorporated aspects from Social Cognitive Theory, Theory of Reasoned Action, Health Belief Model, and the Transtheoretical model, investigators found an ecological approach useful in addressing knowledge, attitudes, and behavior dynamics (Williams, Ekundayo, Udezulu, & Omishakin, 2003). Mugavero (2011) recently used a social ecological model to identify barriers for Linkage to HIV Care. While ecological models are beneficial to identify multilevel barriers for linkage to care, more research needs to be done to address this issue.
Symbolic Interactionism

The development of Symbolic Interactionism as a perspective was strongly influenced by pragmatist philosophy and the works of George Herbert Mead (Charon, 2010). Pragmatist philosophy focuses on how humans interpret, define, and actively participate in their environment (Charon, 2010). Mead emphasized that consciousness (or perceived self) is the result of the interaction between a person and the environment with an emphasis on the interaction within the person’s social environment (Coser, 1971).

Mead and Blumer identified two types of social interactions: non-symbolic interaction and symbolic interaction (Coser, 1971). Non-symbolic interaction takes place when humans respond without interpreting the action of another (such as in reflexive action) (Blumer, 1969; Coser, 1971). Symbolic interaction involves a response through interpretation of another’s action, and this interpretation is based on the meaning of that action (Blumer, 1969; Coser, 1971). Charon (2010) identified five central ideas of symbolic interactionism. First, humans are social beings and our interactions in a social system influence our actions. Second, humans think, and therefore action is not only the result of social interactions, but also a result of the interaction within themselves through thought. Third, humans define their environment through the use of symbols. The symbols are a result of the ongoing interaction of the person within a social system. Fourth, the cause of human action is based on that which is currently happening and not what is in the past. While past interactions, and how they were defined (meaning) may influence human action, current action is oriented in the present. And fifth, humans are not passive to the stimuli from their
environment, but are active and can overcome environmental influences (Charon, 2010).

Herbert Blumer identified meaning as a result of the interaction between people (Coser, 1971). There are three central premises to Symbolic Interactionism as defined by Blumer – human action is based on meaning, meaning is defined through social interaction and process, and meaning is modified through an ongoing interpretative and interactive process (Blumer, 1969). Charon (2010) explains how we use symbols (words, objects, and acts) to communicate the interaction between the environment and ourselves.

When someone is diagnosed with HIV, the meaning of that experience is based on the interaction between the provider and client during that experience and the client’s previous interactions in their social system. Their subsequent decision to seek care will be influenced by the meanings that are formed during these interactions. The perspective of Symbolic Interactionism (SI) helps to identify individual and social responses to HIV and through the process of the inquiry into this research, the meaning of the process of linkage to care can be identified.

Grounded Theory

Glaser and Strauss (1967) introduced methods for the discovery of grounded theory, or theory derived from the data in their book *The Discover of Grounded Theory: Strategies for Qualitative research*. The methods introduced in their first book were reflective of their academic backgrounds from the Chicago School of Sociology and Columbia University Department of Sociology. The Chicago School adhered to a pragmatist approach to research, whereas Columbia was well known for a more positivist approach (Charmaz, 2006; Glaser & Strauss, 1967). Glaser and Strauss
introduced the methods of comparative analysis and theoretical sampling in the
formation of grounded theory. Today, multiple versions of Grounded Theory exist, but
core characteristics exist in most versions: 1) simultaneous data collection and analysis;
2) use of coding and categories developed from the data and not predetermined based
on knowledge or experience; 3) development of theory to explain behavior or process;
4) the use of memos or analytic notes to build theory; 5) theoretical sampling of
participants and data to complete the development of theory; 6) initial brief literature
review to sensitize to topic and broad literature review specific to concepts identified in
data; and 7) the constant comparison of the data and developing theory throughout the
analytic process (Glaser & Strauss, 1967) (Charmaz, 2004). Since grounded theory is
suitable in studies where the researcher seeks to understand social processes, it is
appropriate to investigate the decision-making processes of linkage to care for people
with HIV (Charon, 2010; Richards & Morse, 2007).

As grounded theory evolved, Glaser (and followers) took a positivist stance about
grounded theory in which the researcher discovers theory that exists within the data
independent from the researcher (Charmaz, 2006). Strauss and Charmaz took a
constructivist approach, believing the interpretive nature in the generation of theory
could not be overlooked and theory was discovered through shared interpretation of the
data between the researcher and participant (Charmaz, 2006). Charmaz (2006)
explains the interpretive approach of constructivist grounded theory in how and why
participants construct meaning and action. Similar to ecological theory, and how an
organism behaves based on the environment (context), constructivist grounded theory
(based in symbolic interactionism), explores how persons perceive phenomena within
the larger social context (Charmaz, 2006). In this study, I chose a constructivist qualitative grounded theory methodology to develop a theory that identifies broader social (ecological) and personal factors that influence linkage to HIV care and seek the methods through which decisions are made to link to HIV care. Figure 3-2 illustrates relationships between a Social Ecological Model, the generation of grounded theory, and outcomes of linkage to care.

Constructivist grounded theory methodology will assist in the discovery of the nature of the relationships between persons with HIV and their environment, and the decisional processes they use to seek care. An inductive comparative analysis will guide development of theoretical constructs (Charmaz, 2006) and how system factors influence these decisions. Using comparative analysis, substantive theory explaining factors related to linkage to HIV care can be developed. Insights gained from using grounded theory methods in combination with the CBPR approach and Community Advisory Board (CAB) collaborations, will lead toward development of the next phase in this program of research.

**Strengths and Limitations of Using Grounded Theory**

Grounded theory is not suited for the determination of direct causality. Positivist approaches, including the randomized controlled trial, are better suited to determine the effect of an intervention (i.e., medicine or procedure) on outcomes such as morbidity and mortality (Stolberg, Norman, & Trop, 2004). Biomedical models, which have been the dominant theoretical foundation of healthcare research, indicate a causal relationship between disease and pathology. Randomized controlled trials have been the hallmark for testing this causal relationship (Wade & Halligan, 2004). However, as science progresses, many researchers are realizing there may be other influences on
illness which are more challenging to explain with biomedical models (Wade & Halligan, 2004). The CBPR to Facilitate Linkage to Care for Persons with HIV study recognizes that despite recommendations and encouragement from the healthcare system that people receive treatment immediately after diagnosis (the evidenced-based recommendation), there are still large percentages of persons who do not seek care. A causal or biomedical approach to the question is not appropriate.

Grounded Theory, when it was introduced by Glaser and Strauss (1967), began to merge positivist and interpretivist philosophies by upholding a systematic and rigorous approach to the collection of qualitative data and the generation of theory. Green and Britten (Green & Britten, 1998) highlight ways qualitative research can address a different focus of clinical research that cannot be explored with purely quantitative methods including provider’s and patient’s attitudes and beliefs about treatment(s), preferences, and translating research into practice. Using orientations prevalent in qualitative research, e.g. naturalism, interpretation, process, interaction, and relativism, we can begin to address the limitations of RCTs and other quantitative methods (Green & Britten, 1998).

Qualitative research is a method that will inform the evidence base in relation to why and how an intervention works (its effectiveness), and integrate influences from cultural values, beliefs, social, environment, and policy into research (Weiner, Amick, Lund, Lee, & Hoff, 2011). Qualitative methods may be more appropriate for addressing issues such as determining aspects of the community that encourage a more positive outcomes, or having community members identify determinants of health instead of the traditional positivistic needs assessment (Raphael, 2000). Qualitative methods are also
appropriate for explaining study variability and contextualizing results from quantitative methods (Fagan, Bertolli, & McNaghten, 2010; Garland et al., 2011; Gruber et al., 2011; Kempf et al., 2010; Kneipp et al., 2012; Mallinson, Rajabiun, & Coleman, 2007; Petticrew & Roberts, 2003; Prost et al., 2007; Thomas et al., 1999). Qualitative methods, including grounded theory, may be more appropriate for exploring issues such as determining aspects of the community that encourage an outcome, or having community members identify determinants of health instead of a traditional positivistic needs assessment (Raphael, 2000). Using a grounded theory method, it may be possible to determine what aspects of the HIV counseling, testing, and diagnosis process support or do not support linkage to HIV care.

**Community Based Participatory Research**

Community Based Participatory Research (CBPR) is a method of community engagement that involves full collaboration and shared decision-making in all phases of the research process, and builds on existing knowledge, skills and resources known to the community, while addressing health from an ecological perspective (Israel, Schulz, Parker, & Becker, 1998). With a CBPR orientation, the creation of evidence can shift from an intervention delivered to a community (best practices) to an intervention developed by the community (best processes), with attention to the ecological environment influencing the outcome (Trickett et al., 2011). Types of research appropriate for CBPR include: descriptive research to understand determinants of health, research to understand disparities, community assessments, and research to design and improve existing community policy (Israel, Coombe, & McGranaghan, 2009). Research designs appropriate to CBPR are similar to other traditional research designs...
except the design must be acceptable to the community partners and the focus of the research must benefit the community (Israel et al., 2009).

Community Based Participatory Research includes eight key principles (Israel et al., 2009).

1. The community is the unit of identity in the research and members share a common culture, norms, and values.
2. CBPR builds on the strengths and resources within a community to improve the health and quality of life in the community.
3. CBPR promotes an equitable partnership in all phases of the research.
4. CBPR facilitates co-learning and capacity building.
5. CBPR fosters a balance between knowledge generation and action for the benefit of the community.
6. CBPR focuses on the determinants of health from a local perspective within an ecological approach.
7. CBPR disseminates the findings to all partners and involves the partners in the dissemination of the research.
8. CBPR promotes a long term process and a commitment to sustainability.

CBPR is based on the work of Kurt Lewin, who used action research to address social problems, and later work by Paulo Freire, who had communities identify their own problems and create tailored solutions (The Examining Community Institutional Partnerships for Prevention Research Group, 2006). At this time, scientists realized that successful interventions discovered in traditional research methods were still not addressing complex multi-level social issues (i.e. disparities in hypertension control) (The Examining Community Institutional Partnerships for Prevention Research Group, 2006). By using a CBPR approach, community member-researcher partnerships were able to take an approach to the research process that would yield culturally relevant interventions (The Examining Community Institutional Partnerships for Prevention...
Research Group, 2006). Furthermore, feelings of being used for research sometimes exist within a community, and these feelings can impede the research process (i.e. recruitment). The CBPR process helps to overcome these feelings and also helps the community to build trust and respect for the researcher and research process (The Examining Community Institutional Partnerships for Prevention Research Group, 2006).

During preliminary work, I initiated the CBPR process by engaging in conversations and meetings with providers of HIV care, HIV prevention specialists, and consumers of HIV care services. Through these interactions, I learned how stakeholders in the community valued linkage and adherence to care and offered ideas to enhance these areas. As the dissertation proposal began to emerge, community members embraced the idea of a research project that would recognize how HIV was different for people in their community, involve members of the community in the design of a culturally sensitive intervention, and ultimately help members of the community achieve better health outcomes. After the preliminary work in the community, I began to formalize the CBPR process by convening a Community Advisory Board (CAB) for a linkage to care research project for smaller metropolitan and rural areas. In CBPR, community members are considered the experts and focus group discussions are appropriate to elicit their experiences with linkage to care and recommendations to address linkage (Olchansky, 2008). In addition to the focus group during the initial CAB meeting, community partners reviewed preliminary materials (question guides, advertisements, recruitment strategies) for appropriateness and cultural sensitivity. Results from the focus group and review of materials are covered in Chapter 4.
Summary of Conceptual Frameworks

The relationships among the conceptual models from this research are shown in Figure 3-3. As stated in the previous section on Symbolic Interactionism (SI), George Herbert Mead, was heavily influenced by pragmatist philosophy, and later inspired the works of Kurt Lewin. Lewin, whose research also focused on the interaction between environment and person, helped introduce the idea of participatory action research which led to the development of CBPR. Bronfenbrenner, who was inspired by the works of Kurt Lewin, applied the interactive concepts between person and environment to the field of ecology which led to the development of modern social ecological theories.

A constructivist approach and the SEM both provide a combined framework to explore how persons perceive phenomena within a larger social context. These approaches are consistent with CBPR principles whereby reality is constructed upon the interactions and interpretations between the researcher and all involved community participants (Charmaz, 2006; Israel et al., 1998). Social ecological models represent a method to analyze a situation at a specific moment in time, but it is difficult to analyze a process at multiple levels of influence. Symbolic interactionism helps in understanding how decisions and actions are made based on previous and current interactions within a system. A constructivist Grounded Theory method and a CBPR approach will allow me to bridge SEM and SI through inquiry specific to the decision-making process. SI acknowledges the use of symbols to convey meaning in a culture, while the SEM has more of a bio-psychosocial orientation and focuses on the physical organism in the physical and social environment. Both are relevant in examining how a different perspective may evaluate a phenomenon of interest. As a result of these evaluations,
all three frameworks (SEM, SI, CBPR) appealed to me in the design of this dissertation research.

**Researcher Assumptions (Reflexivity)**

Reflexivity is a process of examining the potential biases a researcher can bring to the research process in qualitative analyses (Cohen & Crabtree, 2006). There are several mechanisms that help the researcher develop reflexivity in the research design. First, the researcher needs to include multiple investigators in the process. Second, the researcher will develop a reflexive journal, which aids in determining the personal thoughts and feelings that may influence the decision-making process during the course of the study. Finally, the researcher endeavors to disclose any perspectives, values and beliefs that emerge during the process of the research study (Cohen & Crabtree, 2006).

For the purposes of this doctoral project, other investigators will include members of the student’s doctoral committee who have been chosen due to their expertise in grounded theory methodology and HIV. Also for this proposal, the investigator worked towards equality of treatment for persons with HIV through work, education and prior research endeavors. How these experiences potentially influenced the findings from the research were reviewed and discussed with other members of the research team. In addition, methods of disclosure in manuscripts and publications were evaluated.

I came into the dissertation process with experiences that would influence my thoughts, decisions, directions and interpretation about the data. Exploration of my personal history helped me to recognize whether my methodological decisions and analytical interpretations were based on the data or personal perspectives. In this
section, I will share this history so the reader may draw his or her own conclusions about the decisional process of my research.

I began nursing school in the mid-1990s as a second-degree student. My first degree, psychology, led me to work at an inpatient psychiatry unit. For the first time in my life, I felt excited about what I could do as a profession. Teasing out the reasons for this excitement remains an ongoing process, but I think it comes from my childhood experiences. My mother remarried several times and as I changed schools, I felt like I never fit in (although I realize now this is a normal feeling kids have). For me, however, I went from fitting in at one school, to not fitting in at another. I was the same person and did not understand the social issues at play. This experience helped develop a keen awareness of how people who are perceived of as “different” feel when those around them do not understand or accept who they are. Psychiatric patients are viewed as different by our society and I felt the need to reach out and help. As a result of my experiences, I enrolled in nursing school to become a psychiatric nurse.

During the time between when I graduated with my psychology degree (1990) and undergraduate nursing degree (1996), HIV was in the news a great deal. Ryan White, a teenage hemophiliac who acquired AIDS from a contaminated blood treatment, died; a teen was set on fire because of HIV; AIDS was considered the leading cause of death for African Americans, basketball player Magic Johnson admitted to having HIV; and Olympic diver Greg Louganis admitted his HIV status. Debate ensued over forced disclosure of someone’s HIV/AIDs status (The Kaiser Family Foundation, 2012). In nursing school, we discussed HIV/AIDS and universal precautions. I realized many of my classmates were clearly afraid of caring for someone with HIV, despite the absence
of risk of contracting the disease as long as universal precautions were used. The paranoid reactions many nurses (and other healthcare professionals) displayed towards persons with HIV contributed to the psychosocial stress of the patients. My feelings of helping out a group that was being treated differently surfaced again and I joined forces with several nursing student colleagues to educate ourselves and classmates about HIV. I learned of the interplay between psychosocial issues and HIV (stigma, depression, etc.) and decided to do my honors thesis on the psychosocial issues of HIV-positive African American women. At that time, African American women were disproportionately impacted by the disease, but not seeking care.

I moved to Pittsburgh, started a position in inpatient psychiatry, had children, and began graduate school with the intention of continuing with the research begun in my undergraduate honors thesis. Instructors urged me towards a PhD and seeking grant funding for expansion of the undergraduate thesis. Due to a hectic schedule, I was forced to put my research on hold. Ten years later (winter 2008) I attended a nursing research conference while debating whether I should finish my masters or get a PhD. At the conference, I saw a poster on the topic of my undergraduate thesis and, after talking with the author, sadly realized nothing had changed in the 8-10 years since I had last examined the topic. Four years after seeing the poster, I can now describe these feelings within the epistemology of my profession (public health nursing). Social justice, and equal treatment for all is crucial and persons with HIV are not receiving equal treatment for a multitude of reasons.

I will continue to explore and journal about how my experiences in childhood, college, and professional life have impacted the choices that have led me to a program
of research assisting people newly diagnosed with HIV into care. It is clear that this population is a vulnerable group often treated as different because of their diagnosis. Unfortunately, the paranoid reactions of my classmates 15 years ago are still evident in many health care professions today, with those newly diagnosed referred to hospice or excluded from a medical practice.

When I started this reflexivity statement, I was early in the process or my program of research. How these experiences have impacted my decisions and analysis is yet to be fully discovered. I put forth mechanisms to assist with the subjectivity of my research: inclusion of multiple researchers, a reflexive journal, and disclosure of perspectives, values and beliefs (Cohen & Crabtree, 2006). First, multiple researchers were incorporated into this process through my dissertation committee and members of the University of Florida Health Science Center Qualitative Data Analysis Group. As Glesne (1999) also suggests, I needed to be aware of the inter-subjectivity between my participants and myself. By choosing a Community Based Participatory Research approach, I hope to understand how the research relationship with the participants and community impacted the process. This reflexive journal was incorporated into the analytical process so I could understand the interplay of my feelings, values, and experiences, and the research. Finally, I plan to disclose my perspectives to others in my writings and discussions in order to allow others to understand how it is used in my research and evaluate the integrity of the findings (Glesne, 1999).

**Research Methods**

**Specific Aims**

The primary purposes of this study were to initiate a community partnership with local HIV agencies and persons with HIV, and to identify decision points and factors that
impact the decision to seek HIV-related health care among a spectrum of persons with HIV. The long-term goal of this research program is to prevent the spread of HIV through increasing both early linkage to and retention in HIV care for persons with HIV/AIDS. Early linkage may be a key in decreasing: (a) HIV-related mortality and opportunistic infections at the individual level and (b) transmission risk behaviors and infectiousness at the population level.

Specifically, the aims of this study were to:

1) Create an HIV linkage to a Care Community Advisory Board (CAB) for a 15-county area in North Central Florida.

2) Identify decision points (timing) and factors that influence decisions regarding the likelihood to initiate (i.e., linkage to) HIV care among persons with HIV.

Based on study findings, I plan to collaborate with the CAB to develop a community-based intervention for persons with HIV in future research beyond the dissertation.

**Sampling Plan and Recruitment**

In the state of Florida, geographical regions divide HIV/AIDS services. Area 3/13 is a 15-county network of HIV care providers and consumers in North Central Florida (which includes both small metropolitan and rural areas) (Figure 3-4). The Alachua County Health Department (ACHD) is an Area 3/13 provider of HIV prevention services and case management to persons who have sought care. Additionally, Well Florida Council, a planning group, oversees federally allocated Ryan White funding and conducts meetings with consumers and providers through the Area 3/13 Ryan White CARE Consortium (Area 3/13 RWCC), which determines priority needs for the area. Faculty at the University of Florida, the ACHD, and the RWCC played integral roles in
assisting with identification of a CAB and study participants. I have been building strong ties with the ACHD and RWCC for the past two and a half years. Both of these organizations have strengths in addressing and supporting the needs of the local HIV community while operating on a limited budget, and have identified engagement in HIV care as a priority need (Well Florida Council, 2010). I have also been attending RWCC meetings for over 2 years, I currently serve on the RWCC Board as chair, and completed clinical experiences for an MS in Public Health Nursing with the *Linkage to Care* program at the ACHD to establish collaborative relationships with the community.

Purposeful sampling involves selecting participants for inclusion in the research based on specified characteristics and includes many variations, such as criterion, theoretical, snowball, critical case, etc. (Patton, 2002). For the aims of this research, participants were sampled using purposeful sampling, specifically, convenience and snowball. Convenience sampling targets participants who are available for recruitment and snowball sampling identifies participants from previous participants or people familiar with the research (Patton, 2002). Theoretical sampling involves seeking data specific to development of the emerging theory with the goal of saturating the properties of categories (Charmaz, 2006).

For development of the CAB (Aim 1), CAB members were identified through contacts at the ACHD, Area 3/13 RWCC, and the University of Florida (UF). Members of the CAB included providers of HIV care and services, community-based organizations, and consumers of HIV care and services from Area 3/13. A suitable University of Florida representative was also identified to assist in the CBPR/CAB process (for a total of 8-10 members). The University of Florida member had extensive
experience in both CBPR and HIV, and was able to mentor me as well as contribute expertise to the focus group process. All CAB members were 18 or older. Once a potential member was identified, written informed consent was sought. The consent was carefully reviewed and all questions were answered prior to collection of any study data. Once members were identified and agreed to participate, a convenient time and place to meet was arranged. I met with the seven members of the CAB to discuss issues related to linkage to HIV care and sought recommendations for addressing this issue in Area 3/13. At the end of the CAB meeting, participants not affiliated with the Department of Health or the University were offered a gift card ($25) from a local business to compensate them for time, transportation, and parking.

For the participant interviews (Aim 2), participants from the community who were over 18 and had a diagnosis of HIV were recruited. All interview participants provided written informed consent. Under Florida law, 18 is the age of majority and is, therefore, the usual age at which participants can consent to engage in research. Participants contacted me by phone or email and I described the study for them in detail, allowing them time to ask questions. If they were interested in meeting and reviewing the consent, I scheduled an appointment at a time and place that was convenient, yet offered a private place to conduct interviews. For example, the Alachua County Health Department allowed me to use their case management interview rooms for individual interviews.

I was responsible for all recruitment but enlisted assistance from the CAB and members of the community to facilitate the process (inform potential participants about the study). Recruitment of participants took place through Area 3/13 RWCC, support
groups conducted through Area 3/13 health departments (e.g., Positives Empowering Positives (PEP Club) and Health Street, a local agency affiliated with the university that seeks to identify community members with health issues or concerns and help to connect them with local research projects. To recruit participants from Area 3/13 RWCC, I explained the study and passed out informational flyers at the monthly meetings I already attend. Participants interested in the study either called or emailed me to discuss further. To recruit from HIV support groups (e.g., PEP Club), a member of the group that attends these meetings assisted by inviting me to the meetings to explain the study and distribute informational flyers. One support group shared the flyer with their members, and the members individually selected times for me to come during a lunch and conduct interviews in a private conference room.

For HealthStreet recruitment, I met with their navigator and submitted a copy of my recruitment flyer and consent form. She contacted HealthStreet participants who were HIV positive and had expressed interest in research participation. She briefly explained the study to them, and if participants were interested in hearing more information, she provided me with their contact information. I would then call and describe the study in more detail, answer questions, and set up an appointment to fully review the consent and participate in an interview. For each interview completed by a participant, an incentive of a gift card for $25 was provided to compensate for time, transportation, and parking. Participants completing interviews were asked if they were aware of others interested in the research.

From these initial interviews, theoretical concepts were identified and theoretical sampling was used to identify participants based on emerging concepts or gaps
identified from the ongoing data analysis (Patton, 2002, Charmaz, 2006). For example, I specifically sought people who were not currently receiving care once I realized the initial interviews focused on people who were currently receiving HIV care. Theoretical sampling continued until theoretical saturation occurred, or no new categories emerged from the ongoing analysis of the data (Charmaz, 2006). For example, in later interviews, in the category of support, participants did not identify any other dimensions beyond emotional, cognitive, and tangible. At that point, I concluded theoretical saturation was achieved in that category. Saturation for all categories was reached with a final sample of 20.

Three types of participants were targeted for conducting interviews. Sampling from these diverse groups allowed me to set parameters within the sampling process, given the scope of this research, but still allowed for a more complete picture of the processes these individuals employed in deciding to seek care or not to seek care (Miles & Huberman, 1994).

The first type of research participant consisted of persons who engaged in care immediately after receiving the diagnosis (usually within 6 weeks due to system delays). From this group, I attempted to capture the decision-making process and influencing factors that contributed to seeking immediate care. The next type of participant consisted of persons currently engaged in care but who had a delay in care of 9 months or more. I encouraged them to reflect on the factors influencing them to delay seeking care. The final type of participant consisted of people diagnosed with HIV who had not engaged in HIV care. My close connections within the HIV community, and support
from the local HIV community, enhanced my ability to recruit an adequate number of participants.

However I was limited to people who had engaged in care at some point in the HIV care trajectory. HIV-positive people who had not received any care presented recruitment challenges. Given the parameters of the IRB approved protocol, I did not collect any personal health information prior to a participant signing the consent. Therefore, I was not able to ask about care status until after a participant had enrolled. This limitation prevented me from targeting specific subgroups in the HIV care trajectory.

Eligibility criteria.

**Inclusion Criteria:** Age 18 or older, fluent in English, and have a diagnosis of HIV or AIDS.

**Exclusion Criteria:** None

**Recruitment Procedure (Data Collection)**

**Aim 1 – Community Advisory Board**

In Aim 1, an HIV CAB based using a CBPR approach was established. The CAB was used for collaboration, network building, and promotion of research among (a) persons with HIV, (b) community HIV agencies, (c) local health departments, and (d) the University of Florida Colleges of Nursing and Public Health/Health Professions. Responsibilities of this board were to identify key barriers to linkage to care and potential solutions, provide input on study design and recruitment strategies for study participants, and ensure cultural sensitivity for data collection. At the conclusion of this
research, I will engage the CAB in dissemination of data, and seek guidance for the next phase of this research.

Through the creation of the CAB, I built on the relationships established from my ongoing work in the community. At the first meeting of the CAB, I conducted a focus group to review linkage to care issues for Area 3/13. The outline/procedure for the focus group interview is presented in Appendix C. The CAB focus group lasted approximately 2 hours, and the meeting was recorded and transcribed verbatim.

To begin the focus group dialogue, Community Advisory Board members were presented with a table of known barriers to linkage to care identified in the literature, and then asked how things may be different in this area or small metropolitan and rural areas in North Florida (Figure 3-5). After reviewing and discussing experiences and perspectives regarding HIV Linkage to Care, the CAB reviewed the research procedures (i.e., who should conduct interviews), the participant interview guide (Appendix B) and draft advertisements (Figure 3-6). They discussed alternative approaches and made recommendations, such as altering the advertisement to improve sensitivity to the participants. Specific recommendations are covered in Chapter 4.

Analysis of the focus group data (discussed later) took place prior to data collection with interview participants in order to inform the data collection process for Aim 2.

**Aim 2 – Participant Interviews**

Data collection for this aim of the research project consisted of in-depth interviews with persons with HIV. In qualitative research, data collection with interviews involves an interactive process between the researcher and the participant (Richards & Morse, 2007). A semi-structured, interactive interview format in a private setting was chosen in order to allow the participant to tell his or her story. Clients consenting to
participate in the study scheduled a time to conduct the first interview at a time and place of their convenience.

Before beginning each interview, the consent form was reviewed with participants, with pauses to allow time for questions. If they consented to be in the research, we signed two copies of the consent. One copy was given to the participant, and I then turned on the recorder and began the interview. The first interview lasted approximately one hour. Participants were told they may be contacted for an additional interview which would range from 30-45 minutes. The intended goal of the second interview was to review, clarify, and verify my interpretations of the concepts identified from the initial analysis of data, to show they reflected an accurate representation of the process of HIV linkage to care. However, instead of conducting a second interview, the process of verification took place by discussing earlier study findings at the conclusion of interviews with participants 12-20.

While the constructivist nature of grounded theory does not call for a detailed interview guide, most ethics review boards and Institutional Review Boards require interview guides to ensure adequate protection of subjects (Charmaz, 2006). Examples of questions from the interview guide are as follows: (1) What was it like to find out you had HIV? What thoughts did you have? (2) Tell me about how you decided to seek [or not seek] care once you learned you were HIV positive.

Appendix B provides a sample of questions that were utilized in the interview process, although questions were adapted specifically for each individual interview following the study participant’s lead and as theoretical coding directed. For example, as the conditions of support began to emerge, I questioned participants in more detail
about support – including types of support, who best delivered support, and the timing of support. During the interviews with participants 1-12, in order to probe the perceptions of these participants regarding linkage to care barriers and suggestions for overcoming barriers, I drew a model to visually describe the fragmentation of HIV care between prevention and patient care. Figure 3-7 is a representation of the drawing used during the interviews. In this figure, a wall was placed in the middle with HIV Diagnosis (prevention) on one side and HIV care (patient-care) on the other side. The wall represents the barriers between prevention and patient care. I used this figure to explain the current process of passive linkage as being equivalent to throwing a ball over the wall, with the ball representing the person with HIV. Due to fragmentation between patient care and prevention, the patient care side did not always know the ball was coming and sometimes missed it (i.e., was not aware there was someone in need of care). There could also be a situation where the wall was too high (there were too many barriers) for the prevention person to throw the ball (i.e., the system does not have enough time to help the person navigate the barriers they may face). Using this sketch, I asked each participant to tell me how they could have been helped over the wall (if they delayed care), or what helped them over the wall (if they entered care). I also asked them to think about what others may need to get over the wall. This technique helped facilitate discussion regarding strategies to promote care engagement and to visually orient the participant to the phenomenon of interest.

Questions evolved as a result of ongoing analysis. For example, in early interviews, participants discussed grief and crisis. In later interviews (12-20), I specifically asked participants to explain the grief or crisis experience, what types of
support were needed and when, and their recommendations for intervention at
diagnosis. To facilitate their understanding, I shared early iterations of the draft
versions of the HIV Care Decision Process Model (example Figure 3-8). Towards the
end of each interview, I explained to them that I wanted to share with them a model of
the data I had collected to that point and to examine the model and identify what was
missing, and how it did or did not work to explain their process. This procedure
continued until the model was complete (i.e., participants did not have anything more to
add) and saturation was reached. As an example, from the initial model, participants
modified the initial perspective that once someone entered care, they stayed in care.
Participants noted that the process did not stop after engagement in HIV care. They
pointed out that even if someone was receiving care, they could still experience a
pivotal event that might lead them out of care.

During the interviews and immediately afterwards, I wrote field notes on the
interview guide. Field notes included points for probing during the interview (i.e.,
remember to probe about person they said was just awful), initial thoughts during the
interview (i.e., sounds like grief response) and potential areas of questioning to pursue
in future interviews (i.e., concepts specific to patient-centered care such as
understanding patient context). During the initial coding, I reviewed the field notes and
began to record analytic memos in NVivo10™ (QSR International Pty.Ltd., 2012). All
interviews were digitally recorded and transcribed by a professional transcriptionist.
Transcriptions were spot checked for accuracy and an error rate greater than 5% would
have necessitated re-transcription of the interviews; no transcriptions met these criteria.
Data Analysis

Data analysis began immediately in the CAB focus group and individual interviews, and continued during each interview and afterwards. A qualitative data analysis management program, NVivo 10™ (QSR International Pty.Ltd., 2012) was used to manage transcripts, coding, memos, and literature specific to linkage to care. NVivo 10™ was chosen because of its ability to retrieve and code data and tools to aid in theory building, such as hierarchical coding and modeling (Jones, 2007).

Aim 1 Analysis

Community Advisory Board Focus group transcripts were analyzed using a thematic analysis. Using thematic analysis techniques and coding methods developed by Charmaz (2006), I initially coded segments of data and identified specific codes that were identified in the data (Braun & Clarke, 2006). Constant comparison of codes began in this stage, with all new codes compared to existing codes. Within the iterative process of coding, focused coding assisted in synthesizing initial codes into conceptual categories. Finally, codes were examined for relationships to aid in the emergence of the final themes and model. Peer debriefing with the Health Science Center Qualitative Data Analysis Group assisted the research team in validation of emergent themes. For example, provider knowledge, provider communication, and cultural understanding were categorized under the theme of Interactions with Providers or Health Care System. The themes identified during the thematic analysis helped to sensitize me to the perspectives from area experts regarding linkage to HIV care. Detailed results from the thematic analysis of the CAB focus group are presented in Chapter 4.
Aim 2 Analysis

For the participant interviews, techniques in grounded theory guided the process of analysis and included methods by Glaser & Strauss (1967), Strauss & Corbin (1990), and Dimensional Analysis (Schatzman, 1991). Grounded Theory is an iterative process, and the stages listed do not necessarily occur in order but happen throughout analysis. A visual overview of the analytical procedure used for the analysis in this research is depicted in Figure 3-9.

During the interview, the researcher interprets the answers to the questions and makes decisions about the direction of questioning (Richards & Morse, 2007). Analysis began during the interview with the interaction process between this researcher and the participant. As described earlier, field notes and memos were also written and used throughout the analysis process. After transcriptions were received, interview transcripts were read and all identifying information was removed.

Even though coding and the generation of grounded theory is an iterative process, the process must have an entry point for coding. Given the sparse amount of research and theory related to engaging in HIV care, line-by-line open coding was used to ensure that I remained open to what emerged from the data (Charmaz, 2006) and to develop provisional concepts from the initial codes that were grounded in the data (Strauss, 1987). Open coding aided in sorting and clustering of data into concepts, and memos were created for areas that needed further investigation (Charmaz, 2006). For example, as crisis and support began to appear frequently in early coding, I created a memo of how these may be related (Figure 3-10). Open coding thus helped determine the fit and relevance of the data and aided in removing personal interpretations (Charmaz, 2006).
Next, a process map for each participant in the research was created (Figure 3-11) to understand that person’s comprehension of and experience with the HIV Linkage to Care process. The process diagrams also helped identify concepts from the initial coding and how they related to timing within the HIV Care Trajectory and to the move towards preliminary identification of relationships in the data among the individual participants.

Once the initial codes become saturated, or reached a critical mass, and process maps were complete, I began using dimensional analysis techniques to examine the data for conditions, context, processes, and consequences. To facilitate this process, I created a spreadsheet of each person’s process map (Kools, McCarthy, Dunham, & Robrecht, 1996; Schatzman, 1991). A partial segment of this spreadsheet is presented in Figure 3-12. The spreadsheet allowed a visualization and comparison within and between subjects and aided the process of constant comparison in which coded data is continuously compared, with emerging categories, and with emerging theory.

Similar to axial coding as described by Strauss and Corbin (1990), Dimensional Analysis and the Explanatory Matrix was also used to guide the coding process. Initial concepts (and representative codes and quotes) were printed on card stock and sorted according to an explanatory matrix: conditions, context, processes, or consequences (Kools et al., 1996; Schatzman, 1991). According to Kools, (1996) and Schatzman (Schatzman, 1991) context represents the situation in which the dimensions exist, conditions influence action and interaction of the phenomena or process, processes are influenced by conditions and result in intended or unintended actions or interactions, and consequences are the outcomes of these actions or interactions. The results of this
initial sort are included in Figure 3-13. When using Dimensional Analysis, the analyst examines the data in its totality seeking to discover all that is happening and examines each code with the potential of it providing the most explanatory power of the phenomenon of interest (Schatzman, 1991).

A more formalized card sort was conducted with the University of Florida Qualitative Data Analysis Group after the completion of open coding, process diagramming, and categorization using the Explanatory Matrix for the first 12 interviews. Card sorts for qualitative research can assist the researcher in arranging coded segments of the data into categories and begin the process of moving from initial codes to more abstract conceptualizations (Ryan & Bernard, 2003). The card sort technique helped move analysis into the next phase of the coding process.

As the core categories became saturated, and the categories were examined by later participants using the explanatory matrix, analysis moved toward theoretical coding. For theoretical coding, I re-examined the data specific to emergent categories to help establish dimensions for each category (Charmaz, 2006; Kools et al., 1996; Schatzman, 1991). Theoretical coding helped identify areas in the data that should be explored by theoretical sampling. As these areas were identified, earlier interviews were sampled to explore how the concepts were presented. For example, as the concept of support emerged as a condition with the most explanatory power, I re-examined earlier interviews to understand what support looked like, when it was provided, how it was provided, and the role of support at each stage of the HIV Linkage to Care process. An example of this examination of the process is represented in Figure 3-14.
Four criteria will be used to evaluate the applicability of the developed grounded theory to HIV linkage to care (Strauss & Corbin, 1990). In this study the theory 1) must fit the area of HIV linkage to care, 2) should be understandable by persons with HIV and other members of the CAB, 3) should be general enough that it can be applied to many persons newly diagnosed with HIV (not only those in a certain situation such as substance abuse), and 4) must have enough structure and control for persons using the theory to apply it in everyday situations.

**Integrity and Protection of Human Subjects**

**Evaluation Criteria**

Guba and Lincoln (1989) identified criteria used in constructivist inquiry for use in evaluation of qualitative research to enhance trustworthiness of the data and conclusions: credibility, dependability, confirmability, and transferability. Credibility, similar to internal validity in quantitative research, refers to the truth in findings that is established between participants and the researcher (Guba & Lincoln, 1989). To enhance credibility in this proposal, peer debriefing and member checks were employed. Peer debriefing occurred through the presentation of data and conclusions to the HSC Qualitative Data Analysis Group during all stages of the research process. Member checks with participants (via phone or in person) were conducted after initial coding and categorizing to confirm that the conclusions adequately reflected accuracy of the initial analysis of interview data (Cohen & Crabtree, 2006).

Dependability in qualitative research, similar to reliability in quantitative research, can be achieved when outside reviewers can reach the same conclusions from the research process. This is measured through an inquiry audit (Guba & Lincoln, 1989). To ensure dependability, the investigator will prepare for an audit trail by keeping careful
track of both the content and quality of the data and methodological decisions (Cohen & Crabtree, 2006). Using the same audit trail, I will seek confirmability of the research to ensure all conclusions are reflective of participants (and not the researcher) (Cohen & Crabtree, 2006).

Finally, transferability ensures that the findings from this research will have applicability in other contexts, and this will be ensured by the utilization of thick description. *Thick* (i.e., rich, in-depth) description aims to provide enough detail that conclusions can be transferable (Cohen & Crabtree, 2006) and can be achieved by obtaining detailed narratives from transcriptions of taped interviews and detailed field notes from the researcher (Charmaz, 2006). Thick description will be incorporated in all presentations and publications to enhance transferability. The development of a reflexive journal will aid in determining personal thoughts and feelings that may influence decision-making and findings during the course of the study (Cohen & Crabtree, 2006). I have experience in working toward equality of treatment for persons with HIV through employment, education and prior research, including that with persons who have HIV. It will be necessary to review how these experiences may potentially influence findings from the research, and this will be discussed with members of my committee as well as disclosed in manuscripts and publications.

During the coding process, I met with select participants, advisory board members, faculty advisors, and community advocates to discuss interpretation of the data (member checking). Throughout the research process, from open coding to theoretical development, I reviewed the analysis process and used peer debriefing with the multidisciplinary HSC Qualitative Data Analysis Group to ensure that the codes
being developed were grounded in the data. Led by Dr. Lutz (chair), this group is comprised of expert faculty and graduate students with experience in qualitative methods and backgrounds in public health, nursing, and disability research. The group meets biweekly to review and critique qualitative proposals, analysis, and publications from faculty and student research. I presented my ongoing data analysis and memos (several times throughout the dissertation research process) to this group for feedback and assistance with data analysis. Dr. Lutz and I also meet regularly for feedback and to review ongoing analysis and evaluate theory development.

**Protection of Human Subjects**

**Sources of data**

Data were obtained from participants in the form of voice recordings and demographic data including age, race, ethnicity, gender, and contact information. No tissue, blood, or body fluids were collected. Voice recordings were transcribed verbatim, and no identifying information was included in the transcriptions (de-identified), although the voice recordings themselves are considered identifying information. A UF-approved professional transcription service was employed for transcription of all recorded interviews. All voice recordings will be destroyed six years after the close of the study, per University of Florida policy. Study materials were kept in a locked cabinet in a locked office at all times. The only people allowed to see the raw data received training in the protection of human subjects and privacy and were approved by the University of Florida Institutional Review Board. My dissertation committee, mentors in the Colleges of Nursing, Public Health and Health Professions, College of Medicine, consultants and the Health Science Center Qualitative Data Analysis Workgroup may review de-identified data.
Potential risks

Issues related to HIV/AIDS are sensitive and may be difficult for some persons to discuss.

Aim 1 - Participants in the CAB were not expected to disclose their HIV status or discuss any issues that caused discomfort. Furthermore, engagement in the CAB took time, without pay, from the participants’ schedules. I tried to remain sensitive and respectful of this contribution at all times (i.e., making sure I kept the focus group within the allotted time frame). I reminded CAB members of the importance of complete confidentiality of all discussions at the beginning and end of each session. During the consent process, all participants were duly informed of the potential for other group members to disclose another member’s HIV status outside of the CAB if a participant chooses to reveal his or her HIV-status. A brief training session about the importance of confidentiality was conducted at the beginning of the study and all CAB members were reminded at the beginning and end of sessions to respect the confidentiality of all participants.

Aim 2 – Although the primary risk of study participation was a risk of disclosure of HIV status related to issues of confidentiality, this risk was expected to be minimal according to IRB-01 policy and regulations (University of Florida Institutional Review Board, 2010). Some persons may experience psychological discomfort when discussing issues related to HIV/AIDS and I remained sensitive to this all times. Participants were not required to answer any questions that caused discomfort and they had the option to discontinue their participation at any time if they desired.
Protections against risk

Prior to any study and enrollment procedures, the research was approved by the University of Florida IRB-01 (University of Florida Health Science Center) for both aims in this application.

Risk of Confidentiality – Precautions were taken to ensure all research materials were not available to anyone except the researcher and the committee chair. De-identification of participants’ names or any other identifying information began with the interviews—all participants were assigned a study number that corresponded with their interview. Documents linking participant ID numbers to participant names were kept in a locked file cabinet in a locked office at all times. Participant contact information was kept on a password protected encrypted drive managed by the College of Nursing Information Technology staff. Digital recordings were stored on a digital recorder and transported in a locked case between the place of interview and the computer where they were uploaded to the protected drive. At completion of the upload of the recording, the digital recorder was reformatted to erase the recording from the portable device. Any information in the transcriptions that revealed the identity of the participant was removed. Prior to presenting any data to the UF Health Science Center Qualitative Data Analysis Group, I ensured there was no identifying information contained in the transcripts and no results will ever be reported in a personally identifiable manner. My chair (Dr. Lutz) has extensive experience in the protection of data and helped oversee this process to ensure confidentiality.

Risk of Psychological Distress - Issues related to HIV/AIDS are sensitive and may be difficult or cause psychological discomfort during discussions in CAB sessions and interviews. I remained sensitive to this at all times, and participants were reminded
they were not required to answer any questions that caused discomfort. I have several years’ experience as a psychiatric staff nurse and was able to provide psychosocial care if needed or refer distressed clients to the Crisis Center (in Alachua County Health Department) if deemed necessary.

**Potential benefits of the proposed research to human subjects and others**

There were no direct benefits to participants for participation in this research. However, CAB participants may have become more knowledgeable about issues related to HIV and linkage to care, and may be empowered to work more effectively with persons with HIV/AIDS and to learn about the research process. Interview participants may have gained knowledge about HIV care options and feel encouraged about seeking care. Successful strategies to enhance linkage to care identified from results of this study have the potential to improve outcomes and may eventually be seen at (a) the individual level through decreased mortality and fewer opportunistic infections and (b) the individual and population level through decreased transmission risk behaviors and infectiousness of persons with HIV.

**Importance of the knowledge to be gained**

This research is the first, to our knowledge, to examine the decision-making process of linkage to care among persons in small metropolitan (<500,000) and rural areas who have been diagnosed with HIV and not sought care, who delayed care for over 9 months, and who initiated care immediately after diagnosis. The incorporation of community involvement in identification of barriers to seeking care for HIV, and potential solutions to facilitate linkage to care, is expected to yield important data for informing the development of a future intervention. Implemented and refined in a future study, the intervention is expected to provide benefits at both individual and population levels by
improving linkage to care while being sensitive to both the barriers faced by persons newly diagnosed with HIV and the financial limitations of small metropolitan and rural health care providers.
Figure 3-1. Bronfenbrenner’s Social Ecological Model
<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrapersonal</td>
<td>Characteristics of the individual such as knowledge, attitudes, and behaviors</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Formal and informal social relationships and support systems such as family and friends</td>
</tr>
<tr>
<td>Organizational</td>
<td>Social institutions with organizational characteristics (i.e. workplace)</td>
</tr>
<tr>
<td>Community</td>
<td>Groups to which individuals belong, relationships among organizations and groups, and/or geographical or political community</td>
</tr>
<tr>
<td>Public Policy</td>
<td>Local, state, national laws and policies to protect the health of the community</td>
</tr>
</tbody>
</table>
Figure 3-2. Development of a Linkage to Care Grounded Theory Using a Social Ecological Model
Figure 3-3. The Relationships Among Conceptual Models

Mead
Development of the mind is a social/interactive process

Kurt Lewin
Behavior is a function of person and environment and should be studied in real-life events

Bronfenbrenner
A variety of influences on behavior, including personal environment, external influences on environment, and relationships of a person within and to the environment

Pragmatism
Symbolic Interactionism

Participatory Research
CBPR

Ecological Models
Social Ecological Model
Figure 3-4. Area 3/13
<table>
<thead>
<tr>
<th>System Level Actions</th>
<th>North Central Florida</th>
<th>Community Level Actions</th>
<th>Client Level Actions</th>
<th>HIV Care Trajectory (Adapted from Mugavero, 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unaware of HIV Status</td>
<td>HIV Diagnosis</td>
<td>Linkage to Care</td>
<td>HIV CARE</td>
<td>Unaware of HIV Status</td>
</tr>
<tr>
<td>HIV Testing/Treatment Guidelines, Funding, Workforce, Reimbursement, Surveillance, Service Integration, Clinic Distance, Clinic Culture, Appointment Availability</td>
<td>Private, Public, Ryan White funding for care.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decrease in use tertiary care resulting in overall health care savings.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surveilliance identifies all HIV positive test results for tracking purposes. Separate database compiles all lab notifications of CD4 and HIV viral load lab results. No integration of databases. One way data - goes into surveillance but not out to public health departments for tracking.</td>
<td>Prevention Specialists, community volunteers, (and some health care providers) identify at risk persons and provide counseling and testing services. DIS interviews positive persons.</td>
<td>Seek HIV Test</td>
<td>Obtains Results</td>
<td>Sexual Risk Factors, Substance Abuse, Transportation, Housing, Income, Education</td>
</tr>
<tr>
<td>Decreased transmission, decreased incidence</td>
<td>Neighborhood, Poverty, Education, Social Norms, Stigma, Trust</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV Care Providers (Physicians, Nurses, Case Managers, Pharmacists, Dieticians)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decreased Viral Load, Improved CD4, Fewer Opportunistic Infections</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private, Public, Ryan White funding for care.</td>
<td></td>
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</tr>
<tr>
<td>Figure 3-5. Barriers to Care Model Presented to Community Advisory Board</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
HIV/AIDS Linkage to Care

Study Title: A CBPR Approach to Facilitate Linkage to Care for Persons with HIV – Part 2: Participant Interviews

We are seeking persons with HIV to participate in a research study to explore ways to help persons with HIV into care. The research involves a 1-2 hour interview with a nurse researcher with the possibility of a second 1 hour interview. We are specifically seeking:

- Persons with HIV that engage in HIV care or services or
- Persons with HIV that delayed care for more than 9 months after diagnosis or
- Persons diagnosed with HIV that have never sought care.

You may not participate in this research if you have been incarcerated in the past year or are pregnant.

Participants will receive either a $25 gift card or a gift valued at $25 for transportation and time.

For more information, please contact Christa Cook, principal investigator at 352-275-9565 or christacook@ufl.edu
Figure 3-7. Representation of Drawing used in Select Participant Interviews
Figure 3-8. Early Model Iteration
Figure 3-9. Grounded Theory Analytical Process
Figure 3-10. Example of Early Analytic Memo – Support as a Mediator for Crisis and Outcomes
### Participant #4 – Process Diagram

<table>
<thead>
<tr>
<th>Before Diagnosis</th>
<th>Diagnosis</th>
<th>Immediate Response</th>
<th>Transition</th>
<th>Decision to Initiate Care</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risky Behaviors</td>
<td>Mandatory Testing in Jail</td>
<td>Denial</td>
<td>Went back to streets</td>
<td>Did not know if it had moved from HIV to AIDS</td>
<td>Privacy</td>
</tr>
<tr>
<td>Jail</td>
<td>“Just give me a piece of paper”</td>
<td>Did not want to accept it</td>
<td>No support</td>
<td>Niece pushed her to find out. Said a lady her age should not be in the streets.</td>
<td>Confidential situation (have RN consultant in jail to talk to)</td>
</tr>
<tr>
<td>Drugs</td>
<td>“You got to fend for yourself”</td>
<td>“Didn’t want to face reality”</td>
<td>Kept on doing drugs</td>
<td>Spiritual awakening. realization she had hit bottom.</td>
<td>Help people with all they need at one time</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Trouble”</td>
<td></td>
<td>“I was shame”</td>
<td>“I wasn’t living, I was existing”</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>“I was hurted”</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Cried for a month</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Notes:**
Going from day to day trying to struggle, trying to survive
I trust in God to carry me

Figure 3-11. Example of Process Diagram from Early Coding
<table>
<thead>
<tr>
<th>Age</th>
<th>Circumstances of Infection</th>
<th>Ethnicity</th>
<th>Race</th>
<th>Highest Level Education</th>
<th>Place of Diagnosis</th>
<th>Stigma</th>
<th>Response to Diagnosis</th>
<th>Barriers to Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>45-54</td>
<td>Risky Behaviors and Substance Use</td>
<td>Non Hispanic</td>
<td>Black or African American</td>
<td>High School Diploma</td>
<td>Rehabilitation (Drug)</td>
<td>When, um, me and my physician talked about it, it was like I was scared because I didn't want anything to change. I didn't want to lose my appearance. I didn't want to lose some things. Because then, the whole world would know. Yeah, she got it. Somebody said she did and I wasn't sure. So I was, I was struggling with the image thing of what people think.</td>
<td>Increase Risky Behavior and reluctance to deal or cope with diagnosis.</td>
<td>Not ready to deal. Competing life stressors.</td>
</tr>
</tbody>
</table>

Figure 3-12. Excerpt from Spreadsheet used to compare data within and between participants.
Figure 3-13. Initial Coding Categories and Schatzman’s (1991) Explanatory Matrix
<table>
<thead>
<tr>
<th>Support</th>
<th>Before Diagnosis</th>
<th>At Diagnosis</th>
<th>After Diagnosis</th>
<th>Prior to Care Initiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>- What did it look like?</td>
<td>None</td>
<td>None – Handed Paper</td>
<td>None</td>
<td>Direct</td>
</tr>
<tr>
<td>- When provided?</td>
<td></td>
<td></td>
<td></td>
<td>Direction and concern from niece. Spiritual awakening (God provided support).</td>
</tr>
<tr>
<td>- How was it provided?</td>
<td>Not influential</td>
<td>Not influential</td>
<td>Brief support from mom until death. Afterwards, not influential</td>
<td>Influential</td>
</tr>
<tr>
<td>- Role of support at each stage.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Pivotal Moments |
|---|---|---|
| - People? | Niece | |
| - Life Events? | Spiritual Awakening | |
| - System Initiated? | | |
| - Impact of Others? | Niece | |

| Activation |
|---|---|
| Physical – Niece began, HD promoted Emotional – Interpersonal decision from spiritual awakening |

Figure 3-14. Example of Exploration of Conceptual Ideas in Data
As outlined in Chapter 3, I formed a community advisory board to oversee and advise on the research process. The advisory board met once, and a focus group format was used to help elicit their perspectives on linkage to care. At the beginning of the first meeting and focus group, I reviewed the definition and objectives of CBPR research, asserted my desire to work in partnership with the members of the CAB, and welcomed feedback at all points in the process. I offered suggestions for operating guidelines that included respect for confidentiality, respect for other members of the CAB, shared decision making, identification of common goals and objectives, democratic leadership, and access to data. Responsibilities of the board included sharing perspectives regarding barriers to linkage to care and to offering potential solutions. In addition, the advisory board would provide input on study design and recruitment strategies for study participants, to promote cultural sensitivity for data collection. The focus group format elicited important information regarding each of the tasks set before the CAB and will be reviewed in this chapter. The results of the focus group were analyzed for thematic awareness and not for the generation of grounded theory. The themes presented in the first half of this chapter were a means of synthesizing the data to orient me in regards to the local perceptions of Linkage to HIV Care in Area 3/13. The second half of this chapter presents the CAB recommendations about the methods of the research. Finally, an evaluation of the CBPR process is presented at the end of the chapter.
Demographics

The CAB consisted of seven participants ranging in age from 35-64 and included representatives from the local health department, local planning council, the University of Florida, and consumers of HIV services. The three male and four female representatives included racial representation from the following groups: white, American Indian/Alaska Native, and Black/African American. Table 4-1 summarizes the demographics of the CAB. Several participants had more than 20 years of experience working with persons with HIV, either as advocates or through employment.

Perspectives on Linkage to Care

Members of the focus group acknowledged the concepts identified as barriers from The Linkage to Care Model (Figure 3-6). In their discussions, they identified what they perceived were the key barriers and facilitators regarding linkage to care. Three major themes emerged from the analysis of the focus group: interactions with the health care system, the impact of an HIV diagnosis, and individual circumstances.

Interactions with Providers or Health Care System

Three types of provider issues were raised by the CAB: education, communication, and cultural understanding. Participants identified four types of education present in the linkage process: basic education or health literacy of the client, provider knowledge of pathophysiology, provider knowledge of history of HIV, and provider knowledge about communication. First, basic education (reading and writing), is helpful to understand the information provided by providers for clients. In addition, providers need to understand the basic pathophysiology of HIV and the history of HIV. However, CAB members were most adamant about provider knowledge of communication, or how to discuss issues related to HIV and sexuality. For example:
CAB Member: I think you can add a fourth education, knowledge thing to that in with the practitioners, they may be book smart, they may be smart about the disease, but when it comes to interaction with people, we have had practitioners who do not have bedside manners.

CAB Member 2: And clients are put off by that.

CAB Member: That, and I have to say that is not specific to just HIV. Nor is the lack of ability to take a sexual history and talk straight-faced is restricted to HIV.

Another factor regarding communication and linkage to care focused on how the providers delivered the diagnosis. They felt there were certain ways that the diagnosis could be delivered that would have an impact on the client and the decision to link to care. For example:

CAB Member: Even I’ve heard clients in the old days talk about [name deleted] when [name deleted] used to give results from, the counseling and testing days. And they would say [provider’s name]r saved my life. He told me I have a choice. I can either die or I can keep living. And I mean, you know, something in that there’s that just that linkage person. We didn’t have a very developed, we didn’t have a system back in those days. But still, that person that delivers that message and how they, how that message comes. It’s not just, here is your test results, next.

While the participants considered knowledge of the disease and how to talk to people as important competencies, the concept of cultural understanding and sensitivity was also introduced during the CAB focus group. Participants felt a better understanding of cultural differences was necessary in order to help clients link to care. As noted by one member:

CAB Member: They’re not sensitive to the transgender population. I think there is cultural sensitivity that still needs to be addressed as far as ... I think there is just a lot of cultural issues, gender issues that still need to be addressed that play a big part in a client’s decision to seek care.
In the scientific literature, the concept of cultural competence in HIV care was recently examined to understand how it contributes to racial disparities, receipt of antiretroviral therapy, and suppressed viral load. Investigators found that providers with low cultural competency had more racial disparities in receipt of ARV and suppressed viral load (Saha et al., 2013).

**Impact of Diagnosis**

The impact of a person’s new HIV diagnosis centered on fear of disclosure, stigma, responsibilities to get into care, and needed support. Focus group participants described the impact of an HIV diagnosis as leaving the person in shock and with the perception that everyone would know his or her status. Living in a small community further impacted the fear of disclosure, even if someone was only testing for HIV. For example, a participant discussed a comment made by her son when he was tested:

CAB Member: My son got tested by a community health worker. And his first question to her was “well is this, just, gonna, will my mom get this?” Because I am with a local AIDS organization…I mean that. OK, he’s a little close. He kind of knows something about HIV. But, you know they do, they think that everybody knows. If you are connected in any way, everybody knows.

In addition to the immediate fear of others finding out about their HIV status, newly diagnosed clients are overwhelmed with information and tests. Often they are not able to process all the information that is being delivered at the time of diagnosis. The advisory board described the following situation:

CAB Member: Well, somebody that’s newly diagnosed not only do they have to accept and get over that initial shock of the diagnosis, someone’s telling them you’ve got to get into care, you’ve got to get on meds, you’ve got to do eligibility, you need to see where your insurance will send you, if you don’t have insurance, you’ve got to apply for Medicaid, I mean it’s just –

CAB Member 2: More needles sticks.
Members of the advisory board talked extensively about the support needs of clients newly diagnosed and commented about how for some, these support needs continued into the HIV care environment. Support can have many dimensions: informational, emotional, and tangible (Peterson, Rintamaki, Brashers, Goldsmith, & Neidig, 2012). While the board members stressed an overload of informational support, they felt emotional support was not adequately met.

CAB Member: And that, and that crosses all kinds of cultural groups. Because I think at the core of what you are talking about, in terms of prevention, is about getting emotional needs met. You really hit it right on the heart. It doesn’t matter, rich, poor, gay, straight.

Later in the focus group, emotional support came up again, and this time it was compared to a cancer diagnosis, as a board member talked about how the emotional support he received when he had cancer helped him connect. He explained that with cancer, the emotional support was there for you without having to look, along with other services that were readily explained and available.

CAB Member: Well, that is kind of interesting because the cancer kind of thing was kind of in that mode. It was the first person before you would go in for your treatment of the day or whatever kind of thing, that was a hand hold, before you would go to the treatment center, or the chemo, the lab. And that was an important linkage point and they were, they weren’t - I don’t know if they were full RNs or what, but they were hand holders…Can we get you something? Can we do this for you? Are you comfortable? Is the temperature too warm? Is it too cold? All of those kinds of things affect how you might be affected by the treatment kind of stuff.

Individual Circumstances

Oftentimes, other issues in a person’s life can influence the decision to seek HIV care. Basic needs such as food and shelter may need to be met before someone can consider taking the necessary steps to seek HIV care. As the CAB deliberated on this subject, a member noted the increased challenge when diagnosing someone with HIV
CAB Member: I think that something that interferes, too, is just that people, some people, have this overall life chaos. And I say this a lot - HIV is the least of the problems of our clients. You know they are dealing with basic needs. (background people saying “right”)

CAB Member 2: Necessities …including food, jobs, kids. That kind of stuff. Where are they going to sleep tonight? (someone in background saying, “right”).

CAB Member: So us giving them a diagnosis that requires kind of high level thinking in terms of planning and doing the right things when they are hungry or their kids are hungry. (someone in background saying, “right”)

Views of HIV illness and treatment may impact the decision to seek care.

Several times during the focus group, CAB members compared an HIV diagnosis to a cancer diagnosis. The trajectory of illness for HIV is unique in that people often feel better in the first years after contracting the virus. For example:

CAB Member: I just think it’s much easier for someone to be in denial with HIV than it is with cancer when they might get really ill with cancer three months after their diagnosis. And HIV, we have people that never take drugs, they may have low CD4 counts and high viral loads but they don’t feel ill...

CAB Member: We’re telling them that they are sick.

**Summary of Community Perspectives on Linkage**

Community perspectives regarding linkage to care suggest a myriad of influences on the decision to seek care. The complexity of personal, social, cultural, and system factors impacting linkage to care reflected other research in this area. For example, Beer and colleagues (Beer et al., 2009) conducted a qualitative analysis of 37 persons from five major US cities and found three key themes that influenced their decisions to initiate care: **disbelief** about HIV status; **conceptions** about illness and appropriate health care; and **negative experiences** and distrust of health care – closely
related to the themes about the impact of diagnosis and individual circumstances which are represented in Figure 4-1.

Provider system interactions have also been highlighted in previous research regarding linkage to care. Gilman (2012) examined successful linkage to care programs and noted a lack of adequate training among clinicians as a challenge for linkage. Furthermore, Gilman (2012) reported staff perceptions of challenges to linkage included a patient’s lack of knowledge about HIV, stigma, and cultural issues. In our data, cultural barriers and lack of knowledge were also reported. However, the CAB focus group stressed a lack of knowledge and cultural barriers among providers rather than among patients. HIV models of care tested in the literature deal with concepts including: coordination, continuity, advocacy, outcomes, quality, and costs. Most successful Linkage to Care models and concepts are initiated after an HIV diagnosis (Bradford et al., 2007; Gardner et al., 2005). However, from the analysis of the CAB focus group data, some barriers to HIV care can exist before someone is diagnosed (individual circumstances). It is possible that we should begin the idea of engagement in HIV care when the client is seeks an HIV test.

In summary, the CAB confirmed the Linkage to Care Model (Figure 3-5) but also highlighted specific areas to target. Future research should explore interventions to address barriers to linkage at testing. As noted in the findings, an HIV diagnosis can be traumatic for many given the stigma associated with the disease. Client responses to the diagnosis are sometimes equated to a traumatic event with increases in depression, denial, substance use, risky behaviors, shame, and suicidal ideation (Stevens & Doerr, 1997; Stevens & Hildebrandt, 2006). Consideration of when care begins for the newly
diagnosed patient to ensure continuity through the entire course of illness may be necessary.

**CAB Study Method Recommendations**

**Sample and Recruitment**

I shared possible recruitment strategies with the advisory board, including where to recruit, who to recruit, and methods of increasing participation. Board members were initially concerned that the planned recruitment locations would only gather information from the public health care sector and the private sector would not be adequately represented. They recommended a diverse sample be ensured by recruitment through SHANDS Infectious Disease Clinics or the Veterans Health Administration Clinics. Subsequently, extension of recruitment through HealthStreet was able to address this recruitment concern and ensure representation from both the public and private health care system.

After reviewing the literature, I found that women with HIV who become pregnant, or pregnant women who are newly diagnosed with HIV in their pregnancy, receive additional linkage to care strategies to protect the child from vertical transmission. Furthermore, people in jail who are known to be HIV positive or are diagnosed in the jail also receive additional services to engage in HIV care. Initially, the plan was to gain understanding only from those who did not receive support services. The thinking was that people who had received such services could possibly bias the results. The community advisory board was the first to point out that the perspectives of people who had additional services were important to include because they would provide valuable information about what worked for people who did link to care after receiving these types of services. Furthermore, as I learned more about constructivist grounded theory,
I realized the concept of bias did not fit with the conceptual framework guiding this research. Bias is a term used to describe the inability of a researcher to remove his or her perspective from the research process. and the perspectives of all were needed to inform the creation of grounded theory. Therefore, the decision was made that participants in the research would include anyone over 18 with a diagnosis of HIV.

Board members had many recommendations regarding enhanced recruitment strategies, including advertisements and incentives. When reviewing the draft advertisement (Figure 3-6), board members from the public health care sector initially commented on the prominence of the HIV Red Ribbon badge. They felt some people with HIV were tired of being associated with the HIV badge. Board members representing the private sector felt the badge was important to help people with HIV identify that the study may be of interest. There were a few things board members felt were lacking: a clear explanation of who constituted the research team; why participants should trust the team; and that all results were confidential. Members felt the study explanation and inclusion criterion was too academic and wordy. They said community perceptions of academia being “uppity” and could be a barrier. One board recommendation was that the study title be removed from the flyer since it sounded too academic and there was sometimes distrust of the academic community. However, this was a violation of IRB policy. We were able to reach a compromise by placing the title at the bottom with less emphasis. While the board felt it was important to include the incentive, IRB policies required me to remove mention of them from the advertisement. The modified, final IRB approved version of the participant interview recruitment flyer is included in Appendix A.
Some board members expressed concern about the incentive to participate. They worried that if participants who were on the border for eligibility of services reported the $25 income, this could cause them to lose HIV services and assistance with care and medicines. In order to address this concern, I included an option for participants who might be worried about their eligibility. Instead of the $25 giftcard, they could receive $25 of goods they were unable to purchase through federal assistance (foodstamps), such as toilet paper and paper towels.

Data collection

Data collection was discussed with the board, including who should conduct the data collection, what format it should take, and a review of a tentative interview guide for comprehensiveness and cultural sensitivity. I expressed concern to the board that some people who were not in care might be hesitant to discuss issues regarding care with me since I was a nurse. I specifically asked if they thought I would get data more reflective of the process if I were to find someone to interview participants who they could relate with. The board felt I would be the best person to collect the data. However, they encouraged me to be sensitive and aware of the possibility of discomfort and to make sure I did not make the participant feel guilty about not being in care.

We also discussed whether an interview format was the best for data collection. Board members thought interviews would elicit more honest information since HIV is a sensitive issue. However, they felt a focus group format with peer navigators may elicit interesting information. While I decided it would be too challenging to coordinate focus groups, I was able to gain perspectives from peer navigators on data collection by specifically including people with peer navigation experience in the participant interviews.
Finally, I reviewed a tentative interview guide with the Community Advisory Board. They recommended starting with a clearer explanation of why I was conducting this research. Board members also identified words like “should” that seemed judgmental and replaced them with words like “need”. For example, they suggested replacing the question, “Do you think you should receive HIV treatment?” with “Do you think you need HIV treatment?” Finally they offered suggestions for questions they thought would build rapport and trust, such as “describe an average day before or after diagnosis” and “what are your beliefs regarding HIV treatment.”

**Evaluation of CBPR**

Mercer, et al. (2008) established guidelines to determine the extent a research project adheres to the principles of CBPR. The guidelines include 4 categories, each with multiple defining characteristics. The defining characteristics of each guideline are weighted along a continuum from no community participation to full engagement, and partnership between researcher and community. For this section, I will identify each guideline from Mercer, et al. (2008) and address the level of community participation for each of the defining characteristics.

The first guideline of the CBPR evaluation begins by reviewing the participants and the nature of their involvement in the research. The first defining characteristic of this guideline evaluates the description of community participants. The community participants were briefly described earlier in this chapter. However the sensitive nature of the research question and the agreement of confidentiality at the initial meeting prevents explicit descriptions in publically available written materials. The second defining characteristic addresses representation of the community to benefit intended users. I sought to achieve representation from case managers, prevention specialists,
administrators, planners, consumers, minority advocates, and researchers. At the initial meeting, due to unforeseen circumstances, the minority advocate and one consumer were not able to attend. I was able to speak with both after the meeting and the consumer felt participation in the interviews (Aim 2), instead of the board, would allow her voice to be heard. The minority advocate was unable to attend because of competing priorities at the time of the meeting, but will be included in future meetings.

The third defining characteristic evaluates the effort to address barriers to participation in the research process by members who may be underrepresented. In order to focus on barriers that could limit participation, members requested the use of email correspondence instead of frequent meetings to address any issues that would arise in the conduct of the research. Given my inexperience in the CBPR process, I chose to keep the initial board small, which may risk underrepresentation. As I become more familiar with the CBPR process, future steps will include possible expansion of the existing board to assure adequate representation from the community. The fourth defining characteristic addresses the establishment of trust between researchers and intended users participating in the process. To address this, I began the process of building trust years before the initiation of the project, through regular attendance at community advocacy meetings, and by volunteering at the local health department. The final defining characteristic of the first guideline regards the use of formal or informal agreements in the project. During the initial focus group meeting, guidelines and operating norms were reviewed and agreed upon by participants.

The second guideline to evaluate the CBPR process focuses on shaping the purpose and scope of the research. The first defining characteristic evaluates the
development of the research question. For this project, prior to creating the CAB, I met with health department representatives to discuss linkage to care after reviewing the literature in a health promotion class. The health department representatives agreed that linkage to care was an important concern in the community and, given the limitations in staffing, welcomed my work on the project for an internship. The development of the research question came from that initial work with the members of the community (providers and consumers of HIV services). The second defining characteristic of this guideline assesses the applied knowledge of the CAB in the design of the research. While the research question originated with the community, the researcher introduced the initial design. However, during the CAB focus group, design issues such as inclusion/exclusion criteria, who should conduct the interviews, and review of interview guide questions relied on the expertise of the members from the CAB. The provision of mutual learning between the researcher and community was the third defining characteristic. For this project, mutual learning was optimal for two reasons. First, the topic, linkage to care, was important to providers and consumers in the community and they do not have adequate resources to address the problem. Second, the question was of interest to me, the researcher, to help achieve my goals in learning the research process and helping the community. Determining whether the research addresses multiple ecological levels is the fourth defining characteristic of this guideline. This was evident in the initial focus group meeting as we reviewed current barriers to linkage from an ecological framework (Figure 3-5) that addressed multiple determinants of health. The final defining characteristic evaluates the plans to build capacity to address the multiple ecological influences on linkage to care. For this
characteristic, while I am hopeful for continuation of the collaboration, plans to build capacity will be evaluated after the results of this research are presented to community members.

The third guideline focuses on research implementation and context. This guideline’s defining characteristics relate to the application of the CAB experience in implementation, providing opportunities for mutual learning between the researcher and community, agreement regarding changes in methods, and opportunities for community involvement in data collection, analysis, and interpretation. For the implementation of the research, I relied heavily on the CAB’s knowledge and experience for identification of participants, advertisements, and strategies for conducting the research that would assist in obtaining an accurate representation of the participant’s experiences. We agreed that any major changes in methods beyond the advisory group meeting would be addressed by email correspondence.

For data collection, analysis, and interpretation, there was a varying amount of participation from the CAB. Due to the sensitive nature of the participant stories, the details of their experiences revealed in the interviews, and the involvement of the CAB with members of the community at large, I was not able to allow the CAB members to see the data without potentially breaching confidentiality of the participants. However, as the theory began to be developed, I met individually with members of the CAB to discuss the model, and gain their perspective on the emerging theory. They were able to offer feedback and clarification on several issues. For example, when understanding activation in care, I met with a CAB member, described the concept identified from the data, and gained an understanding of the department of health protocol regarding how
engagement is implemented with the pregnancy of a woman with HIV. I will continue to work with the CAB to interpret the data and theory developed from the analysis, and further develop the program of research.

The final guideline used in evaluating adherence to the principles of CBPR is concerned with the nature of the research outcomes. The defining characteristics of this guideline pertains to the commitment of the CAB to use the outcomes of the research for action, an agreement for resolving differences in interpretation, ownership and sharing of the data, feedback of research results, dissemination, and application of the results. During individual interactions, members of the CAB have expressed enthusiasm regarding the results of this research. Furthermore, they have expressed an appreciation of my willingness to share the results with the community, saying in many cases they never learned the outcomes of research conducted on members within the community.

As covered in the initial meeting, any differences in interpretation, feedback, dissemination, and application of the research results will be resolved using a democratic process. The CAB understands that I will need to retain ownership of the data due to regulatory guidelines from the University of Florida Institutional Review Board (IRB). However, any member of the CAB who wishes to complete necessary IRB training may request access to de-identified data. During my work with community members before the formalization of the CAB, select members of the community served as co-authors on poster presentations. CAB members contributing to the preparation or review of manuscripts for dissemination will be offered authorship on publications.
Finally, application of the findings from this research, as well as plans for the next phase of this research, will be negotiated in the next meeting.

Using a CBPR approach to research is an ongoing and lengthy process. The investigator must take time to earn the trust of the community in order to begin to build an effective partnership. This dissertation research initiated the CBPR process with community members who were knowledgeable about HIV prevention, care, and linkage. While I did not meet formally with CAB members beyond the initial focus group meeting, I was able to individually engage with them at least monthly for discussions regarding the research process.

In future collaborations, I will strive to address the guidelines and defining characteristics that did not offer complete partnership between me and the community, including more comprehensive representation of community members, plans for sustainability, inclusion in the development of the next research question, formally convening CAB members for interpretation of analysis, and creating formal agreements for management of the project, changes in the research process, and offering community members the option of participating on the research team. I will continue to donate my time to the community (Ryan White Care Consortium and Statewide HIV Prevention Planning Group) to promote trust and build the partnership.

**Summary**

Members of the HIV Linkage to Care Community Advisory Board assisted in the process of inquiry by orienting me to the issues and culture within Area 3/13. The CAB resulted in collaboration, network building, and promotion of research among (a) persons with HIV, (b) community HIV agencies, (c) local health departments, and (d) the University of Florida Colleges of Nursing and Public Health/Health Professions. The
CAB was able to identify local perspectives on linkage to care specific to interactions with providers, the impact of the diagnosis, and individual circumstances. Members of the CAB offered solutions to improve HIV linkage to care, make recommendations on study design and recruitment strategies for participants’ interviews, and encourage cultural sensitivity for data collection.
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Figure 4-1. Community Advisory Board Overview of Area 3/13 Linkage to Care
CHAPTER 5
PARTICIPANT INTERVIEWS

The previous chapter covered the first aim of this research, the formation of a community advisory board (CAB). In this chapter, the results of the second aim, the participant interviews, will be presented. In qualitative research, the findings are a combination of what we are told during data collection and interpretations through the analytic process. Therefore, in this chapter, both the conceptual findings and discussion relevant to the concepts presented will be reviewed.

The chapter begins with a description of the sample followed by a conceptual overview of the Decision Process and Recommendation Model. Next I will describe the context of Linkage to HIV Care and conditions that influence linkage to care. In later sections each component of the model will be described in more detail, integrating and discussing literature relevant to that concept, and including participant recommendations for system interventions to promote linkage at that stage.

Demographics

There were 10 men and 10 women participating in this phase of the study. Participants ranged from ages 25-64 and represented a variety of HIV transmission categories, including heterosexual, men who have sex with men, rape, and blood transfusion. Education levels varied among the participants, ranging from less than a high school education to a master’s degree. Participants had been diagnosed HIV positive on a timescale of between the past 2 years to 25 years. See Table 5-1 for complete demographics.
The Decision Process and Recommendations of Linkage to Care (Model Description)

From the data collected during 20 participant interviews, I created a theoretical model that depicts the decision process from HIV diagnosis to HIV care and recommendations to promote improved linkage to care. Figure 5-1 presents the conceptual model of the grounded theory generated from the data in the research, *A CBPR Approach to Facilitate Linkage to Care for Persons with HIV*. According to the HRSA Linkage to Care continuum (Table 1-1), the process of linkage to care begins when a person is infected with HIV. However, the focus of data collection in this research is on the process beginning when the person receives an HIV diagnosis. The model represents the context of linkage, conditions that impact the linkage to care decision, the decision process for linking to care, and participant recommendations to improve the linkage process. In this section, I will briefly describe the model and in subsequent sections of this chapter, carefully describe each aspect of the model and incorporate representative quotes from the data and discussion from relevant literature.

At the top of the model (Figure 5-1), the word stigma is in grey. The grey color extends to the box that encompasses the model. The area in the grey box represents the context of the linkage to care process. From the description of Dimensional Analysis in Chapter 3, recall that context represents the environment in which the dimensions of the phenomena of interest exist (Kools et al., 1996; Schatzman, 1991). For people diagnosed with HIV, that context is stigma. Stigma influences the entire HIV Care Trajectory and will be fully described in the next section.

Conditions influence action or interaction in the process of Linkage to Care (Kools et al., 1996; Schatzman, 1991). In the model, conditions are shown in an orange
color. From the data, some conditions influence the decision-making process after the diagnosis, including a person’s definition of care, their activation in care, and conflicting messages of care.

The large arrow of support (in orange and grey) serves a dual purpose in the model. First it is a condition that influences the decision process and is critical before a person is diagnosed, throughout the decision process, and continues after they link to HIV care. Second, participants recommended the provision of support throughout the entire process.

According to dimensional analysis, processes are influenced by conditions and result in intended or unintended actions or interactions (Kools et al., 1996; Schatzman, 1991). In this model, the decision process begins with the HIV diagnosis, continues to the grief response, and then comes to the point of resolution or appraisal. At this decision point, a person will decide to begin the HIV care process (intended action) or delay care (unintended action). The length of time a person will stay at their resulting decision can vary and therefore is not depicted linearly in the model. Pivotal events, in the blue box at the bottom of the model, bring the person back to the decision point of resolution and (re)appraisal. The light grey boxes under the blue boxes in the decision process represent participant recommendations to promote linkage to care. For example, participants recommended anticipatory guidance and improved diagnosis delivery during an HIV diagnosis.

During the crisis period, participants recommended three ways that would help facilitate entry into care. These included maintaining a connection between the client and healthcare system; assistance in navigation of available resources, and counseling
to help them through the crisis period and deal with the grief and loss of being
diagnosed with HIV. Once someone entered care, a holistic understanding and shared
decision-making were important. Specific aspects of the model are explained more
thoroughly in the following sections.

The Context of Linkage to Care: Stigma

As shown in the model (Figure 5-1), stigma provides the cultural context for HIV
Linkage to Care in the United States, and in particular, in the small metropolitan and
rural areas of North Central Florida. Stigma refers to prejudice and discrimination of
people with HIV/AIDS (Herek, 2009) and is considered a personal/cultural barrier to HIV
care in the social ecological model constructs (Tobias et al., 2007). Stigma can be a
characteristic someone possesses that is viewed negatively by others, or it can be
considered an outcome when someone is associated with the characteristic and
subsequently experiences negative consequences (Berger, Ferrans, & Lashley, 2001).
Without the stigma surrounding HIV, Linkage to Care would not be as challenging as it
is today. In general, barriers to health care exist, but when those barriers are combined
with a stigmatized disease, such as HIV, accessing health care is more difficult. The
fear of disclosure of a stigmatizing condition such as HIV leads to decreases in HIV
testing and linkage to HIV care (Berger et al., 2001). Participants discussed stigma
extensively in the interviews and included examples of stigma:

Participant: When me and my physician talked about it, it was like I was scared
because I didn't want anything to change. I didn't want to lose my
appearance. I didn't want to lose some things. Because then, the whole
world would know - Yeah, she got it. Somebody said she did and I wasn't
sure - So I was, I was struggling with the image thing of what people think.

HIV-related stigma is not only prevalent outside of healthcare. Stigmatizing attitudes, or
attitudes correlated with misunderstandings and misperceptions regarding HIV also
exist within the healthcare system (Parker & Aggleton, 2003). People knowledgeable about HIV and how it is transmitted still stigmatize HIV. A participant commented on his experiences in a healthcare setting (hospital).

Participant: In this day and age, you know? Yet they [healthcare providers] don’t realize that they’re taking a—if they’re sitting on a toilet in a public restroom. And this happened at the Local Hospital, we had people who would, there’d be a known HIV or an AIDS patient, and I had staff say, “You, you can’t use that.” They’d say, “Where’s the bathroom?” “We don’t have any bathrooms on this floor, you have to go down to the first floor.”

And I’m like why did you tell the patient that? Well I don’t, I use that bathroom down there, I don’t want them to use it. Well, what about all the people who might have AIDS that are using that bathroom that you don’t know about? If it bothers you that much, then wipe the seat off. Take some spray disinfectant and wipe the seat off if that’s your problem, but you can’t tell patients that they can’t use the bathroom…Just because you use that bathroom, you know? And they just look at you with this blank stare on their face.

Stigma is challenging because it creates an insurmountable barrier for HIV linkage to care for many people with HIV. Fear of rejection or being rejected because of the stigma influences decisions to engage anywhere in the HIV Care Trajectory. While HIV-related stigma is prevalent throughout our society, the impact of living in a small metropolitan or rural area can further increase feelings of stigma.

**Stigma and Rural or Small Metropolitan Areas**

Confounding stigma is the geographical location of people with HIV in small metropolitan or rural areas. Stigma may be amplified if the person with HIV fears status disclosure due to limited choices of providers and support services. Friends and relatives may work in the offices providing care. Participants in this research identified issues related to privacy and confidentiality due to living in a small town or rural area and how the stigma of HIV impacted their decision to engage in HIV care. For example, one participant talked about the thought processes of someone newly diagnosed:
Interviewer: Especially when you just found out?

Participant: Because you, you, you know, you, you gonna withdraw …You know what I’m saying? You all already put in your mind, “Oh, hell, I don’t want nobody to know I’m sick.” …You know? People gonna talk about you again, especially when you think you [finger snap] was the shit on the streets. See what I’m saying?…You know, you had it going on and all this here. Don’t want anybody to know you sick. Hell, I mean, that’s the real thing. You don’t want nobody to know you sick.

And another participant commented on the challenges of getting care in a rural area where people know each other.

Participant: That’s a smaller, a small little town and everybody knows everybody’s business and a lot of people that’s in that—in that town, they could have HIV and they wouldn’t even know it because they’re scared to go to the health department because of people that works there that knows everybody. It’s like everybody knows everybody, where they work and basically, they might even tell you who’s sleeping with who [laughter].

Interviewer: Yeah. So they—the people they just don’t trust the system there?

Participant: Right. They don’t trust the system. You said it. Bingo.

Interviewer: And is that just because of the nature of the small town or—

Participant: Yes…I’d say the nature of the town.

Another participant, who was diagnosed in jail, decided when she was released she wanted to get into care. She describes how living in a small town and awareness of the delivery of HIV care impacted her decision.

Participant: I had to think. Um, I had to get more information on how would me goin’ to the Health Department here in Local City—how can I keep it from gettin’ out to the community…Because you have the Health Department in Large City 2 hours away. They—the Health Department that they have for HIV and AIDS people is just for those people. They have no more services goin’ on in that particular Health Department…So, when I came home from the jailhouse, I was like—is our Health Department like that? At that point we had prenatal care, we had STD’s, we had all other services there at the Health Department. So, I was like, “Wow.” Throughout your care at the Health Department, I noticed that you only go on two particular days.
Given the social nature of stigma, living in areas with low populations and fewer choices for healthcare and related support services increases the challenges presented when someone begins the decision process to link to care. Feelings regarding being treated differently were similar to findings in other research regarding HIV related stigma in small areas. Zukowski and Thorburn (2009) explored stigma and discrimination in a predominantly rural area in Oregon and differentiated their findings between the experiences in day-to-day life and experiences with providers. In their day-to-day lives, participants feared social rejection, differing rules of social contact, and being treated differently. They described their experiences with providers as feeling the providers were afraid of them, providers refused to care for them, or they were treated differently by providers. A study focusing on provider perspectives in a rural Midwestern town revealed four ways in which stigma impacted linkages to HIV services: staff of medical referral agencies stigmatizing clients; physicians stigmatizing clients; medical specialists stigmatizing clients; and client perceived stigma (Yanessa, Reece, & Bastia, 2008). Similar to Yanessa, et al. (2008), the community advisory board identified ways in which providers in Area 3/13 stigmatize their clients and interview participants shared experiences of perceived stigma.

**Stigma and Minorities**

Blacks have been disproportionately affected by HIV since the epidemic began (Centers for Disease Control and Prevention, 2011). Stigma has been associated with negative attitudes towards the groups that are believed to be effected by HIV (Parker & Aggleton, 2003). Participants spoke of how having HIV was different if you were a member of a minority population, and research has shown stigma is greater for some
populations than others in regards to HIV (Wilson, Wittlin, Munoz-Laboy, & Parker, 2011).

Participant: Family situations, we've got people who are afraid that their families are going to find out that they're HIV positive even in this day and age. We have, um, one person who I know of who, uh, basically hides their medicine because they're afraid somebody will see it and then go Google their medication and find out it's only used to treat HIV...So there is still a tremendous amount of lack of support, particularly in the black community. Lack of understanding, lack of understanding of transmission. This same client tells these horrendous stories about how some of the family comes to their house or they go there, they make them put paper on the toilet or something like that, you know?

And another participant commented on his experiences with the transgender community and being black:

Participant: And I still find some of that right now is that the transgender community is—it's—although it's part of the community, it's not really—part of the community. It's like just there, and I—I felt that way about the black community, because, you know, for some reason there's that stigmatism. We will not call any of our children crazy after—or have mental problems, and Lord forbid we say that any of them are HIV positive. That's just taboo...Yeah, yeah, because most transgender African American people, a lot of them grew up in the church...And we know the stance of the church on homosexuality, and we know the stance of the church on AIDS, and so, you know, it's just one of those things that's kind of like, shh, it's a wig, don't tell.

When the people in someone's social system perceives HIV negatively, fear of being stigmatized compounds the challenge of linking to HIV care. The reasons for the stigmatization of HIV are complex and often associated with the black community perceiving HIV as a disease more prevalent among homosexuals. In community support group meetings, providers and consumers in the local community have indicated that a black man diagnosed with HIV is more stigmatized than if that same man goes to prison.
Stigma Summary

As presented in the data and evident in the literature, stigma exists throughout the Linkage to Care trajectory (Parker & Aggleton, 2003). Research has indicated high levels of stigma are associated with poor self-reported access to medical care (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). Parker and Aggleton (2003) thoroughly explore the concept of stigma and place stigma at the intersection of culture, power, and difference. They conclude that in order to fully understand the role stigma plays in HIV/AIDS, we must begin to address stigma as part of a social process and not from a behavioral or psychological stance.

What are the Conditions that Influence Linkage to Care?

According to Schatzman, conditions facilitate, block, or shape actions or interactions within the chosen perspective (Kools, et al., 1996). Conditions regarding how participants defined and engaged in care, and the conflicting messages of care in the system, impacted the decision process for linkage to care. Anticipatory guidance and improvements in the delivery of the diagnosis were suggested as a means to facilitate linkage to HIV care after diagnosis.

Defining Care

Multiple challenges exist in defining care status and defining HIV care may be a matter of perspective. Health Resources and Services Administration (HRSA) (2006) describes several ways of defining HIV care and acknowledges the fluidity of the concept of in HIV care. Possible ways to define care include:

- Clinical measures (the most frequently used in the Linkage to Care literature)
- What qualifies as HIV care (medical visits, case manager visits, ancillary services)?
- Client needs and choices
- Self-Reports – can be accurate with clear definitions of time and services
- Disconnected data sources to monitor multiple care sources
The Engagement in Care Continuum, (Table 1-1) was designed to take into account the complexities of defining care, However, system practice still considers the clinical measure the dominant means of determining someone’s care status.

Participants talked about the fluidity of care and how they did not define themselves as being in care until they reached acceptance of their HIV diagnosis, even if they were attending appointments and following HRSA guidelines. For example, one young woman interviewed met the conditions of being *in care* as defined by HRSA (regular attendance at HIV appointments and routine lab testing), and yet talked about how she had just entered care even though she had been receiving services for three years:

Participant: And I was still out there doing what I wanted to do. I was still drinking, clubbing—I was still having sex. Up until January of this year, I just came and said, “Okay, this is—this is real. Now I’m ready to learn about what’s going on with my body.” And up until that, I still—I was going through the motions. I was still going to my doctor’s appointment, because the lady made the appointment for me. And I went to my first appointment and they did, you know, the process that they have to do when they draw your blood. And then you go to the doctor, and then they reschedule my appointment every three months. So I was going through the process because of how I was raised—you have to go to the doctor to see about yourself. So I think my background of how I was raised has something to do with that as well. So she made my appointment, and I continued to go to the doctor, but in—I was still in denial. I was still in denial, but I would still make sure I’d go to my appointments. But I was just going through the motions of—I was just going through the motions—just—just going.

Through the process of going through the motions, when the participant above was ready to fully engage in care according to her perception or definition of care, she was already receiving services in the HIV care system. How a patient defines care, and provider awareness of how they define care, are important facets of the linkage process. While affirming the client’s perception, providers can share their perception of
care, and both can move towards mutual goals of care. When the provider can understand that the client is “going through the motions,” the provider may feel less frustrated that the client is not reaching the provider’s care goals through behavior change and adherence to antiretroviral therapy.

Engaging in Care

Hibbard, Stockard, Mahoney, & Tusler, (2004) identified 4 stages of engaging in the health care system: 1) believing the patient role is important, 2) having the confidence and knowledge to engage in health care, 3) actively taking action to improve health, and 4) staying active in the system, even during times of stress. It is interesting to note that none of these stages include a measureable lab value or clinical value, suggesting engagement in care goes beyond showing up at a doctor’s appointment and having lab values measured. Furthermore, in this study, the measures developed to determine engagement represented persons who had already entered the care process, but had varying levels of activation within the care process.

Participants in this study were activated to enter into the health care system by a feeling of responsibility for someone else (a child or family member), or someone close to them urging them to move forward (family member, close friend, or health care system). For example, when one participant became pregnant, the health care system provided broker style case management (Table 2-1) to protect the child from vertical transmission. This added support often brought participants into the system, but did not necessarily keep them in the system. One participant commented on staying adherent to her medications throughout her pregnancy but stopping after her baby was born.

Participant: I went to Local Area Health Care System—I actually went and I stayed there the whole time. I mean, they put me on all these different medications and stuff like that but I stayed there the whole time.
Interviewer: How was that process?

Participant: For the medication?

Interviewer: The medication.

Participant: Medication. It was all right because I was like in denial. I was still in denial. I took it due to the fact I was pregnant. To keep that baby from getting it, I took my medicine.

Interviewer: How about when the baby was born? What did you decide to do then?

Participant: When she was born I continued to take it for a while, then I stopped. Then I take it, then I stop. It's like an on/off switch because it depends on what medication it is. Basically sometimes I just feel out of it, won't move, won't budge, stuff like that. Then be time I do go to the doctor and they check my T-cells, they're back, "Oh, they're too low." Then they switch medicine again. Then, I even have it to where—cuz I can get sick at any time.

Another participant experienced a health care system initiated activation into care while she was in jail and pregnant. For her, the support she received from this activation helped her to stay in care.

Participant: They did...Department of Corrections, I don't even want to call it a jail, but they really help provide structure for me to say, this is your life (begins to cry). This is your child's life (quiet pause while crying). When I got out, I mean everybody—I got all the special attention, 'cause everybody want to see my baby and...and it was good to know that people didn't look at me being—ones that knew didn't look at me as somebody that had, that had a virus or a disease. They just want to say a person's going to have a baby. So after I got out, I stayed in contact with RW Case Manager and Jail Linkage Coordinator. And I've been on my meds ever since. I go through things. That's when I got involved with the Local Support Group at the health department. And I met the Regional Minority AIDS Coordinator, Local Support Group Leader.

Again, a common reason why people activate in care is because of a feeling of responsibility for someone else. For example, one participant talked about her daughter and her choice to seek care:

Participant: So I'm just ready to deal with it. I wanted to find out what was going on with my body. I wanted to find out what this virus is and how can I maintain a healthy body. How can I maintain a healthy life? Because I
have an 11-year-old daughter and this year she just entered middle school. So I want to live around—I want to be around for my child.

Identifying ways to activate someone in care is an important strategy for programs devoted to linking persons with HIV to care. System programs exist that assist people into care such as jail and pregnancy programs. However, pregnancy programs are not universally accessed. For example, in Area 3/13, if someone receives their first diagnosis when they are pregnant, the county health department will offer services to prevent vertical transmission. If someone is already receiving HIV care or non-HIV care and becomes pregnant, getting services is more complicated (Davis, 2013). Conducting a comprehensive assessment of the person with HIV may help identify possible motivators to help activate someone in care. For example, a client may feel responsibility towards a child and that feeling of responsibility can be used to help motivate them towards engagement in care in order to be able to care for the child.

**Conflicting Messages of Care**

Participants sometimes identified receipt of mixed signals from various health care providers. Some participants received the emotional support they needed to enter care, but once at the provider’s office, were told there was nothing that could be done at that time. For example, one participant decided to make an appointment to enter care and, once at the clinic office, was confused by the message he received from the provider.

Participant: He says, well, he says, everything with you is clear. He said, your viral counts are high. You’re not low enough to even start taking medication right now, so basically, there’s nothing we can do for you. ..So that was another blow. It was, like, okay. Hold on a minute. I’ve finally got myself up the nerve to come and get tested again to see if I can get some help, and now you wanna tell me I can’t receive help because I’m not sick enough? And I—I took it the wrong way and just started—I became rebellious. Like, what kinda mess is this? How are you gonna say—
you’re gonna help me, and then I come and take a test and—and then now you’re telling me I’m not sick enough? What you want—you want me to be sick before I can get some help? And so I kinda took it the bad way, and I went and talked to one of the counselors there who I had met who I had, who I had connected well with.

This participant was confused by receiving messages to enter care from the person providing the counseling and testing, and then going to the provider and hearing there was nothing that could be done. As noted in the case management section of the literature review, fragmentation in health care is a challenge to care delivery and often results in poor communication between providers (U.S. Department of Health and Human Services, 2008).

Central Need throughout Trajectory: Support

As defined by the Oxford English Dictionary (2013b), support means, “the action or an act of helping a person or a thing to hold firm or not to give way.” While the definition seems simple, support is a complex term with many dimensions—formal, informal, social, physical, emotional, cognitive, tangible, etc. Support began was a central theme early in the coding. The type of support, the timing of support, and who delivered the support seemed to have an important impact on the participant’s perception of the care process and their recommendations about what is needed in the care trajectory. Types of support predominant in the results were emotional and cognitive support. When tangible support was mentioned, it was more in terms of learning where to get services, i.e. informational support. Participants commented that support was needed through the entire HIV care trajectory. However, when asked to think about the types of support and when support should be delivered, most said that emotional support at diagnosis was critical. For example, a participant who was
diagnosed over 25 years ago and worked for years with people newly diagnosed
commented on the need for emotional support at diagnosis.

Participant: That care is available, they’re not alone. First of all they’re not alone. There’s other people out there like them...There is treatment available, even if they can’t afford it...And there’s probably people who have been through some similar experiences that they’re going through.

The participant stressed the importance of letting the person with HIV know they are not alone, and there are others going through similar experiences. The stigmatization of HIV leads some people to believe they are going to be alone.

Another participant talked about the need for immediate emotional support before other types of support were delivered.

Participant: No, that’s when you really need emotional support; it is diagnosis—when you’ve been diagnosed. Because when you've been diagnosed, I mean somebody come and tell you something, but like I say—for instance, if a friend of mine went, and they had HIV tested, and they come to me, and they be like, I’m afraid to go find out what my results is. I need you to go—I want you to go with me for support. Of course, I’m gonna go, because I know how it was for me when I found out...With me, it was—I was more concerned with my life, and how I was gonna deal with this, and how I was gonna tell—tell my family, and how my family was gonna accept me now, and how I’m gonna live with it.

What was surprising was how participants did not want to learn about the technical/medical aspects of HIV such as viral loads, CD4 counts, and Antiretroviral Therapy, which is the type of information many providers provide when delivering test results.

The preference for “who” delivered the support varied among participants. Some strongly felt the initial support should come from a peer (with HIV) in order to alleviate the anxiety related to disclosure. Others felt it was not necessarily about who was delivering the support, but instead, what was more important was how the support was
One male participant who went directly into care after diagnosis shared the following:

Participant: I think it would be great. You just start right off the bat. I mean what really gets—it’s the personality and how you talk to the person. You don't want to talk to them aggressively…you need to do this and you need to take this and you need to—that doesn't get it.

In his experiences, the providers he encountered in the transition from diagnosis to care showed support through kindness and understanding. For example,

Participant: I mean because they treated me real nice. And, I mean, they knew what my symptom was. They knew, I guess it was my personality, how I would, you know, talk to them and how I would treat them and it's just like, I never gotten an ugly response…Out of the whole eight years, I never gotten an ugly response…So it was…immediately...started talking to me and everything and they understood my situation. And once I understood a person knows my situation and how they respond to me, then I can respond to them back in that same tone now, in that same tone.

For him, the supportive environment contributed to linking to HIV care. However, a supportive environment may not always be present, such as with the new home HIV test kits. Another participant commented:

Participant: That’s dangerous. You don’t know how a person’s mind is gonna perceive this but if it’s someone that’s living with this. Okay, I see somebody right there just told—I just went to the doctor finding I was HIV positive. I feel that doctor should say, well, let me let you talk to somebody that understands where you are right now.

And take me, walk me to the peer as living with this, introduce me and let them know okay this person here has just been diagnosed. And I’m bringing you to this person here because they understand because they’re living with it. [Coughing] And if the person that’s the peer never gave, came, opened up and said that they’re positive, they don’t need to be there.

The provision of support was clearly an important theme brought up by participants. They felt the receipt of support led to better outcomes and lack of support led to poor outcomes. While all types of support were important, emotional support delivered at
diagnosis was the most salient. Other specific types of support were discovered in the interviews (i.e., counseling, navigation) and will be discussed more in the next sections.

The Process of Linking to HIV Care and Decision Points of Linkage

HIV Diagnosis

Participants in this research received their HIV diagnoses in a variety of settings including the local county health department, substance use and physical rehabilitation facilities, jail, primary care physicians’ offices, and obstetrics and gynecology offices. Some were aware they were being tested for HIV while others were tested because of institutional policies. Participants mentioned that improvements could be made to help people transition to HIV care by evaluating the way the diagnosis was delivered and improving the lack of direction after diagnosis. There is limited evidence evaluating the quality and delivery of counseling and testing services, and attention to the provider role in the delivery of these services is in much need of future study (Obermeyer & Osborn, 2007).

Participants in the ARTAS study completed a questionnaire about their perceptions of counseling and testing services. The perception by 27% of the sample was that the counselor did not spend enough time with them, and 21% said the counselor failed to answer all of their questions. Participants were more likely to indicate inadequate time spent or questions were not answered if the testing took place in an emergency room/hospital, private setting, or jail (Rudy et al., 2005). Participants in this research identified a need for anticipatory guidance and improved diagnosis delivery to promote linkage to care at the diagnosis point in the model.
Participants described a need for anticipatory guidance, an intervention frequently utilized in the pediatric discipline to guide parents with practical information about potential challenges and impending changes (Titley, 2006). Participants in this study talked about the need to be informed of the process ahead, such as what to expect in the next few days, what the clinic visit would be like, and how it was going to feel to adjust to the news. The earlier participant, who described the conflicting message of care, went on to describe what he thought was needed to help him understand the process.

Participant: So I went and talked to him (prevention counselor), and he explained to me what was going on and he called them (provider), and he (provider) says, “Well, I’m sorry that happened.” He said, “Well, what’s gonna happen now,” he said, “they are gonna set you up with a case manager. …as you go through the rest of the process, they’ll get you started and get you in where you can get—receive help.” And he said, “Take it easy. Just come back and keep getting checked out and make sure everything’s fine.” He said, “Right now, we can’t provide you any assistance medically until you are at a certain point”…He said that’s just the way our system runs. And I I just don’t understand that. What was my purpose of even coming here to get tested… if I can’t get help now. And that’s just the way I saw it. And so when that happened, I left him….I called Another participant and told Another participant, and then he tried to call and schedule me for another appointment, ‘cause they wouldn’t do it when I called… I called a few times, and they didn’t even return my call back, so I guess they kinda felt like I didn’t want the help, and the truth was that I just didn’t—I truly did not understand. It was shocking.

As he stated, he felt like he did not understand the process of entering HIV care because it had not been explained to him after he was diagnosed. He was angry and confused about the situation and felt they did not want him there. Fortunately, he was able to contact a family member (with HIV) for guidance. Other participants also commented about how they needed to have an understanding of what were the next steps in relation to their care. Study participants believed that providers often assumed
that persons with HIV automatically knew the process and assumed participants had a high degree of health literacy. Furthermore, patients were often too upset about hearing they had HIV to process complex directions about seeking care. Anticipatory guidance can begin at diagnosis and be reinforced by all providers a patient encounters in the system to help maximize the chances of linking someone into care.

**Diagnosis delivery**

The advisory board members brought up the diagnosis delivery during the meeting and in the individual interviews. Some participants reflected on the way they were told and others on how they wish they had been told. For example:

Participant: The most I say, support, and—and having the person that’s gonna tell it to you be sensitive and caring enough not to just blurt it out. Oh, you got HIV. You know, that’s not nowhere near—that’s not no way to do it.

Another participant was told of her HIV status when she went for a prenatal visit. At the time, she did not have any suspicion that she was HIV positive. She commented:

Participant: When I was diagnosed with it—when I was diagnosed with it, it was when I was pregnant with my child. When they did the blood work or whatever at the doctor when I went back in it was like, oh, we can’t see you here anymore. I’m like, “Why?”... No, I was actually shocked, to be honest with you. I was shocked. When they told me that, I wasn’t that far along when they told me but it shocked me to where I actually—you know how you think you like in a dream or something? It’s like okay; I went straight to the bottle cuz I’m—I can’t believe this. I think I drunk that whole bottle. It was real confusing cuz I’m like how that so? I just had a child (a few years earlier).

And another participant spoke of feeling judged when he received his diagnosis:

Participant: Well, when I was given my results, the person that gave ‘em to me knew that I was employed and just gave me the results, and was nasty and sent me on my way. His remark to me was, “Whatever behavior you were doing that got you—got yourself in this trouble, you need to stop now.” This is in front of my aunt. And then he said—then his next comment was, “Now, when you came to me and did your test, you wrote that if you were tested positive, you would kill yourself. Do you intend to?” I said, “No.” He said, “Okay, good.” And I left.
For people with HIV who have little experience with the health care system, negative experiences during diagnosis can influence the decision to link to care. It is not surprising that if someone is scolded for a behavior at diagnosis and they already feel discomfort getting care due to stigma, it may impact their decision to not return to care. Garland, et al. (2011) interviewed people with HIV who had never received medical care and asked them what could have been done differently. Most participants in that study were dissatisfied with their counseling and testing experience and said they needed more support, including counseling and active linkage.

**Grief or Crisis Response**

Grief is a response to an anticipated or perceived loss and most often associated with the death of someone close (Mallinson, 2013). When HIV was first emerging as an epidemic, and before antiretroviral treatment, there was a loss and grief component associated with the disease as partners died. However, grief responses can also be associated with the diagnosis of a chronic illness since the person perceives a loss from not being able to fully return to their formal lifestyle or function (Sidell, 1997). A crisis is a temporary alteration or disruption in a person’s normal ways of coping and can be experienced as a result of receiving bad news such as an HIV diagnosis (Lewis & Lewis, 1989). Consequences of a grief response to a chronic illness diagnosis are similar to the crisis response, and are the result of a feeling of threat or disruption to normal function (Sidell, 1997). Reactions to a diagnosis of a chronic illness may include depression, alienation, withdrawal, anxiety, abandonment, etc. (Sidell, 1997).

All participants in this research described a crisis and/or grief response after they were told the results of their HIV test. Their responses included feelings of anger, denial, disbelief and fear. Participants also stated they felt dirty, numb, hurt and
overwhelmed. Even participants who knew they were most likely positive because of an infected partner experienced a crisis response after confirmation of the diagnosis. Behaviorally, participants said they withdrew, continued or initiated risky behaviors, gave up living (passive suicidal ideation), and ran away. The tone of one participant’s description of the situation resonated throughout the interviews:

Participant: With me it was devastating. It was heartbreaking. Like I said, I screamed. I hollered. I told the doctor to get out of my room. I didn’t want to see him. I did it all.

Another participant described the grief response and agreed that grief was an accurate description of her response to being diagnosed.

Interviewer: The words you were just using sound very familiar to a grief response.

Participant: Yeah.

Interviewer: Do you think that that is—explains how you were feeling?

Participant: Yeah. Grief.

Interviewer: What are you grieving?

Participant: Oh, just knowin’ that my life will be cut short because of this. That’s something that is hard to grab onto. To grasp. But I figured—I don’t know—I figured it’s like with God, I have good closeness with God, and I think when your time’s up, your time is up.

This participant described feelings of depression, denial, and shock. However, she talked about having support through her family and spiritual foundation, as well as encouragement and referral from her provider to attend support groups, and assistance to work through her grief response and move into acceptance and HIV care. At the end of the interview she stated:
Participant: Yeah. It's wonderful. I'm just happy about it. I'm not happy that I have it, but I'm happy that I've come this far. I've seen a lot of changes in my life, and it just is wonderful. I've become a stronger person.

However, other participants withdrew, continued or initiated risky behaviors, gave up living (passive suicidal ideation), and ran away. One participant described her experience, stating that she liked drugs and that she ended up leaving the rehabilitation facility where she was diagnosed.

Participant: To be honest, I liked it (drugs). And, um, I ended up walking away from the place and when I walked away from the place I walked to the streets because there’s nowhere. I, I could've went home… I didn’t—and the drugs just, they just seemed to be the filler for that moment… And it was easy to just fall into that loop and just be numb. Because I didn’t wanna feel. It was too much pain, pain was coming from every angle. I didn’t—they didn’t give me a therapist to talk to—

She spent 13 years on the streets, in and out of rehabilitation centers, before being able to overcome her grief and enter care through support from her church and a therapist that “took time with me.”

Several participants interviewed knew they were probably HIV positive before they took the test. Their responses also included elements of crisis/grief. For example, one participant’s partner was diagnosed with AIDS and since they had been together for many years, he knew he probably had it and said he delayed testing because he felt he could not deal with a positive diagnosis at the time. As he reflected on the time when he finally found out, he responded:

Participant: So when I—when I got that, I thought, “Oh, boy, here we go.”…And then a couple of rashes. I didn’t know, but I suspected. I thought, “Oh, wow.” Not at first, with the thrush. I thought, “Oh maybe, I—” [laughter] thinking, “Oh, maybe it could be something.”…You know, I have allergies…There are a lot of trees here. I do take, uh, allergy medicine, so I thought, “Oh, maybe it’s that.” But when I started to get a little bit of rash on my legs and on my arm, I thought, “Uh-oh, something is bothering me here environmentally, and the reason why it’s bothering me is because my
immune system must be suppressed, so you better need to check this out,” and that’s what I did.

Interviewer: So what was it like to find out for sure?

Participant: Devastating.

Interviewer: Even though you suspected it?

Participant: Yeah. Yeah, it sure was.

And another subject, diagnosed 20 years ago, whose partner was positive, also suspected he might also be infected. He commented on how it felt to definitively know he was positive:

Participant: So, yeah it put a, it put a knot in my stomach and scared the shit out of me. But after that I got over it pretty quickly and—because there wasn’t anything I could do about it.

As a person works through the crisis or grief period, he or she comes to a decision point about whether to engage in HIV care. Successful resolution of the grief/crisis period tended to move people towards HIV care. Participants were asked what they thought our system could do to facilitate entry into care and responded with concepts about transition and ideas for facilitating transition, including navigation and counseling.

**Maintaining connection through the transition**

A transition is described as a process of change or movement from one condition to another and an HIV diagnosis represents a transition into wellness (Oxford University Press, 2013c). Participants felt like the crisis period following diagnosis was overwhelming and maintaining a connection (contact) through this transition was important for linkage to care. One participant provided her perspective on how people with HIV would end up at the point of delaying HIV care if connection was not maintained.
Participant: Yeah, because I think at that point in time (resolution) that you can really, you'll catch that person. You'll catch that person and be able to really help them get on the right track...Before they get lost. Because they will get lost. You don't want 'em to get lost, you want to be able to keep connected to 'em. You want it because, , I know, I got lost...Because you don't really have anything to connect to once they tell you you're positive. They might tell you to go to the health department. What? Who?

This participant recognized the challenges of linking to care due to unfamiliarity with services and a feeling of being lost in the system. She felt maintaining contact with health care providers or prevention counselors was important in keeping people moving towards care.

Another participant had similar comments about connection:

Participant: That way, they can call me and say, “Hey, Mr. [participant's name]. This is so-and-so. I remember you came and saw us at the health department, but we were just calling, just check in on you, and we haven’t seen you in a couple of months. You want, you know, you wanna set an appointment to come back in and—and see where you’re at now?” Someone to kinda monitor you and kinda keep you wanting to come back and still get checked, but—’cause, see, once you gonna find out and they tell you, okay, you’re fine y—and you get—like, I get busy with things, and I kinda just g—I keep going, okay, all right. They said I’m fine. I’m not gonna worry about it. Oh, they said I was okay. I’ll—I’ll go in a couple of months... And I don’t know what can happen in those couple of months. Some—in those couple of months, something can happen to me and I can get just sick as I don’t know what, and because I didn’t have someone, you know, checking in to let me—hey, Mr. [participant’s name]. We’re not calling to aggravate you, just calling to see how you’re doing, if—see if you wanted to schedule another appointment.

When HIV care providers call to inquire about how the person with HIV is doing and ask to schedule an appointment it convey a message of caring and offers an opportunity for Linkage to Care. Most participants described a need for active connection from the health care system during this transition time—meaning they did not want to only feel the connectedness when they chose to engage in care. They wanted representatives
from the healthcare system to actively reach out and connect with clients who may have been lost to follow up.

Participant: I think the physician, the health care community needs to work with patients. Don’t just tell them they’re positive, you need to go seek treatment, here’s an appointment card; go talk to these people. You need to have some follow-up, nurses need to call the patient…Transition them into and be supportive during that transition period and don’t let them fall through the cracks. And in this day and age with cost of health care and the stresses on the health care system people easily fall through the cracks. I guess they need support from the very time—even before they get tested, especially if they have risk factors. Even before they get tested you need to start that transition in case they are positive…Now if you are positive, this is what we’ll do, blah, blah, blah. And let them start thinking about it. And you do have some risk factors, you know, for this. And, uh, therefore if you do turn up positive then we need to think about how to get you into treatment and let’s talk about some of the ways we could do that, right there. Even maybe even before testing. If they have risk factors.

There is literature supporting the concept of connection to transition people to HIV care.

Participants in a study by Mallinson, et al. (2005) identified connectedness as important for engagement in HIV care and patients who had a perceived personal connection with staff were able to transition into care. Similarly, Rajabiun, et al. (2007), found that when program staff facilitated communication between patients and doctors or sent appointment reminders, patients said it felt like someone cared and helped them stay in care.

**Navigation**

As stated in the literature review, system navigation and peer navigation are interventions for linkage to care that have yielded positive outcomes (Bradford et al., 2007; Hallum-Montes et al., 2013). Participants in this research commented on navigation after diagnosis and the importance of having someone to help them through the crisis into care. While some said anyone caring and compassionate would be able to provide system navigation, most said they felt like it should come from a peer, i.e.,
someone with HIV, immediately after diagnosis, since they had a better understanding of what it was like to be diagnosed and live with HIV. For example:

Participant: Okay, you get diagnosed, don’t leave me there to figure it out, to understand because now I’m in a state of mind where I don’t know what to do. Okay, that’s when you need to take my hand to help, to guide me to the point where I know I need to get into care. I know that—how important it is to get into care and I need to know someone like me...Because you’re not the person I want to talk to, you ain’t HIV positive...You don’t understand what I’m going through. I need someone that’s dealing with what I’m dealing with, that understands, that’s compassionate but strong. I don’t need someone to s-, you know, that’s not, not gonna put me on the right track...Or to make me feel like I, I’m not strong enough to stand up, uh, on my own two feet. But I need your compassion as well but I need to understand how important that I do the things I need to do to stay healthy. So you don’t want someone that’s gonna hold your hand and lead you around. You want someone that’s gonna put you in the position where you can take care of you the way you need to be taken care of.

Interviewer: But you need somebody to give you those tools.

Participant: Yeah. So the tools will come from someone that’s dealing with this, that’s living with it, that’s doing the things they’re supposed to do.

HIV Linkage to Care in Florida consists of passive referrals which are made when someone is diagnosed. In the practice setting, staff have commented that people with HIV need to take responsibility for their own care. While this may be true in some situations, the woman above identifies the gap in the logic. As she explains, someone newly diagnosed may not have the knowledge or ability (tools) to navigate into HIV care. She also explains how someone with HIV who is already linked into care (i.e. a peer) can help the navigation process better than others because they understand the challenges of living with HIV day-to-day. Finally, she feels providers need to go beyond holding someone’s hand and telling them where to go. Once the initial crisis of the diagnosis is resolved, it is necessary to teach people how to advocate for themselves as they enter HIV care. Mallinson, et al. (2005) found the ability to navigate and
understand the complexities of HIV care influenced health literacy and subsequent engagement in HIV care.

**Counseling**

At a recent Ryan White Care Consortium meeting, a representative from a local mental health agency came to the meeting to share services available for HIV patients. The consumers in the meeting were so passionate about the topic that we had to delay some topics until the next meeting so we could adequately address mental health support. Patients shared many ways in which counseling helped them decide to enter care. For example, one participant who delayed care and later received counseling stated she needed counseling at diagnosis.

**Participant:** I feel that they should have had counseling available. I felt like they should have had more people to come and just—cuz I was in a total wreck.

Often, as subjects thought about what they would tell someone newly diagnosed, they brought up counseling. One participant who delayed care, and continued with a risky lifestyle for many years, said what assisted him onto HIV care was counseling. When asked what he would tell someone newly diagnosed, he responded:

**Participant:** I would tell them, I’d say, “Listen, it’s not as bad as you think it is. You know, um, like I said, I could sit down and tell you my story, if that would help you. We can sit down and we can do that. But, my advice is, I know you’re going through some stuff, it’s best to get yourself some counseling, man. Listen and talk with your doctors. If you can get around people that are positive and doing positive things, you can see the difference. It’s not bad as we take it to be. It’s just a disease. It’s just—and they got so much good medication now till you may outlive, you know, your brother.” You know, I actually would really give them some good information to motivate them to lift their head up. Call me anytime if you need me. If you need me, call me.

Offering counseling services may help people effectively work through the grief/crisis period that results from an HIV diagnosis. Joseph, et al., (2011), found
participants from focus groups wanted to be linked immediately to ongoing mental health services. However, not everyone diagnosed with HIV will want counseling. Like HIV, mental health services carry a stigma in our society. Assessment at diagnosis is needed in order to determine if counseling services are desired and appropriate.

**Resolution (Re-Appraisal): The Decision Point of HIV Care**

With varying amounts of time, all participants came to a decision point about whether they would begin HIV care or they would delay care. When asked what factors helped them decide, it was discovered that the decision was not always a choice. The decision to enter care may have been influenced by an external condition (see Engaging (or Activation) above, such as pregnancy or a feeling of responsibility towards someone else. Some moved into care because this was the way they’d been raised, while others sought care because of a feeling of responsibility for someone else.

However, coming to terms with the HIV diagnosis helped people make the decision to engage in HIV care and work towards acceptance. For example, one participant commented:

Participant: It’s just like one of the steps with the twelve step program...With twelve steps. When you accept that you have it, you can move on. You can start gettin’ the care that you need, you’ll start—I mean, it’s like basically livin’ a normal life...But you have to accept what you have first. If you can’t accept it, then you gonna be depressed, you gonna be sad...You gonna be angry. And with me...You’ll stay in that space (of delayed or intermittent care).

This participant compared the decision to her experiences with substance use treatment. In 12-step programs, in order to move away from dysfunctional behaviors, one has to accept that he/she has a problem (Alchoholics Anonymous, 2013). She went on to describe how people would begin to experience a physical health decline, and would “count, your CD4, your um, viral load, all of that,” if they chose to delay care.
While the resolution (re)appraisal point is the critical decision point in this model, it is also complex. Many personal, community, and system factors can influence this decision but it is different for each person. For most, the decision is not a clearly defined point. Instead it is a part of the process in the trajectory. Recommendations to influence the decision therefore happen at other points in the system – such as at diagnosis, during crisis and grief, and during HIV care (discussed next).

**HIV Care**

As described in the section above concerning conditions influencing linkage, defining HIV care is a challenge. Participants in this research had varying views of what being in care meant. Some told me they were not in care, yet later in the interview they would reveal that they attended care but did not like it. Or they would tell me they just entered care, but later admitted they had regularly attended all of their HIV appointments for years. What seemed important about those who considered themselves in care was that they had come to terms with their diagnosis, and this led to acceptance, change in poor preventive health behaviors, or an engagement with the system to help identify when the need for more serious engagement in the system was needed (i.e., the initiation of Antiretroviral Therapy to achieve viral suppression and maintain CD4 counts). HIV care is considered the outcome of this process model even though it is not necessarily the outcome of the linkage to care trajectory as defined by the health care system. People with HIV, who had made it to this point in the model, described steps necessary to stay in care once introduced. These recommendations included a holistic understanding beyond the patient role, and the initiation of shared-decision making.
Holistic understanding beyond the patient

A holistic approach to care looks beyond a person’s diagnosis and attempts to understand the whole patient – their physical, mental, social, and spiritual health. In other words, an attempt is made to understand living conditions, values, spiritual needs, relationships, and anything about a patient that may influence health and quality of life. Failure to understand the patient from a holistic perspective can hinder engagement or continued adherence to care. For example, one participant talked about the delivery system at a provider’s office and the challenges of keeping her appointments due to child care issues. She thought that provider’s office was her only choice for care, but asked for alternatives. She commented:

Participant: Basically if your appointment is like 10:00—You actually be there until about 4:00, 5:00, yeah...Okay. I have kids. I can’t do that. Then I end up switching up to go to [Local Area Health Care System]. They (Health Department) used to make it sound like I couldn’t go no other place but the Health Department...Is there anywhere else I can go? No. I didn’t have a choice of where to go. I had to go to the Health Department. Then, later on down the line—let me tell you how I found out [Local Area Health Care System]. I do the program. Ryan White. I’ve seen him for the first time and the case manager was talking to me, explain to me about the—about the medicine and stuff and how it works and showed me a little diagram and stuff like that. Talked to me. You know there’s other places you can go, right? I’m like no, cuz every time I ask nobody answers that. That’s why I been coming here and then that’s when she told me about [Local Area Health Care System]. She was the one that actually scheduled an appointment through them and told them to follow-up with them and that’s what I did.

In the interview she described being a very active person and did not like to take the antiretroviral medications because the medicine made her feel sick to her stomach and that made her stay in bed all day. She wanted a way to be in care that did not make her feel sick and she felt like the providers did not understand.

Participant: Basically they said I should have full-blown AIDS. Basically they said I should be in the hospital bed sick, about to die, whatever. That’s how they
tried to explain it to me. Well me, personally, I'm here for a reason. I said I have kids, but I'm here for a reason. I said cuz some of that medication, it makes me sick on the stomach. I'm not gonna take something if it make me sick on the stomach; that's why I take cuz I have like maybe 13 pills to take.

In the interview she described being a very active person and did not like feeling sick to her stomach because that made her stay in bed all day. She wanted a way to be in care that did not make her feel sick and she felt like the providers did not understand.

At the end of an interview, another participant summarized the importance of comprehending more than the biological patient and of the necessity for understanding the entire patient.

Participant: But as a team with you working from different angles coming from the University of Florida, the study that you're doing is going back out in the community for the doctors and everything. And they will be able to come up with a plan to really, really, really reach patients where they are...Because that's the most important thing. I mean we can only do so much. But with the patients, the doctors don't really understand where they are, they can't really help them...I mean if you don't know me in a different, in a ca-, in a different spot. I mean you can come in there and examine me and stuff like that and—but there's a whole 'nother side of me and—that you don't really get to know. Then you can't really help me totally...Part of the care is not gonna be there.

She came to terms with her diagnosis and works with others in the community to be self-advocates. However, she was interested in this research study because she saw the need to help providers understand there is more to the person than HIV.

Finally, one other participant described the need for providers to understand the entire patient by comparing the relationship to that of a cosmetologist.

Participant: Oh, I think the biggest thing that the health care system needs to do is to always try to put a human face on the person that they're working with. It just can't always be words, and standards, and procedures. It has to be a human face...Well, for example, I'm a hairdresser. And a cosmetologist...And if you were getting married, I can't just talk to you on the phone and figure out what you're going to do. I'm going to actually
have to put a human face to you to figure out what hairstyle’s gonna look good on—what color’s gonna look good on you.

And I’m saying that you just can’t sit me in an office in a cubicle and tell me that I gotta do this, I gotta do that, I gotta do this—all right, done—next...Because I’m just—I’m either a guinea pig or an object that you’re working on; I’m not a human. And it’s not just these people, it’s the churches—it’s society. You have to put a human face to—to a disease like this because of all the stigmatism that goes with it. You have to put a human face to it. If not, the stigmatism never goes away. The hatred never goes away. The fear never goes away. The humility never goes away. You just never get over it. You begin to feel like people are always gonna be against you.

For this participant, putting a human face to HIV will help promote understanding of the entire patient.

**Decision making**

Shared decision-making was identified as an important method by which the healthcare system helped people with HIV enter care. One participant thought it should begin early, but go slowly, with the patient when deciding on care options. He stated:

**Participant:** Yes, it’s, it’s internal and secondly, I think people need support in coming to grips with it. Certainly you don’t tell somebody they’re HIV positive and, uh, okay you gotta start, you know, wearing condoms and we need to test you for all this other stuff, uh, here come back in, um, you know, let’s, let’s get some blood and, and, uh, see where you’re at. You probably need to go slowly into that. Patience, it’s like timing of when you gotta start treatment...Patients have to decide when they want to start treatment and there’s—I’m not sure that there’s that many up. I, I think the standard now is as soon as you find out you’re positive, the earlier the treatment the better.

This participant understood that immediate initiation of antiretroviral therapy is the standard of care for people newly diagnosed with HIV. However, the standard does not take into consideration the individual circumstances of the patient, such as readiness, goals, and choice. Choice is important to some participants who may seek or are seeking HIV care.
For example, another participant commented how shared decision-making was most important to him for linkage to care (and continued engagement in care).

Participant: The most helpful thing is that I have to have a physician that allows me to do my health input. And I don’t want somebody that’s just, oh, if you don’t do this, you’re gonna do that, blah, blah, blah, blah, blah. You know? More—a more relaxed physician that is willing to listen to you, and not just blurt out things to you.

There has been a tendency in the US health care system to treat clients from a biomedical perspective and focus only on medical needs (Boyer & Indyk, 2006). The participants above described the need for providers to treat them beyond a diagnosis. Shared decision-making and understanding the holistic patient are two key features in the delivery of patient centered care, which will be discussed in the next chapter.

**Delay or Intermittent Care**

Much research has been conducted on barriers associated with linkage to care for people newly diagnosed with HIV (see Figure 3-5). People who were unable to successfully resolve the crisis/grief process or (re)appraisal from a pivotal event (discussed below) entered into delayed or intermittent care. Examples of behavioral outcomes of the crisis/process without perceived support included a return to a risky lifestyle, anger, passive suicidal ideation, and a refrain from engagement in health care for HIV. Many participants who did not enter care immediately after a diagnosis described this point in the model as *being in denial*. The time people would stay at this point in the model varied among persons with HIV and depended on many ecological factors influencing the outcome, including stigma, access to care/services, substance use, mental health issues, and perception of illness. When probed about what helped them out of this phase, many participants described pivotal events.

Another participant discussed what he thought happens at the decision point.
Participant: Two things. Either you’re smart enough to read up on it, and try to educate yourself. Or you’re smart enough to go to someone else to get help. But they’re—that’s the first thing. The second thing is that you are still so afraid of getting that help, and being stigmatized, that you just don’t care. So then you go here (points to delay of care on early model).

People who end up at this point in the model are at risk for poorer health outcomes from HIV and also increase the risk to the population through the spread to others. We need to recognize the complex social issues that influence the decision to not seek care, or the failure to make a decision about care.

**Pivotal Events**

Participants in this research reflected on events that took place in their lives that led them to re-appraise their circumstances. During analysis, as I began to identify this concept in the interviews, I defined it as a sentinel event, similar to a sentinel event in a hospital. With further thought, however, I realized sentinel event was often associated with death. The word pivotal means *being that on which anything turns or depends; central, crucial, vital* (Oxford University Press, 2013a). I chose the term *pivotal event* to represent the point at which a participant made a decision to seek care since they described the event as vital to someone’s decision to link to care. The pivotal event led to a reappraisal of the participant’s situation and a subsequent response in the form of crisis or crisis resolution. For instance, some patients may arrive at the decision to seek care because of a pregnancy, or a spiritual awakening, while others may find the pivotal event begins with their actual diagnosis. If the response was crisis resolution, the participant was able to move towards becoming fully engaged in care (Figure 5-1).

The pivotal event differed in timing, scope, and substance for each participant. One participant who struggled with addiction after learning she was HIV positive in a physical rehabilitation facility described her realization of a broken pact with God.
Participant: It’s like this aura comes over me and I go and I cry to the Lord and I knew, I said, “Well you know I’ve tried everything and I always come back to this point and I can’t do it.” And I say, “If you’re real, if everything in the Holy Bible is true, and you are who you say you are.” I said, “Well you set me free.” I asked Him and I’m on my, I’m, I’m bawling and I’m bawling and I’m bawling, I’m about to bawl now… Is that the way He engulfed me and, He, I know He’s so real because He set me free right then and there. Haven’t picked up drugs since, it’s been over 19 years ago….And I asked Him, I said just take the desire away…Don’t just set me free, take the desire and, He did, and I tell you I don’t know what He did to me, I went—He, He took my body through something, it’s like junk that was in me was coming up and out….And I cried in a way—I’ve never cried again since, and it was one of those snot, everything that’s in you comin’. …Now one of those cries that you really…Yeah, a total release, a total release….

And I knew when it was over I was, I was, I was free. …I, I knew I was free. And it’s so weird the way He did it because my, my, my son’s brother-in-law goes to this church. He plays the guitar in church. And then this voice in my head—And then he comes walkin’ by and He says, “Ask him can you go to church with him in the morning.” I don’t want to do that. And—but I couldn’t help myself…And then he says, “You want to go to church in the morning?” and I said, “Yeah.” He said, “Yeah you can ride with me in the morning.” And it’s like t-, He woke me up early that morning and I’m s-, I’m gung-ho to go, and I, I’ve got this happiness about me that I can’t explain. And I’m gung-ho to go to church… And I sat way in the back of the church…But there’s an alter call and He speaks to me again…And He wants me to come up there. Now I’m in the back of the church. I gotta pass everybody, I don’t want to go up there…But He tells me to go and to give my life to Him. And so I get up and I do-, I’m not, I’m not getting up but I’m getting up, but I’m telling myself I’m not getting up but I’m getting—Right, and I’m getting up anyway and I’m going up there and when I get up there all I could say is, “I want to be saved” and then it’s like I just go to bawling and then everybody goes—the church just erupts. People are just praising God and I’m in a world, I don’t even know where I’m at. God has taken me somewhere that is so much—

From this event, she was drawn towards returning to church where she met prayer partners that began to show her another lifestyle that did not involve drugs and alcohol. Her spiritual family introduced her to support activities at the health department and she met other people who were comfortable with their diagnosis. During these interactions, she met people who were not afraid of her because she had HIV and learned to accept her diagnosis and engage in regular care.
Another participant talked about how her pregnancy brought her back to care:

Participant: But his dad and I had a wild night. We had been drinking. And when I found out I was feeling real ill. And my cycle still came on, but I feel real ill and I went to the doctor and I found out I was pregnant. And I panicked. I panicked, I panicked, I panicked. By that time, I had a warrant for my arrest. I got arrested. That's when I got involved with RW Case Manager and Jail Linkage Coordinator. They were like, "You want to take these meds. You're going to have a healthy baby." They stayed on me, they stayed on me and I love them to this day. And it made me feel better about myself. I had to be—for me to deal with this, I had to be in structure to stay focused (begins to cry).

Both of these participants had reached low points in their lives. The pivotal events brought them into a care environment where they received the acceptance and support they needed to engage in regular HIV care.

In addition to changing the course of HIV care for people who delayed care, pivotal events also changed the care trajectory for some who identified themselves as in care. For example, one participant described his reaction the first years after receiving an HIV diagnosis as accepting, but then had a religious experience that moved him away from care.

Participant: Yeah, for me, in the beginning, I was—it's interesting, this thing, acceptance. I was—I did accept it...And in my—in those days, I—I did not want God in my life, for a long time, and so, I spoke with my power of tongue, in those days, and said that I—I did have it, and um, [laughter] the doctors, of course, continued to use theirs and said I did have it, and everybody all around me, all telling me I do have it, and blah, blah, blah...And—and then, I came to a point where I just denied it anymore, because I was believing—and I'm still believing, to this day, God, that I do not have it.

He later went on to describe his frustration with the doctors for not understanding his spirituality and desire to not take medications for his HIV, and when he came to the decisional point in the model, he chose to stay out of care.
Pivotal events are not new to the HIV literature. A grounded theory study by Rajabiun, et al. (2007), suggested pivotal points in the engagement cycle that presented opportunities for interventions targeted at linking people to care and keeping people from falling out of care. Strategies described to facilitate engagement included: providing knowledge, helping to obtain HIV care, building skills and abilities to deal with HIV, providing services to reduce barriers, and providing support networks (Rajabiun et al., 2007). Like the model presented in this paper, pivotal points provided an opportunity for intervention. However, Rajabiun, et al. (2007) did not explain the events that would lead up to this opportunity.

**Summary**

In this chapter, results from the participant interviews were presented and explained via the grounded theory of the HIV care decision process. Participants were able to provide recommendations throughout the HIV Care trajectory about how our health care system could promote linkage to care from diagnosis to full engagement in HIV care. In the next chapter, I will discuss how concepts identified in the results relate to existing literature, and make recommendations for future research in Linkage to Care.
Table 5-1. Demographics of Participant Interviews

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Figure 5-1. HIV Care Decision Process Model
CHAPTER 6
DISCUSSION

This chapter provides guidance and direction concerning the findings about HIV linkage to care, and how we can incorporate them to improve the health of persons with HIV. The findings from the community advisory board and participant interviews identified the decision-making process for linkage to care and recommendations to improve the linkage to care process. The beginning of this chapter includes a review of the types and timing of support, which was considered a critical need by all participants. As presented in Chapter 4, the findings show a disconnect between current practice for HIV Linkage to Care and participant recommendations. Table 6-1, The Disconnect between HIV Patient Needs and System Practices, highlights the points in the Linkage to Care Decision Process, the recommended improvement by the participants, the concept central to that recommendation, current practice, and recommended practice changes. Next, recommendations will be presented for public health nursing practice to address the discrepancy between current practice and HIV patient needs. At the end of this chapter, I will review the limitations of the current study and directions for future research.

Support

As support began to emerge in all of the interviews, I started looking more closely at the literature to understand the concept of support, specifically social support, and how it may be relevant to people with HIV. According to Jacobson (1986) social support is a complex phenomenon and may be defined in multiple ways, such as type (emotional, cognitive, tangible) or delivery (informal or formal). Emotional support focuses on the provision of comfort for an individual and fosters feelings of security.
Cognitive support is delivered through providing information with a goal of helping someone understand a situation and give them tools for change. Tangible support involves the provision of goods and services in order to overcome a stressor or problem. Dutcher et al (2011) identified an additional type of support, affiliational support, which refers to support delivered from someone who is a part of a similar social network. Many HIV care providers underestimate the impact an HIV diagnosis has on a person and are likely to view structural barriers, such as transportation or child support, as primary reasons people with HIV do not seek care. Conversely, people diagnosed with HIV were more likely to view emotional barriers as the primary reason for not seeking care (Mayer, 2011). All participants in this research said they needed support, but there was variability in the type of support (emotional, cognitive, tangible), the timing of support (emotional at diagnosis), and the person who delivered support (affiliational).

Participants consistently described various types of support in linking to HIV care. In a study by Walsh, Horvath, Fisher, & Courtenay-Quirk (2012), women recently diagnosed with HIV consistently identified a need for social support soon after diagnosis. The provision of support differed for the women in the Walsh, et al. (2012) study. Some women needed to find support outside their families through peer support or support groups. Another type of support was available through ancillary services. One type of ancillary service, treatment advocacy, incorporates patient-centered care concepts through assessing client’s needs and conveying HIV education (Mutchler et al., 2011). Mutchler, et al. (2011) qualitatively evaluated a treatment advocacy program and found it helped clients to understand treatment options, helped connect patients and providers and increase self-advocacy in the patient-provider relationship, and
allowed the patient to explore the impact of the HIV diagnosis beyond the traditional counseling and testing session.

There is also research focusing on the timing or delivery of support in response to a crisis (transitionalist approach to support) (Jacobson, 1986). Jacobson (1986) indicates the types of support needed in response to a crisis situation, and specifically, how emotional support is most needed during the crisis or grieving phase. Furthermore, when people are in the midst of crisis, they are unable to use (or even perceive) other types of support such as cognitive and tangible support. This is of particular importance in the process of Linkage to Care and our current practices in delivering an HIV diagnosis. Failure of people returning for HIV results and/or care has been well-documented in the literature (Sullivan, Lansky, & Drake, 2004). Our health care system response to the poor return rate has been to convey as much information as possible to the person at the time of diagnosis. This information is usually focused on cognitive support (i.e. why it is important to seek care and use condoms) and how to obtain tangible support (i.e. eligibility for HIV-related services such as Ryan White). From the data in this research, participants agreed they needed emotional support at diagnosis, during the crisis, and, as they began the transition, we could begin to incorporate other types of support.

Peer Navigation, a type of affiliational support, was identified as a way to deliver emotional support through connecting people newly diagnosed with HIV to others previously diagnosed. People with HIV are able to understand the feelings at diagnosis and the process of linking to care since they shared the same experience at one point in their life. For example, all participants talked about the crisis period when they received
the diagnosis and were trying to assimilate it into the rest of their lives. A peer (with HIV) can help people newly diagnosed with HIV by describing that time to help them identify and deal with their feelings. Funding for peer navigation programs is sparse, especially in mostly rural areas. For example, Area 3/15, a 15-county region, only has half-time peer navigators in one county. Recent literature about peer programs in HIV indicate mixed results due to varying types of program evaluations (Dutcher et al., 2011). Results from a qualitative evaluation of peer programs by Dutcher et al. (2011) indicated that the common characteristics shared among peer programs is they promote engagement in care but they advise that more research is needed in this area.

**HIV Care Decision Making: Crisis and Decisions**

Receiving a diagnosis of HIV is a significant stressor that participants identified as a crisis with a grief-like response. The response of the participants to this crisis varied widely, with some moving directly into care, and others engaging in behaviors detrimental to health promotion. Examination of the literature related to crisis and decision-making offers insights into the decision-making process for persons newly diagnosed with HIV.

**Crisis and Decisions**

A crisis response from a change in health status can manifest in biophysical symptoms (tension, anxiety), negative feelings (i.e., anger, shock, shame), altered thoughts and perceptions (i.e., anguish, confusion), and a change in behavior (i.e., substance use) (Hoff, 2001). Interestingly, Hoff (2001) notes how altered thoughts and perceptions contribute to difficulty in making decisions, and, in the case of people newly diagnosed with HIV, difficulty in making the decision to link to care. According to Hoff (2001), people often do not seek help for a crisis until after they have responded with
negative outcomes. For example, participants in this research who chose not to fully engage in care noted a continuation or increase in risky behavior and/or substance abuse.

Decision theories focus on how humans make choices from options they are given (Hansson, 2005). Early decision theories looked at the decision-making process in a sequential manner. However, modern decision-making theories recognize that such decisions are not made in a linear fashion (Hansson, 2005). Aids to decision-making, based on decision theory, are tools to assist people in making decisions about health care choices and allows for partnership between the patient and provider. During the decision process, the patient must realize that a choice needs to be made, know the options available, understand values that may impact the choice, understand the preferred options, and discuss the values, options, and choice with the provider (Stacey et al., 2011). Variables that impact the decision process include decisional conflict, patient-provider communication, shared decision-making, and satisfaction (Stacey et al., 2011). From the findings presented in this research, participants discussed a need for a better understanding of the process after diagnosis (cognitive support). They did not understand that other options were available when their situation was not acceptable (for example, not being told about places of HIV care outside of the health department). Understanding how decisions are made, and the resources needed for decision making, can assist in the Linkage to Care process.

**Crisis Decision Theory**

Crisis Decision Theory (CDT) attempts to link theories of stress and coping with theories of decision making to describe the process of response to a crisis (Sweeney, 2008). CDT is appropriate in examining Linkage to Care since an HIV diagnosis is a
crisis event and little is known about the decision making process. The theory is useful in understanding factors influencing the decision making process after a crisis. However it is not meant for prediction of a particular response (Sweeney, 2008). In the first stage of CDT, a person evaluates the severity of the event, and interprets the event based on prior information about consequences (Sweeney, 2008). In the second stage of CDT, a person looks at the response options, and decides what responses he or she is capable of achieving (Sweeney, 2008). In the third stage of CDT, which can sometimes occur simultaneously with the second stage, people identify and evaluate response options based on resources and consequences. Sweeny (2008) acknowledges the social aspect of the decision making process in relation to CDT and identifies how persons within the social environment may help influence the decision-making process.

Several aspects of CDT relate to the findings from the current research. The first stage, evaluation of the severity of the threat, is impacted by stigma and the nature of HIV as a potentially fatal disease. Participants engaging in a social system with a negative interpretation of HIV, such as the church, may evaluate the severity of the threat of HIV as more severe than someone who has a family member with HIV. The second and third stage of CDT assumes participants were given options to evaluate and had adequate knowledge to understand the consequences of a decision. Participants diagnosed with HIV were not always informed of potential options. Hence they did not have a chance to evaluate potential options, which sometimes led to withdrawal and not linking to care. While the CDT was helpful in understanding the process of linkage to care, it does not take into account the complexity of the health care system and limitations in the provision of care for linkage.
How the Diagnosis is Delivered

Goals

Sweeny and Shepperd (2007) explore how people are informed of “bad news,” and the interactions in that exchange can greatly influence someone’s response within the decision process. There are six goals in the delivery of bad news identified in the medical literature: decreasing the discomfort of the person delivering the bad news (emotional support), providing sufficient information (cognitive support), promoting satisfaction for the person receiving the bad news, improving understanding of the information about the bad news (cognitive support), reducing distress (emotional support), and promoting hope (Sweeny & Shepperd, 2007). Participants in this research stressed the importance of emotional support at diagnosis along with a preference for delivery of emotional support from a peer (affiliational support). Sweeny and Shepperd (2007) propose a new model, The Bad News Response Model, which can help proactively guide the recipients of bad news to a desired outcome. The Bad News Response Model begins with an examination of situational factors (controllability, likelihood, and severity) as they relate to what would happen because of the diagnosis if the person does nothing towards prevention. For example, the person delivering an HIV diagnosis should not focus on the how dangerous HIV is, but instead focus on what will happen as a result of the diagnosis if the patient does not engage in care (decline in overall health). Next the person delivering the bad news should have a transmission goal and desired response in order to get to the desired outcome (Sweeny & Shepperd, 2007). If the goal after the delivery of an HIV diagnosis is to assist the person into HIV care, the person delivering the bad news needs to work with the participant towards that desired response. Without the goal of a desired behavioral response to move the
patient towards care, the person newly diagnosed may choose not to respond to the bad news (i.e., not link to care). This occurred with some participants in the research who received their diagnosis in jail and were not given any support during diagnosis. It appeared the goal of the person delivering the diagnosis may have been to inform the client of their status and not move them towards a desired response (i.e. seeking care for HIV). This non-response may create an outcome that is neither beneficial to their own health nor to the health of the population. However, the Bad News Response Model fails to incorporate the goal of the person receiving the bad news. A patient centered care approach, discussed later in this chapter, incorporates the missing element in the Bad News Response Model in explaining the decision making process for persons with HIV.

Quality

Also of concern during the diagnosis is that standard of care in HIV prevention allows lay providers, who have completed approximately 24 hours of training in HIV counseling and testing, to provide test results (Florida Department of Health, 1999). While expanded screening for HIV, outside of the medical facility, has been a very positive public health population intervention and helped many people learn of their status, lay providers may not be the most qualified to deliver a traumatic chronic disease diagnosis, and to attend to the resulting crisis response from the patient. HIV is possibly the only serious medical diagnosis that is not delivered by a trained healthcare provider, and failure to assist people into care jeopardizes their personal health and the public’s health.

A cohort study from New York City in 2008 identified several predictors for delayed initiation of care including testing at a community testing site, community jail,
and department of health STD/TB clinic (Torian & Wiewel, 2011; Torian, Wiewel, Liu, Sackoff, & Frieden, 2008). From this research, facilities in which care and testing were co-located were better predictors of linkage to care, leaving the possibility of training in diagnosis delivery as a potential area for intervention. In an opinion paper by McNairy and El-Sadr (2012), the authors outlined the HIV Care Continuum, with areas to promote engagement highlighted (Figure 6-1). In the paper and model, they did not address counseling, monitoring, and support at the diagnosis phase. From the results presented in this research, this appears to be a critical phase in linking people into HIV care, which is missing from the literature.

**Anticipatory Guidance**

As discussed in Chapter 5, participants in this research described a need to know what to expect. With the fragmentation of care, understanding the system of HIV care is confusing. Unclear expectations about the care process do not ease fears regarding HIV care. Anticipatory guidance is a family centered intervention widely used in pediatric practice in which health care providers share knowledge with parents regarding what to expect developmentally, how to promote development, and the benefits of health promotion (Piotrowski, Talavera, & Mayer, 2009). Behavioral outcomes from a systematic review of pediatric anticipatory guidance literature identified improved knowledge about development, reduced parental stress, and increased parental confidence (Nelson, Wissow, & Cheng, 2003). Incorporating anticipatory guidance to enhance the diagnosis process has the potential to enhance outcomes for people newly diagnosed with HIV. For example, given the complexity of HIV care delivery, anticipatory guidance may help improve health literacy specific to HIV care.
Furthermore, reducing stress and increasing the confidence of patients entering the process may help promote linkage to care.

**Patient-Centered Care**

The concepts central to patient-centered care are not new to the discipline of nursing. In nursing education, the teaching of Betty Neuman’s Systems Model has helped nurses learn about the interactions between a patient and the system and the importance of a holistic approach to care (Neuman & Fawcett, 2011). The discipline of family medicine has refined the model of patient-centered care, and consists of six interactive components: 1) Exploring the illness experience of the patient, 2) Understanding the patient and context, 3) Finding common goals for health and mutual decision making, 4) Incorporating prevention and health promotion, 5) Enhancing the provider-patient relationship through compassion, and 6) Being realistic regarding treatment (Stewart et al., 1995). Physicians, nurses, and ancillary staff sometimes receive formal education regarding patient-centered care. Many learn through experience. This lack of formal training in a patient-centered approach to care, in addition to a lack of training in diagnosis delivery, can have serious implications in linking persons with HIV to care. Based on comments made by participants in this research, the way they were told about their diagnosis made an impact on their crisis response.

The definition of care is also an integral part of patient-centered care. A person’s perspective of care may be very different from our perspectives as providers. Our current public health and health care system tends to send a message that HIV care is equated with antiretroviral treatment (ART), and ART is prevention with a goal more focused on preventing the spread of HIV than helping the person with HIV. From
participant comments regarding conflicting messages of care, we are possibly sending a message that if you have HIV and do not engage in treatment with ART, there is no place for you in the health care system. This takes a biomedical approach and assumes there is only one way to have someone in HIV care – through ART. It does not account for health promotion interventions such as diet and exercise, which could also be very beneficial and is minimized in the current approach. HIV care should be focused on prevention, support, and management, and should accept and care for people at all points of the trajectory. Engagement in preventive health care may, or may not, mean ART treatment. ART should be dependent on the mutual goals and shared decisions between the provider and the patient – a patient centered approach.

**Implications for Practice**

Before implementing any changes in the current HIV care trajectory to alter practice, consideration of when care begins for the newly diagnosed patient to ensure continuity through the entire course of illness is necessary. The participants in this research often voiced a need for help when they were diagnosed, and felt unprepared or unable to successfully navigate towards care without needed support.

Recommendations have been made to begin the care process at diagnosis, instead of care beginning when a referral is *completed* through attendance at an HIV/AIDS care appointment (Stevens & Doerr, 1997; Stevens & Hildebrandt, 2006). However, from the experiences described in this research, this has not been the practice. If engagement begins at diagnosis, transition and care through the *entire* trajectory of the illness could be better ensured. Prevention specialists and health care providers who provide counseling and testing services can embrace this change in philosophy and actively engage the patient in care, rather than refer to care.
Nurses were on the front line when the HIV/AIDS epidemic began. They advocated for their patients at all turns, ensuring fair and equal treatment in the healthcare system (Association of Nurses in AIDS Care, n.d.). From the data analyzed in this research, a disconnect exists between how care should be delivered (i.e., patient centered) and the perception of how care is actually delivered. Collaborative practice and patient centered care are essential parts of nursing practice. Public health nurses should lead efforts to promote delivery of patient centered HIV care beginning at diagnosis. The goal of public health and HIV Infectious Disease Medicine is to treat all persons who are HIV positive with medications, (i.e., Treatment as Prevention) (Nguyen, Bajos, Dubois-Arber, O'Malley, & Pirkle, 2011). However, this approach could conflict with a patient centered care approach. By urging HIV medications onto their patients, providers may in fact, be pushing them away. It is necessary to approach the therapeutic relationship with a patient centered approach. Public Health Nurses can use the findings from this research to promote policy change related to HIV Counseling and Testing and enhancement of the testing procedures to incorporate patient centered care.

**Pivotal Events: A New Opportunity for Intervention**

Pivotal events were identified as occurrences which helped study participants to link to HIV care for those who initially had delayed care. Interestingly, pivotal events also turned people away from care. Stressful events in someone’s life can lead to an appraisal of the person and their environment (Jacobson, 1986). Like the crisis response, people going through a pivotal event may present to health care providers (i.e., primary care physicians, mental health counselors, nurses) for help with resolution of the event (Hoff, 2001). Findings from this research were similar to findings presented
by Rajabiun (2007), in which we both developed models representing the cyclical process of people in and out of HIV care, and the role of pivotal events in providing opportunities for intervention. However, unlike the Rajabiun (2007) model, which only focused on HIV care, the grounded theory developed in this research describes the decision process from diagnosis to HIV care and how pivotal events can impact decisions to move towards care. Practicing a patient-centered care approach calls for providing continuity in care. Thus, HIV providers and primary health care providers have the opportunity to recognize pivotal events as potential chances to assess, provide needed support, and link people into HIV care or help them remain in care.

**Limitations**

As a novice researcher, I developed an extensive plan to address potential limitations. The plan included consistent engagement with faculty experts in qualitative methods, HIV care, CBPR, and health services research. Furthermore, continued engagement with the community from utilizing a CBPR approach helped overcome potential limitations.

Recruitment of persons who had never engaged in HIV care presented a challenge. Community partners were able to help identify persons who were out of care, but links to people never in care, or newly diagnosed did not take place. One peer advocate working in the health department indicated that some people newly diagnosed were still uncomfortable and afraid of the diagnosis, and the research process frightened them because of the stigma associated with HIV. Recruitment of Hispanics also presented a challenge. I attended several community meetings to specifically ask for Hispanic participants. In the local county, however, there are approximately 35 HIV
positive people with a Hispanic background, making identifying them for recruitment a challenge.

Use of the Community Advisory Board (CAB) helped promote cultural sensitivity and community engagement in the research process. However, limitations from the CAB focus group data included a lack of thematic saturation, limited data collection/engagement (i.e., one focus group), and no member checking.

The use of a health science qualitative data analysis group helped assure the author’s interpretations were grounded in the data and not reflective of her own experiences working with the advisory board. Furthermore, the process of analysis of the focus group data was done under the supervision of a faculty advisor, further assuring the results were grounded in the data.

The process of conducting constructivist grounded theory focuses on meaning that is developed from the interaction between the participant and researcher. In the reflexivity statement from Chapter 3, I identified how my perspective may have influenced the development of the shared meaning of the decision process of linkage to care. By sharing my perspectives with the inter-disciplinary data analysis group, I was able to confirm that my interpretations and analyses were grounded in the data and not based on my experiences.

The participant interviews yielded abundant information regarding the process of linkage to care for those newly diagnosed with HIV. However, there were also limitations in this arm of the research. First, with face-to-face interviews, people with HIV may have framed their answers based on their perceptions of who I am, and my position as a researcher and nurse. While participants appeared comfortable during the
interview process, questions regarding an HIV diagnosis can be very personal and bring up memories they did not wish to share that may have enhanced my interpretation of the decision process. I consistently attempted to lessen any potential impact from this possible discomfort by building a non-judgmental, trusting relationship with participants, thanking them for their willingness to share their story, and respecting them as the expert on the subject of living with HIV and making decisions regarding care. It is important to realize that research findings are representative of the Area 3/13 population and may not apply to other populations. The voices of small metropolitan and rural populations have not been incorporated into substantial literature regarding HIV linkage to care, and the descriptions from the findings may help address linkage to care in similar contexts.

**Directions for Future Research**

**HIV Diagnosis**

Research regarding interventions during the delivery of an HIV diagnosis includes a need to enhance training related to an HIV diagnosis, as well as delivery and the provision of anticipatory guidance. Metsch (2012) found no additional benefits from risk reduction counseling which was directed by risk factor questions delivered during testing. Risk reduction questions may not provide benefit for any purposes other than statistical counting and identification of target populations for HIV prevention. Based on the findings from this study, people who are newly diagnosed with HIV want (and need) a different approach. It is important for researchers to focus on a different type of counseling that can help patients identify health issues and transition into primary and HIV care through anticipatory guidance. Anticipatory guidance in HIV care could include the perceptions of HIV care, what types of emotional responses to expect, and
how to find support, plus identification of the next stages of the process (i.e. Disease Investigation Specialists interviewing them to notify partners). Identifying and addressing their personal health concerns may have more relevance to a patient than risk reduction concerns and partner notification to reduce spread.

**HIV Care that is Patient Centered**

The concepts of Patient Centered Care were mentioned throughout the participant interviews, including coordination (navigation), advocacy (support), holistic understanding (patient context), shared decisions, health promotion, and continuity. Research is needed that examines patient outcomes with the application of patient-centered care at any point in the HIV trajectory. For example, comparing known interventions specific to transitional care (active linkage, peer navigation, case management) may help to identify which intervention is most effective in assisting people with HIV into care. Development of new interventions, based on the crisis literature, which will incorporate crisis and grief training of providers at this point in the model, is also worth further exploration.

Research in the HIV care setting is also needed specific to patient-centered care. For example, research might compare 2 clinic settings, either geographically similar or sequential time comparisons. One setting could have specific training in patient-centered care delivered by all staff, and the other could have the standard of care. The patient outcomes (i.e., viral load, CD4, quality of life, satisfaction, adherence) could be examined. Research should address the crisis period immediately during and after diagnosis through the provision of emotional support by personnel trained in crisis counseling to see if it impacts linkage to HIV care.
The CBPR process engages and partners with the community through the entire research process – from identification of the research question to dissemination of the results. Following the identification of the research problem with community members, this dissertation research focused on the formation of the CAB and collection of the data specifically regarding Linkage to HIV care in Area 3/13. Consistent with the principles of CBPR, results of this research will be shared with and interpreted by the CAB and will be presented to the RWCC and to the HIV/AIDS departments of Area 3/13. Through sharing results with the community, feasibility of proposed solutions to linkage to care issues identified by participants can be discussed. Future work with the CAB will expand the nature of the partnership and move towards an equal partnership in all phases of the research process. The CAB can subsequently work together to develop an intervention at the health care organizational level to improve linkage to care.

Summary

The findings from this research identified a need to move towards patient-centered care in approaches to HIV prevention and treatment. Since the advent of Treatment as Prevention (M. S. Cohen et al., 2011), there has been a new surge to focus on HIV Treatment is Prevention, a biomedical and public health approach that seeks to eradicate the virus based on surveillance and the targeted intervention of antiretroviral therapy (Nguyen et al., 2011). As Nguyen (2011) identifies in an opinion paper, even countries with adequately available resources are not able to overcome the growing epidemic with a purely biomedical approach—not all people access the tests, care, or medicine even when available. The biomedical focus fails to remove the complex social and structural challenges that are evident in the epidemic (Nguyen et al.,
A patient centered approach to care, as suggested by the participants in this research, is a step towards addressing the complex social and structural issues people with HIV face in the journey from infection to care through understanding the context and their social role in society. Perhaps it is timely to shift the message from *Treatment as Prevention* to HIV Care as Prevention. HIV Care may or may not include treatment. However, treatment will surely not exist if the care piece is not in place first.

This dissertation research serves as the first step in building a program of research specific to linking people with HIV into HIV care. From this research I was able to develop a theory of the decision process and recommendations in linkage to HIV care. Figure 3-2 identified how the developing grounded theory would identify constructs within a social ecological model relevant to initial linkage to HIV care. Figure 6-2 modifies that figure, incorporating constructs from the results – diagnosis delivery, stigma, patient-centered care, defining care, and acceptance.

Using a CBPR approach, I was able to understand community needs and insights prior to initiation of the research. Again, sharing the results of the research with the Community Advisory Board, and HIV community will help to identify possible interventions that will be culturally relevant to people living in small metropolitan and rural areas. Public health nursing, with its unique perspective in both individual health promotion and population health promotion can guide the improvement of care for people with HIV throughout the HIV care trajectory.
<table>
<thead>
<tr>
<th>Point in Decision Process</th>
<th>Recommendation by Participant</th>
<th>Concepts from Literature</th>
<th>Current Practice or Perceptions of Practice by Participants</th>
<th>Recommended Practice Changes</th>
</tr>
</thead>
</table>
| HIV Care Trajectory      | Support                       | • Emotional support priority at diagnosis.  
                          | (Throughout)              | • Cognitive, tangible, and affiliational support later.   | Educate prevention staff and providers about the importance of emotional support at diagnosis. Clients may have difficulty understanding or receiving other types of support until the crisis starts to resolve. |
| Diagnosis                | Diagnosis Delivery            | • Goals and Quality      | • Cognitive support at diagnosis and passive referrals to other types of support such as tangible, emotional, and affiliational. | Increased training in diagnosis delivery, to include understanding of disease process, crisis counseling techniques, and identification of goals. |
|                          | Anticipatory Guidance         | • Guidance about challenges and changes to expect | • Population health outcomes as focus, providers delivering diagnosis poorly trained in HIV knowledge, care process, and sensitivity to client response |                              |
| Crisis/Grief Period      | Connection Navigation        | • Patient Centered Care  | • Often passive linkages.                                |                              |
| HIV Care                 | Counseling                   | (holistic understanding, shared goals and decision making, prevention and health promotion, continuity.) | • Person delivering diagnosis often is not familiar with process or resources for assistance. |                              |
| Delay of Care            |                               |                          | • Lack of adequate assessment to identify needs such as counseling support. |                              |

Understanding that care begins at diagnosis and patients frequently do not have the health literacy to understand next steps. Educate all providers, clinic staff, and ancillary staff on the importance of PCC. Realize that ART are only one part of a Patient Centered Approach. Other ways to improve health include diet, exercise, and substance abuse treatment. The goal should be to keep them in care so they can be monitored through routine lab work and continued support. Without routine lab monitoring, it will be difficult to detect when the body is no longer able to keep the virus suppressed.
Figure 6-1. Adaptation from McNairy and El-Sadr (2012)
Figure 6-2. Revised Social Ecological Model
APPENDIX A
RECRUITMENT FLYERS

HIV/AIDS Linkage to Care

Study Title: A CBPR Approach to Facilitate Linkage to Care for Persons with HIV – Part 1: Community Advisory Board

We are seeking persons with HIV to participate in a research study to explore ways to help persons with HIV into care. The research involves 4 meetings in the next 2.5 years with a nurse researcher for approximately 1-2 hours per meeting. The initial meeting will involve a focus group among board members. We are specifically seeking persons:

- Persons with HIV that engage in HIV care or services or
- Members of an HIV Community Based Organization with expertise in linkage to HIV care or
- HIV Healthcare Providers with expertise in linkage to HIV care or
- Researchers from the University of Florida with expertise in HIV behavioral studies.

Participants will receive either a $25 gift card or a gift valued at $25 for transportation and time.

For more information, please contact Christa Cook, principal investigator at 352-275-9565 or christacook@ufl.edu

IRB APPROVED
ON 10/21/2011 2:40
Seeking Participants for Interview Research Study

Do you have a story about seeking HIV care after you were first diagnosed?

Researchers at the University of Florida are trying to understand what influences someone’s decisions to seek HIV care. From this research, we hope to explore ways to help persons newly diagnosed with HIV. The research involves a 1-2 hour interview with a nurse researcher with the possibility of a second 1-hour interview. We are specifically seeking:

- Persons with HIV who are currently in HIV care or receiving services OR
- Persons with HIV who delayed care for more than 9 months after diagnosis OR
- Persons diagnosed with HIV who have never sought care.

Participants will receive either gift card or a gift for transportation and time. All information discussed in the interviews is confidential.

Study Title: A CBPR Approach to Facilitate Linkage to Care for Persons with HIV – Part 2: Participant Interviews

For more information, please contact Christa Cook, principal investigator at 352-275-9565 or christacook@ufl.edu
**APPENDIX B**

PARTICIPANT INTERVIEW GUIDE – AIM 2

Linkage to Care - Open-ended Question Guide

**Qualify all questions with a reminder that the subject does not have to answer any questions that make them feel uncomfortable.**

The purpose of this interview is to explore decisions and factors that impact the decision to seek HIV-related health care among persons with HIV. The format is an open-ended discussion covering the participant's perceptions about getting diagnosed with HIV and linked to HIV care. Each face-to-face interview will last approximately 1-2 hours.

The questions below are meant to be a guide. Because it is important to establish rapport, the order and wording of the questions will differ based on the lead of each participant. Additional topics may be discussed as the participant brings them up.

1) I really appreciate that you are here and I am interested in talking to you... Talk to me about why you are interested in participating in this study?
2) Tell me about how you came to be diagnosed with HIV?
   a. What was it like to find out you had HIV? What thoughts did you have?
   b. Probe how they contracted disease if they are comfortable discussing.
3) What was your life like when you were diagnosed? How has that changed?
   a. Any risky behaviors such as alcohol, drugs, risky sex? Mental Health?
4) Tell me how you decided to get tested for HIV?
5) What does being diagnosed with HIV mean to you at this point?
6) What do you think HIV will do to you?
7) How severe do you think this illness is for you?
8) Tell me about how you decided to seek [or not seek] care once you learned you were HIV+.
9) What are your feelings or beliefs regarding treatment for HIV?
   b. Do they feel like they need treatment? A particular kind of treatment?
10) Describe who or what has been helpful to you since you found out you have HIV?
11) Describe who or what has been the least helpful to since you found out you have HIV?
12) Where do you see yourself in 2 years?
13) Is there anything else I should know to understand being diagnosed with HIV better?
14) Is there one key person that has helped you? Why? What is it about that person that made a difference?

IRB APPROVED
ON 7/18/2012 MON
Linkage to Care - Open-ended Question Guide

15) Is there anything you would like to ask me?

Questions (more appropriate for persons engaged in care now but who did not initially seek care)

1) Tell me about how your views about seeking HIV care may have changed? Describe an average day before and after treatment.

2) After having this experience, what advice would you give to someone initially diagnosed with HIV?

Questions for possible second interview:

1) When we last met, we discussed (this may vary depending on the specifics from the previous interview). I have begun to analyze the interview and make interpretations about what all the answers to the questions I have been asking means. Today I want to talk to you about some of those interpretations to make sure I have a clear understanding of seeking HIV care for persons newly diagnosed. I want the results of this research to be as accurate as possible. Please feel free to tell me if I have come to any incorrect conclusions from what we discussed.

OR

2) I have been thinking about some of your responses to (this may vary depending on the specifics from the previous interview). I am not sure if I understood the complete meaning of your responses and want to clarify some of the things we talked about. I want the results of this research to be as accurate as possible.
Appendix C
FOCUS GROUP OUTLINE/QUESTION GUIDE

Linkage to Care Community Advisory Board

1. Introduction(s)

Review and Sign Consent Forms/Demographics

Review principles and processes of Community Based Participatory Research (CBPR)

Linkage to Care Trajectory

Begin Focus Group and Recording.

i) Tell me about the key issues relating to linkage to HIV care after initial diagnosis that you see in your work, experience, or life? Refer to the Linkage to Care Trajectory and comment how that applies to Area 3/13.

ii) How do you think our health care system impacts the decision for people to link to care?

iii) In your experiences, what has worked the best to link people to care?

iv) What do you think hinders linkage to care?

v) Review study procedures—who should conduct interviews? Peer Navigator Focus Groups?

vi) Review the initial question guide that I created for the interviews and comment on: 1) How will these questions will help us understand the decision-making process regarding seeking HIV care? 2) What other things can we address that may help us to understand this process? 3) Are the questions culturally sensitive and appropriate to the local population of persons with HIV?

vii) Review Incentives

viii) Review Advertisement

Review key points from discussion and end recording.

Distribute gifts/gift cards to eligible participants.


Davis, R. (2010, May 28, 2009). [HIV/AIDS Program Coordinator Alachua County Health Department (personal communication)].

Davis, R. (2013, May 28, 2009). [HIV/AIDS Program Coordinator Alachua County Health Department (personal communication)].


BIOGRAPHICAL SKETCH

My long-term research goal is to develop mechanisms to facilitate persons with HIV into care and ensure they remain in care. My academic training thus far has provided me with an excellent foundation to pursue this goal. At the University of North Carolina, I became interested in HIV/AIDS when I recognized the discrimination of persons with HIV within healthcare professions. At that time, I chose to take a class on HIV/AIDS and focus my undergraduate honors research thesis on healthcare providers’ perceptions of psychosocial issues of HIV-positive African American women. At the University of Pittsburgh, I continued my research interests in HIV through work with Judy Erlen, PhD, RN, in two projects: the use of Life Review in persons with HIV and the utility of the Purpose in Life Test in persons with HIV. I chose to return to school at the University of Florida in 2008 to complete my PhD and was surprised to find that many of the same issues relevant to my honors thesis were still problematic. I then knew my research focus would continue to be with people diagnosed with HIV.

Coursework at the University of Florida provided a solid basis in nursing science and public health. Working as a graduate research assistant for Dr. Shawn Kneipp, an expert in health disparities research, I was able to learn and employ the principles of CBPR to develop a public health nursing intervention to improve medical outcomes for women in a welfare transition program. In an independent study with faculty in health services research, we are closely examining the CBPR data to better understand mechanisms that impact healthcare for welfare participants. This experience is allowed me to apply knowledge in health services research to my research with HIV.

While engaged in my Master of Science in Public Health Nursing program, I was able to spend 2 semesters at the Alachua County Health Department (ACHD) immersed
in their HIV linkage-to-care program. I worked on management of a database of all persons diagnosed with HIV to determine rates of linkage and adherence, focusing particularly on persons newly diagnosed or recently falling out of care. I developed a gift card program to help facilitate persons into HIV care and created a means of follow-up within the system for persons newly diagnosed. While working at the ACHD, I was able to complete the AIDS 500/501 Counseling and Testing Certification Course. The ACHD experience enabled me to expand my involvement in the local HIV community through participation with the regional Ryan White Care Consortium and election to the Ryan White Care Consortium Board, where I remain actively involved. This experience also afforded me critical insight into constraints from community members when thinking about prevention, linkage to care, and HIV services—especially financial limitations. My dissertation research allowed me to further develop community relationships, gain more knowledge and experience in qualitative methods and principles of CBPR, and work toward my goal of decreasing health disparities and promoting health in a highly vulnerable population. Outcomes from my dissertation research will inform the creation of an intervention to enhance linkage to care for persons with HIV in smaller metropolitan areas (less than 500,000 people) and in rural areas with limited funding.